

From: Adam Johnston <adamdj1@optusnet.com.au>
Sent: Tuesday, 27 July 2021 2:55 PM
To: Digital Monitoring
Cc: 'DRC Submissions'
Subject: Retail digital marketplace
Attachments: When a gate becomes a trap door.pdf; Attachments.pdf; Previous correspondence.pdf; Inquiry submission.pdf; Fair Trading.pdf; 0251 Mr Adam Johnston (partially confidential)_Redacted.pdf; 0251a Mr Adam Johnston.pdf; Policy reform.pdf; Skinner.pdf; DRC Submissions.pdf; CONSUMER INVOLVEMENT IN HEALTHCARE RESEARCH - WHAT WOULD GRANDMA SAY.pdf; Charity questions.pdf

Categories: Actioned

Mr Rod Simms
Chairman, ACCC

Dear Mr. Simms

I know that you are thinking of companies like Amazon when commencing this inquiry. However, as you say on page 2 of your Discussion Paper, quoting the European Commission:

The growth of general online retail marketplaces in other jurisdictions Online shopping and extensive consumer use of large general online retail marketplaces has been long established in a number of other countries. The large role performed by such marketplaces in retail sales has led to an increasing scrutiny of their market power, and competition and consumer concerns that arise from certain practices. These include consideration of marketplaces' pricing practices, their use of data, and the terms and conditions imposed on third-party sellers. For example: in the US, Germany and the European Union (jurisdictions where Amazon is an established, leading marketplace), regulators have undertaken investigations or commenced proceedings regarding how Amazon uses its market power, and the effect it has upon third-party sellers and consumers. ([Digital platform services inquiry - March 2022 report - Issues paper.pdf \(accc.gov.au\)](#))

I would argue that government itself (State, Federal and local) has morphed into a large online retailer. Citizens have become customers and public agencies as much as private business are called upon to provide a 'return' to investors, be they shareholder Ministers or private companies. Where it is an ASX company, SME or micro-small business trying to turn a profit, I have no objection. Where governments try to make profits, or they engage third parties (like charities) and then let them make largely untaxed profits, this is where I complain. These profits are generally made off the back of the neediest and most vulnerable in our society, often financed by government subsidies. As a disabled man I find this especially reprehensible and far more objectionable than anything Amazon may have done. At least with Amazon, it is my choice whether to buy a book on-line.

With the National Disability Insurance Scheme, you have no choice but to engage with their "market-place" much of which is now mediated on-line through portals, emails, and webpages, as is much of government more generally. If you also have a certain level of incapacity, you have no choice but to deal with the NDIS because it is a nationally legislated monopoly. Yet it provides no services and outsources service delivery and its disabled participants to charity. The modern charity is very much about the financial return or profit on activity, while the NDIS itself has a financial substantiality requirement in its legislation. If this is now the regime people with disability are going to be required to 'live' under, it should be subject to ACCC and State Fair Trading jurisdictions. Indeed, I have had cause to wonder whether under the NDIS/charity cartel, I am the customer or the product? Either way, one potentially dubious charitable provider is much the same as the next to me, while my disabled existence generates their (untaxed and arguably immoral) profits. The attached documents show my doubts over the NDIS, whether it has any real idea where the money goes, or whether much can be said for the probity of its charitable service providers.

They also show my reservations over several years and that many of these concerns remain. I note similarities to your comments 4 years ago - [Privatising NDIS services could be a repeat of the VET-fee disaster \(smh.com.au\)](http://www.smh.com.au) and fear that what you warned against then, has largely occurred now.

It has for me. I don't feel I have much choice and further that, much time and much public money is being wasted on poor services. The NDIS is of a multi-billion size, comparable those markets you do identify as central to your inquiry. While you might consider the NDIS too specialist for your terms of reference, might you ask the Treasurer to amend his request? I would hope the Treasurer might consider such a request but fear that no government is prepared to disturb what hides under the filthy rug called "charity". My experience is of a marked reluctance to do or say anything ill of the charitable sector, as all the attached documents show. Personally, I cannot ignore the money wasted, the misdeeds pushed quietly to one side and, the knowledge that the NDIS will never fund anything which will lead to my functional improvement (see 'Consumer Involvement in Healthcare research – What would Grandma Say,' pp. 14-21 [37 of 70 to 44 of 70 by Adobe numbering]). So, the NDIS/charity cartel wants me and thousands of others to experience permanent impairment to secure its financial future. I am not aware of Amazon doing anything that grievous.

For all these reasons, I believe the NDIS and its providers should be added to your inquiry.

Your truly,



Adam Johnston

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Mobile: 0408 471 089

Email: adamdj1@optusnet.com.au or adam.johnston@hdr.mq.edu.au or

adam.johnston@students.mq.edu.au

Macquarie University, Macquarie Park, Sydney, Australia:

https://law.mq.edu.au/current_students/higher_degree_research_students/adam_johnston/

*You can see my paper on the University of New England (UNE), Armidale e-publications at <http://e-publications.une.edu.au/1959.11/11369> and the Social Science Research Network (SSRN) at: <http://ssrn.com/abstract=1855924>
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www.avast.com

Adam Johnston

From: Adam Johnston <adamdj1@optusnet.com.au>
Sent: Monday, 26 April 2021 8:50 AM
To: 'DRC Submissions'
Cc: 'CHATSWOOD'; 'feedback'; 'NAT@ndis.gov.au'
Subject: How a gate became a trap door
Attachments: Gate opener; FW: Gate opener ; RE: Gate opener ; FW: Gate opener ; Gate opener ; Payment has been made by ██████████ for Adam Johnston for \$AUD 485.28; FW: ██████████ invoice - gate opener; FW: ██████████ invoice - gate opener; Submission to NSW Parliament.pdf; Advice to ██████████.pdf

Cc: NDIS Chatswood Office, National Office, and Feedback Line

Dear submissions team,

I am tired, very tired. I'm tired of a disability system that treats me like an unpaid filing clerk. One is particularly tired of an NDIS Agency that seems to relish making the simplest things difficult. As you will see, most of the emails concern an automatic gate opener, which we decided to buy, given my increasing difficulty opening the manual gate – and my desire to avoid grazed knuckles, arms, and elbows. On 2 April, my mother received and paid an account from ██████████ regarding the gate. I forwarded it to ██████████ on 3rd April. There were two attached documents – an invoice and a receipt.

On 6th April, the email was acknowledged and 'put up for review' – which I noted in another submission to the Disability Royal Commission was 'yet another process'. By 9th April I had remittance advice from ██████████ which showed they would cover the hardware, but not the labour. Then, on 21st April, we heard from ██████████ proprietor ██████████ saying that a company called ██████████ had paid the entire account, which my mother had already paid. The next day, I alerted ██████████ and alerted my ██████████. I followed up by phoning ██████████, while in a taxi at the time, travelling between several appointments and explaining that I just needed the problem fixed; because ██████████ wanted to know what to do with the surplus funds. On 22nd April, ██████████ claimed there was confusion about whether my initial email of 3rd April represented a bill for payment or a receipt for reimbursement. However, ██████████ email of the 6th suggests no confusion whatsoever – indeed, they reimbursed me for the hardware a few days later. ██████████ also tries to blame me over the question of a \$900 figure. This came from an email written by me at about 8.40am in the morning, in a hurry, when I was suitably annoyed and had far better things to do that day rather than clean up a Plan Manager's mess.

██████████ has all relevant records, even if they do not realise it. They clearly do not realise they have also already reimbursed me for the gate hardware, regardless of what initial view they took on the payment of labour costs. However, in the email sent "22/4/21 12:24 pm (GMT+10:00)" ██████████ states:

'There are 2 options:

- The provider can transfer the funds directly to yourself, which would be the fastest option
- The provider can transfer the funds back to ██████████ and upon receipt we can transfer into the nominated bank account on file.'

Following this advice, my mother and I have advised ██████████ to reimburse us directly. This at least gets the supplier out of the picture. It is sad when you come to regret another person's honesty and integrity. Had he chosen not to inform us of the double payment, we would still have the gate we wanted and be none the wiser as to the payments made. But neither ██████████, nor any other part of the vast NDIA or NGO bureaucracy joined any of the dots. It fell to me, my mother and a supplier who is too honest for his own good for this to become known. And still, those officially paid from 'my' NDIS budget to manage the account on my behalf have not seen the double payment for the gate hardware. Personally, I don't want to waste any more time on this ██████████ but I do want the Commission to see it, along with the NDIA. Hopefully, it will fundamentally embarrass the Agency and expose the vulnerabilities and chaos of individual budgets. Again, both my mother and I have wasted enough time on this matter. We have raised the matter; however, we should not be expected to do the jobs others

get paid to do but are clearly not competent to perform. Should I claim the funds as compensation for time and distress caused by having to deal with the NDIS? After 7 long, bad years under the NDIS and its shortcomings, this is a question worth asking.

It is also clear that the NDIA is not serious about fraud, otherwise examples such as the one below, would not happen:

[Gold bullion, luxury cars and drugs seized in alleged \\$10 million NDIS scam \(smh.com.au\)](http://www.smh.com.au)

Whether it is gold bullion or parts for a gate, it is indicative of the same problem. We have so many plans, so much paper and so many bureaucrats but no one has a clue what is going on; and besides, it is only the disabled. Near enough is good enough, even if this is ten miles off. This is certainly the impression left on me.

It was better when we had State-run departments for disability. They provided a more restricted set of services but at least they did their own books and did not expect the client or family to do the accounts on an honorary basis. This is what is expected now, and it should be considered a form of exploitation. Why should people work for nothing, particularly when their attachment to the NDIS is not voluntary but by virtue of critical need? In the meantime, the NDIA still relies on a variety of NGO providers whose governance of money and care of people I would call dubious. The attached submission to the NSW Parliament, while dated, outlines a set of very formative experiences for me in this regard. I took those concerns to ASIC, the Charities Commission and NSW Fair Trading. For a variety of reasons, these bodies decided not to act. And this was in the time just prior to the transition to the NDIS – and governments continued with the transition anyway?

Should anyone in the NDIA have a resolution to my “gate payment” anomaly, they are welcome to contact me.

Yours truly



Adam Johnston

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Email: adamdj1@optusnet.com.au or adam.johnston@hdr.mq.edu.au or

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Macquarie University, Macquarie Park, Sydney, Australia:

https://law.mq.edu.au/current_students/higher_degree_research_students/adam_johnston/

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Adam Johnston

From: Adam Johnston <adamdj1@optusnet.com.au>
Sent: Saturday, 17 July 2021 5:52 PM
To: [REDACTED]
Cc: [REDACTED] 'DRC Submissions'
Subject: Formal request for a review of Decision
Attachments: Your reporting dates and important information_K252954372.pdf; RE: Submission to "Better Management" inquiry; the Disability Strategy inquiry and, the Modern Slavery inquiry; SUBMISSION TO COMMITTEES.DOCX

[REDACTED]

Cc: Disability Royal Commission, Submissions Team
[REDACTED]

Dear [REDACTED]

I note the attached PDF letter from one of your business units – Centrelink. This will mean yet another cycle of mandatory, fortnightly reporting. Firstly, I ask whether this is necessary? The Department knows (or should know) my pattern of part-time work. It should also know that should I do anything else on an ad-hoc basis, I have uploaded it promptly onto your Document Management System. Again, one asks: what is the problem?

Your letter also points out that you can check amounts with the Australian Taxation Office. If you can do that, why do you need me to make reports? Would it not be simpler for both your Department and me to reconcile payments annually through the tax process? Again, in my experience of your Department writing me letters saying that you believe I have been periodically overpaid, it invariably falls to me to ring the Department to remind you that I cannot just pop out to a bank and arrange for payments to be made. Ultimately, your officers will agree to adjust payments and/or make deductions via their system. However, it both annoys and amazes me that these conversations continue to have to be had. It is also noteworthy that these conversations occur both long after any work was done and, long after the upload of documentary evidence.

About two weeks ago, a Centrelink officer contacted me by telephone. Indirectly, it was in relation to a complaint [REDACTED], had made to you as Departmental Secretary. We had believed a letter sent to [REDACTED] concerned her income and eligibility for the Carer's Allowance – Centrelink asserted that it was about my income from 1 day a week of regular employment (which has been in place for a year and is known to Centrelink). The officer also explained that thanks to some legislative amendments passed in December last year, unless people like me make reports, your Department will stop all fortnightly payments. This is one way the Department avoids a *RoboDebt* outcome, while placing all the onus on disabled, possibly chronically ill, part-time, or ad-hoc workers to keep track of much paperwork, dates, and events.

At the same time, I am part of the National Disability Insurance Scheme by virtue of disability. Through the euphemism of 'choice and control' I now have providers, budgets, contracts, and an individual plan. There are always documents needing my approval or providers/staff bringing me their problems. Now Centrelink wants fortnightly reports or else your Department will not pay me any Disability Pension. What has happened to any notion of Government responsibility for public welfare, or that someone may be entitled to support on a basis other than income, say disability or illness? Equally, what has happened to the notion that Government would provide such goods, services, or payments, without the citizen constantly having to prove and reaffirm their need or status. Why am I the secretary to Centrelink and the NDIS, when both agencies under your auspices have far greater administrative resources than I do as an individual? This self-service, individual choice, and do-it-yourself approach to accessing Government services is very tiring on mind and disabled, ageing body. You seem to be laying-in-wait for

me to make some sort of mistake which will give you grounds to either cut a payment or demand a repayment. It seems *RoboCancel* has replaced *RoboDebt*. Was this the intention?

For all these reasons above, I request that you formally review my placement on reporting. In noting my submissions to the Better Management and Modern Slavery Inquiries (Word document and attached email), it seems public policy treats the tax and transfer systems as unnecessarily conflicted rather than having complimentary aims of averting poverty and improving the standard of living. Instead, current settings see people lose support when they receive part-time or ad-hoc work. Where is the incentive to continue to find and do more work, particularly when one also sees many dubious NGOs (allegedly supporting me and those like me) receive many millions in taxpayer subsidies annually, while I must fight over my access to a disability pension. Therefore, I draw parallels with concepts of enslavement quite deliberately and unapologetically and, draw this email to the attention of the Disability Royal Commission and my Federal Member of Parliament.

Yours truly,



Adam Johnston

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Phone: 9402-0539

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Email: adamdj1@optusnet.com.au or adam.johnston@hdr.mq.edu.au or

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Macquarie University, Macquarie Park, Sydney, Australia:

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You can see my paper on the University of New England (UNE), Armidale e-publications

at <http://e-publications.une.edu.au/1959.11/11369> and the Social Science Research

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Adam Johnston

35 Woolrych Crescent
Davidson NSW 2085
Adamdj1@optusnet.com.au

[REDACTED]

Cc: [REDACTED]
[REDACTED]

Dear [REDACTED]

Charities Inquiry

I am writing to you after your appearance on ABC's 730 Report, regarding the RSL. While I have no knowledge of that institution, I would urge you to extend the Commission of Inquiry to encompass all charities in NSW.

My own experiences, outlined in the attached documents, have fundamentally altered my view of charity. I am skeptical of many organisations and their true motives. In my opinion, charitable tax exemptions should be withdrawn, while the State Auditor must be given the authority to examine the accounts of any charity which receives any public money.¹

I sympathise with the former CEO of the RSL. Ask too many questions, look under too many rugs or disturb too many conventions and, "the powers that be" will soon march you out the door. This is true of many if not all charities, and given that the NSW Government has outsourced so many functions and services to third sector bodies, it is long overdue that they were all scrutinised.

In my own case, after being shown the door myself I informed ASIC and the Charities Commission. ASIC declined to take it up, while the Commission could not act because my complaints pre-dated its legislation. In the years since, I've written extensively to countless inquiries and reviews. The RSL maelstrom

¹ Go to my submission at <https://www.parliament.nsw.gov.au/committees/DBAssets/InquirySubmission/Summary/48395/Submission%20No%207.pdf> as at 16 May 2017

shows the lack of accountability or reform to date. Too many people are still misappropriating funds meant for others, enriching, and indulging themselves, with no fear of consequences. Reform must occur or charitable status must be abolished altogether.

Yours faithfully,

A handwritten signature in black ink that reads "Adam Johnston". The signature is written in a cursive style and is positioned above a thin horizontal line.

Adam Johnston

16 May 2017



Our ref: MIN17/1307

Mr Adam Johnston
Via email: adamdj1@optusnet.com.au

Dear Mr Johnston

I refer to your correspondence to the [REDACTED]
[REDACTED], regarding your request for a Commission of Inquiry into all charities in NSW.
The Minister has asked me to respond to you.

At this time, there is a lack of evidence necessary to support a wide-ranging and costly
Commission of Inquiry.

There are approximately 5,600 charities in NSW. Their operations are regulated through the
Charitable Fundraising Act 1991 (the Act). In addition to this, some charities may also be
regulated by the Australian Charities and Not-for-profit Commission (ACNC).

NSW Fair Trading carries out inspections and compliance operations based on complaint
data and marketplace intelligence. Despite the size of the charitable fundraising industry,
Fair Trading receives relatively few complaints concerning financial mismanagement by
charities.

Section 24 of the Act requires that a charity must have its accounts audited annually by a
person qualified to audit accounts for the purpose of the *Corporations Act 2001*. This
requirement has been modified by clause 12 of the Charitable Fundraising Regulation 2015,
which provides an exemption for charities that do not receive more than \$250,000 per year.
However, the Minister may direct a charity to have its accounts audited in accordance with
Section 24.

Charitable tax concessions are applied by the Australian Taxation Office to charities which
are regulated by the ACNC under Commonwealth legislation. The NSW Government does
not have jurisdiction or control over a charity's charitable tax concession status.

If you have evidence of financial mismanagement by a specific charity, please contact
[REDACTED] or at
[REDACTED]

Yours sincerely

[REDACTED]
[REDACTED]
9/6/17

Adam Johnston

From: Adam Johnston <adamdj1@optusnet.com.au>
Sent: Thursday, September 28, 2017 9:53 AM
To: [REDACTED]
Subject: RE: MIN17/1307 Letter for Mr Johnston from the Commissioner of Fair Trading

Dear [REDACTED]

In relation to this inquiry, is there anything further you need from me?

Regards



Adam Johnston

35 Woolrych Crescent

Davidson NSW 2085

Phone: 9402-0539

Mobile: 0408 471 089

Email: adamdj1@optusnet.com.au or adam.johnston@hdr.mq.edu.au or

adam.johnston@students.mq.edu.au

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From: [REDACTED]
Sent: Monday, June 26, 2017 1:07 PM
To: Adam Johnston <adamdj1@optusnet.com.au>
Subject: RE: MIN17/1307 Letter for Mr Johnston from the Commissioner of Fair Trading

Dear Mr Johnston
I acknowledge of receipt of your email and I allocate it to one of my staff who has significant experience in reviewing matters involving charities
regards

[REDACTED]

From: Adam Johnston [<mailto:adamdj1@optusnet.com.au>]
Sent: Monday, 26 June 2017 1:04 PM
To: [REDACTED]
Subject: FW: MIN17/1307 Letter for Mr Johnston from the [REDACTED]

[REDACTED]

[REDACTED]

I write to you on the recommendation of [REDACTED] Originally writing to the Minister in light of the publicity surrounding the RSL. I called for a general Royal Commission on charities.

This came from my own experience as a Board Director of the Spastic Centre of NSW (now Cerebral Palsy Alliance) between 2009-2011. What I saw and heard during that time shook my confidence in charities generally. Refer to the “My files” attachment

1. Appendix 2, page 9-10 of 21, footnote 16. [REDACTED]
2. Appendix 4, page 14-15, footnote 46 (same issues);
3. Statement in Response – my resignation;
4. Various related emails, regarding the submissions above

I also wrote to ASIC – my concerns were not considered a priority. The National Charities Commission advised that my complaint pre-dated their legislation and they could not act.

While accepting my concerns are now dated, it seems from recent revelations that there continue to be many dubious people and practises in the charitable sector. I also find it especially distasteful that as an NDIS participant, I must now accept services from a sector I really do not trust.

If there is anything you can do with my information, or any further way I can assist, please let me know.

Yours faithfully,



Adam

Adam Johnston
35 Woolrych Crescent
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Phone: 9402-0539
Mobile: 0408 471 089

Email: adamdj1@optusnet.com.au or adam.johnston@hdr.mq.edu.au or
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From: CommissionerSM [<mailto:commissioner@finance.nsw.gov.au>]

Sent: Wednesday, June 14, 2017 12:45 PM

To: adamdj1@optusnet.com.au

Subject: MIN17/1307 Letter for Mr Johnston from the Commissioner of Fair Trading

Dear Mr Johnston,

Please see attached letter from the Commissioner of Fair Trading.

Regards,



Department of Finance, Services and Innovation

www.finance.nsw.gov.au

Level 22, McKell Building, 2-24 Rawson Place Sydney NSW 2000



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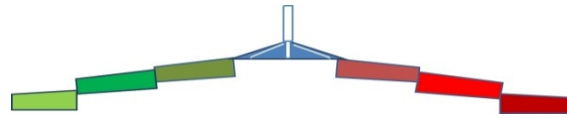
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To:

[REDACTED]

**Joint Standing Committee on Foreign Affairs, Defence and Trade
House of Representatives Standing Committee on Tax and Revenue
Department of the House of Representatives**

PO Box 6021 | R1.120 Parliament House | Canberra ACT 2600

[REDACTED]

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From: Adam Johnston, Proprietor, ADJ Consultancy Services

Date: 16th April 2017

Re: Inquiry into establishing a Modern Slavery Act in Australia

[REDACTED]

I write to support the establishment of a Modern Slavery Act. However, to be effective, such a law must have within its remit, the operation all public laws. In this sense, I am speaking particularly of Commonwealth welfare legislation and, would highlight the recent Commonwealth Centrelink “Robo-debt” debacle as a classic case of reprehensible behavior by Government bureaucrats (and their Minister), which a Modern Slavery Act should cover.

This was my reasoning behind sending you my submission into Centrelink’s *Better Management* system. Any fair reading of what is already on the Australian Statute books¹ should at least give the Human Services Department cause for concern over both its conduct and policy.



My own experience of Centrelink leads me to the conclusion that its processes and procedures do meet many of the indicia of slavery.

Again, the Criminal Code states:

Section 270.4(1) defines 'servitude' as:

*the condition of a person (the **victim**) who provides labour or services, if, because of the use of coercion, threat or deception:*

(a) a reasonable person in the position of the victim would not consider himself or herself to be free:

(i) to cease providing the labour or services; or

(ii) to leave the place or area where the victim provides the labour or services; and

(b) the victim is significantly deprived of personal freedom in respect of aspects of his or her life other than the provision of the labour or services.²

I submit that you could look at “Robo-debt” and the Government’s *Welfare to Work Scheme* more generally and, conclude that many of the elements of servitude are satisfied. Certainly, while one was originally favorably inclined to such policies, you had to begin to wonder when credible, serious journalists like the late Adele Horin wrote reports in which she related things like:

I have vivid memories of a young man I interviewed who had had his unemployment benefit stopped for eight weeks. Even though he had been reduced to sleeping on the streets, he held onto a neat folder containing copies of every job application he had ever made, and all written responses, as well as every piece of correspondence from Centrelink filed in individual plastic envelopes. I marvelled at his orderly habits in stark contrast to the chaotic jumble on my desk. But even he had slipped up in the end, transgressing some rule or other.³

When poverty and homelessness can be the outcome of a technical failure to provide documents or report some meagre income (and that this is somehow

² Ibid

³ Adele Horin, *You'll work like a dog to make Centrelink happy*, January 31, 2009 <http://www.brisbanetimes.com.au/news/opinion/youll-work-like-a-dog-to-make-centrelinkhappy/2009/01/30/1232818724404.html> as at 10 June 2010



viewed as acceptable), how is this *not* a form of state-sanctioned servitude? Certainly, in my own dealings with Centrelink, I have felt the Department of Human (Inhumane) Services demands for assorted documentation, receipts, and the like, weighing heavily on me like full-time unpaid labour. Equally, as stated to you in the prior submission,⁴ the Department has few qualms about ringing people unannounced and even on weekends to 'request' (perhaps more correctly 'demand') information.⁵

Such interventions and intrusions (especially on the weekend) rob one of peace of mind and, the freedom and liberty to quietly enjoy one's life. You

⁴ Here re-submitted to you as Appendix 1

⁵ Refer to my submission to the Senate regarding Disability Employment Services

(<http://www.aph.gov.au/DocumentStore.ashx?id=a6fa4e6a-eb31-49de-bb0f-c9f11849c86c> as at 14 April 2017). Included as part of that document was a submission to the earlier Disney Review of Welfare, in which I said (at page 8):

In my own situation, one often felt you needed a secretary to manage all the forms and letters coming from Centrelink, not to mention drafting responses by a specified date, lest a payment be cancelled. How do people who are desperately ill, or have limited literacy cope with all of this? The short answer is: many do not.

The Review should view this question, not only from the perspective of welfare recipients, but the cost of overall public administration. For example, does it really benefit the Australia taxpayer to have government offices open on Christmas Eve and staff on overtime, just to maintain a payment and reporting cycle? I suggest not, but in the rhetorical flurry of stopping 'welfare bludging' and 'social security fraud' practical and pragmatic questions are not asked.

My own case, which must have cost the bureaucracy hundreds of thousands of dollars in man hours over half a year, in a dispute Centrelink ultimately lost, should stand as an example of why reform is urgently needed.

I make a similar point in Appendix 1, where I say (at page 10 and 13):

there seems to be a view in the Department that Centrelink can contact clients at any time and insist on information. When I found that this included Saturday morning, rather than spending Saturday afternoon with the newspaper, I was drafting yet another email to [REDACTED]. It is acknowledged that the Department sent a letter, dated 10th May 2016, apologizing for any distress caused and affirming I was not obliged to take calls, particularly on the weekend or out of hours.

While I appreciated receiving the letter, had one not complained, I would not have known about my ability to rebuff unwelcome, untimely, and unwarranted callers, even if they are from Centrelink/Human Services...Why should people keep copious records, to inform government of matters the State can find out quite readily (and does) by other means? Why does the State continue to fund/subsidise NGOs and other bodies, forgoing billions in revenue? If this stopped, would we finally have a Budget that could afford the direct delivery of decent goods and services; rather than chasing the sick and vulnerable over debts?



must address yourself to the next reporting deadline, the next letter, the next appeal, the next complaint, or what to do about the sudden cancellation of payments.

And, recent media reports show that Ms. Horin's observations still ring very true. A fearful person is not a free person; such a person is clearly vulnerable and can be more readily coerced. A brief internet search will show a strong correlation between references to 'fear,' 'robo-debt' and Centrelink.⁶ It is also noteworthy that bodies including Victoria Legal Aid viewed robo-debt the system as potentially illegal.⁷

Again, as stated here and in Appendix 1 (though perhaps less explicitly) the elements of servitude can be made out quite reasonably, and applied to Centrelink's robo-debt and *Welfare to Work* programs. Some would claim that as one is accepting public welfare, one has a duty to report to the State what you are doing to justify the receipt of these funds.

However, the first answer is that social welfare was originally conceived as protective, aimed at alleviating poverty and stabilizing the economy. Writers like John O'Brien and Simon Duffy make the point that:

The welfare state did not come into existence for reasons of theory; it was developed as a response to decades of fear, terror and horror. Politicians of all colours came to see that it was going to be necessary to put in place a system of social security in order to avoid the kinds of revolutions, wars and totalitarian states that had grown out of the injustices and insecurities of the previous hundred years or more.⁸

They also cite opinion that, in the Post-War period, only the State was believed capable to deliver many services.⁹ Consequently, people in Australia and

⁶ See https://www.google.com.au/?gws_rd=ssl#q=centrelink+fear+robo+debt&spf=1 as at 14 April 2017

⁷ See *Centrelink robo-debt 'abject failure' and arguably unlawful, Victoria Legal Aid says*, The Guardian <https://www.theguardian.com/australia-news/2017/apr/11/centrelink-robo-debt-abject-failure-and-arguably-unlawful-victoria-legal-aid-says>

⁸ O'Brien, John and Simon Duffy (eds.), *Citizenship and the Welfare State*, 'The Need for Roots,' The Centre for Welfare Reform, March 23, 2016, United Kingdom, p. 12, <https://www.scribd.com/doc/305719429/Citizenship-and-the-Welfare-State#download&from_embed> as at 29 August 2016

⁹ See *ibid.*, p.15



several other similar Western democracies came to accept and indeed expect, that government spending would account for a sizeable portion of Gross Domestic Product (GDP).¹⁰

I do not intend to be diverted into a debate about neo-liberalism or the breakdown of the Post-War consensus.¹¹ Rather, the point is that if welfare payments have changed from being for social support and poverty alleviation, to an exchange of value for labour, then it is legitimate to scrutinise the welfare system in terms of compliance with anti-slavery laws.

In my view, it's when you frame the question this way, a whole raft of government policies and payments become legally problematic. From the *Welfare to Work* scheme, to the BSWAT wage scheme which pays people with disabilities in heavily subsidised Special Business Enterprises a pittance wage (to maintain their Disability Pension),¹² you have a problem. This problem

¹⁰ See *ibid.*, pp. 13-14

¹¹ I discuss this in my submission to the House Economics Committee regarding Income tax deductibility <http://www.aph.gov.au/DocumentStore.ashx?id=00874c93-07f4-4b37-9403-c50fef481832&subId=407687> as at 14 April 2017. Note page 11, where I state:

The concept of 'mutual obligation' marks an important point in critical thinking about welfare, especially the legal, moral and political basis for its provision. Hartman and Darab (in a wider discussion of the Howard Government's *WorkChoices* industrial relations policy), argue that welfare has ceased largely to become "a right of citizenship but as the provision of minimum social standards that are appropriate to the stage of capitalist development". These authors argue that this change is based on the convergence of two ideological policy arguments; the first sees work as a 'social good' while the second views welfare dependence as a barrier to the attainment of the first.

References: Yvonne Hartman and Sandy Darab, *Howard's Way: Work Choices, Welfare Reform and the Working Wounded* (Paper presented to the Road to Where? *Politics and Practice of Welfare to Work Conference*, 17-18 July, 2006, Brisbane), p.8, quoting Mishra, R. 1999, *Globalisation and the welfare state*, Edward Elgar, Aldershot, <http://www.uq.edu.au/swahs/welfaretoWork/Final/conferencepaperHartman.pdf> as at 6 January 2016; also quoting Dean, H. 2004a, 'Human rights and welfare rights: contextualising dependency and responsibility', in *The Ethics of Welfare: Human rights, dependency and responsibility*, ed. H. Dean, The Policy Press, Bristol, pp. 7-28; Dean, H. 2004b, 'Reconceptualising dependency, responsibility and rights', in *The Ethics of Welfare: Human Rights, Dependency and Responsibility*, ed. H. Dean, The Policy Press, Bristol, pp. 193-210.; Andrews, K. 2005, 'A nation of participants – Workplace relations and welfare reform', *The Sydney Papers*, Autumn, pp. 75-82; Australian Government 2005b, *Welfare to Work: 2005-06 Budget*, Commonwealth of Australia, Canberra.

¹² See e.g.: High Court Decision on the Business Service Wage Assessment Tool, <https://rlc.org.au/article/high-court-decision-business-service-wage-assessment-tool>; see also Underpaid disabled workers to claim compensation from Government after Federal Court win - By [Joanna Crothers](#) Updated 16 Dec 2016, 2:09pm



extends to Vocational Education contracts where non-profit providers always seem to get paid, but students can all too often end with no job, no payment, and no qualification. Having had personal experience of this, and having been singularly unimpressed with the reaction of regulators and ministerial offices to my complaints,¹³ I submit there are numerous levels of aggravation to any claim of servitude.

The first is that our governments, at both State and Commonwealth level, have rushed with a sickening haste to 'wash their hands' of the sick, elderly, unemployed and disabled. While watching whole Government Departments close around us (like Ageing, Disability and Homecare [ADHC] in NSW¹⁴) we are told that the non-government sector will provide more choice and flexibility in service delivery.

This is not true; one has lost count of the number of times I have come across poor NGO administration, governance and, service. All too often, hackneyed lines about 'wonderful charities' and 'selfless workers' provide a smokescreen of respectability for otherwise dysfunctional organisations. Those who run these bodies are too often also people the commercial and productive sectors of the economy would never employ; equally, no customer with true choice and market power would choose to deal with many of them.¹⁵ Regardless,

Fri 16 Dec 2016, 2:09pm, <http://www.abc.net.au/news/2016-12-16/class-action-settlement-intellectual-disability-workers-approved/8126860>; also see Q&As: Business Services Wage Assessment Tool (BSWAT) Payment Scheme, <https://www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/for-people-with-disability/bswat-payment-scheme/questions-and-answers-bswat-payment-scheme#howmuchwill> as at 14 April 2017

¹³ See my submission to the Human Rights Commission *Willing to Work* inquiry at http://www.pc.gov.au/data/assets/pdf_file/0004/209749/subpfr356-human-services-identifying-reform-attachment1.pdf; also see my submission to recent review of Federally funded VET at http://www.pc.gov.au/data/assets/pdf_file/0005/209750/subpfr356-human-services-identifying-reform-attachment2.pdf; also see my submission to Department of Social Services, New Disability Employment Services from 2018 - **DISCUSSION PAPER** at <https://engage.dss.gov.au/wp-content/uploads/2016/12/Submission-re-DES.docx> as at 14 April 2017

¹⁴ See e.g. NSW CID Member Speaks Out About Privatisation of NSW Government Disability Services, <http://www.nswcid.org.au/blog/nsw-cid-member-speaks-out-about-privatisation-of-nsw-government-disability-services.html>; also see Even less choice: the latest on the ADHC transfer of services, <http://www.nswcid.org.au/blog/even-less-choice-the-latest-on-the-adhc-transfer-of-services.html>; also see OUR CHOICE IS ADHC. We are opposed to the NSW Government's plan to close down all public disability services and transfer all ADHC group homes, respite centres, staff and clients to the private sector, <https://ourchoiceisadhc.com/> as at 15 April 2017

¹⁵ See e.g. my Submission to the NFP Tax Concession Working Group at <http://www.treasury.gov.au/~media/Treasury/Consultations%20and%20Reviews/Consultations/2012/Tax%2>



those of us who are disabled, elderly, unemployed, sick, poor, or otherwise needy are often herded towards these bodies, as governments put large parts of what were formally public welfare functions out to tender. These tenders are awarded to NGOs; as is my experience with the National Disability Insurance Scheme (NDIS), I must select a NDIS registered NGO, just as much as my entry into the scheme was decided for me by the NSW Government. As mentioned earlier, the State Government tore down ADHC around me, very much against not only my wishes, but those of many other people.¹⁶ It left me and all other ADAC clients with nowhere else to go but the NDIS. After all, our disabilities were not leaving us, even if ADHC was.

Thus, while the provision of services element of servitude is not strictly being met, other elements are. I signed up to the NDIS not as an act of free will, but as an act of dependence and necessity. Obligation and not free will has marked other contracts with NGOs in employment services and VET amongst other programs. In my opinion, NGOs should never have that kind of coercive power over people, either directly or as a delegate of the State. If a Government bureaucracy wants me to do something (or not do something) it should have the courage to stand behind its own policy or law and, come in its own Name. If a government is not prepared to do that, then it should not be permitted to send non-government minions to do its 'dirty work'. Too often though, this is exactly what happens. Then if a disabled or unemployed person, like me,

[0concessions%20for%20the%20not-for-profit%20sector/Submissions/PDF/001_Adam_Johnston.ashx](#); (as at 15 April 2017) the submission referenced at footnote 13 is particularly relevant. The government often mandates that an unemployed, disabled people 'engage' with a Disability Employment Services provider. This is an onerous and pointless exercise, costing the Government millions in grants and subsidies for NGOs, and all so a Minister can tell Parliament that 'something' is being done for the disabled. The client often receives little out of the process, other than a series of mandatory meetings, mountains of repetitive paperwork, which rarely, if ever leads to employment.

Unless you are an effective negotiator, and can point out repeatedly that the \$60 to \$70 in fortnightly cab fares is a meaningful amount of money, you will lose even more money for a failure to attend. You must hope for an agent who is sensible enough to equate a telephone call with physical attendance. In my case, I thought it was best to study, as I was very much over the 'job hunt' and all the bureaucratic nonsense that goes with it. Again, my view is that such schemes do touch on the definition of servitude, because:

- You must attend a designated place (office) at a designated time;
- You must demonstrate your application to the designated task (job hunting) in the intervening period;
- Failure to comply, in any way, will result in a diminution or suspension of payment, significantly curtailing one's freedom of movement and, the freedom to concentrate on anything other than the search for work and the documenting of this activity.

¹⁶ Refer to footnote 14, above



interacts with say a VET provider (as we are supposed to) we run the risk of increasing our indebtedness while we receive an *allegedly* nationally accredited qualification; note my use of the word *allegedly*. And sadly, don't expect too much from government (or the NGO delegate) when things go wrong.

Again, much of this covered in Appendix 1. My point in bringing it here is to underline how much modern training can place the financial burden on the recipient. Some people no doubt end up in poverty; meanwhile government and industry will continue to mandate ongoing training, as much for the unemployed person as for the accredited professional. At times, both the direct costs of participating in training (e.g. entry fees) and indirect costs (e.g. transport costs) will come directly out of the participant's pocket.

When you are at the lower levels of the income ladder (or unemployed) these outlays are quite significant. With many employers also opting to use unpaid trainee or internship places, even finding work does not bring financial relief. These arrangements should as much be regarded as a form of servitude, as should the forced removal of the disabled and elderly from government support and service providers to the charitable sector. We were not asked, we were told and, if we wished to exercise a choice to stay with the public provider this was not made available to us, as ADHC was closed. If the result is not servitude, then I don't know what is; certainly, as I highlighted in Appendix 1, Oscar Wilde put it succinctly, when he observed:

But (charity) is not a solution: it is an aggravation of the difficulty. The proper aim is to try and reconstruct society on such a basis that poverty will be impossible. And the altruistic virtues have really prevented the carrying out of this aim. Just as the worst slave-owners were those who were kind to their slaves, and so prevented the horror of the system being (realised) by those who suffered from it, and understood by those who contemplated it...Charity degrades and (demoralises)...Charity creates a multitude of sins.¹⁷

¹⁷ Oscar Wilde, "The Soul of Man Under Socialism," Appendix 1, p.12 (footnote 29)
<<https://www.marxists.org/reference/archive/wilde-oscar/soul-man/>> as at 16 April 2017

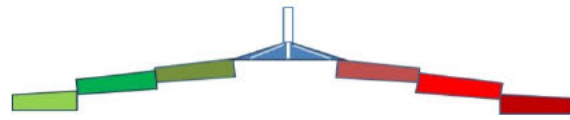


I hear the words louder every day. The NDIS, employment services providers and others in the NGO/charitable arena can talk all about choice, autonomy, and flexibility, but it's simply not credible.¹⁸ They say if it waddles like a duck, quacks like a duck and looks like a duck it is a duck. Similarly, much in the charity, NGO and human services sector runs on obligation, little or no choice and, little or no remuneration for services given or training completed. As stated earlier, if the fundamental premises on which social welfare is delivered have changed (and there seems overwhelming evidence for this) then the legal framework by which it is judged should reflect the change.

People now receive welfare as an exchange for labour; it is no longer poverty alleviation and as the quote from Adele Horin showed earlier, it has long ceased being about social or community protection. While I am fortunate enough never to have been made destitute, not everyone (particularly those who are disabled) can come from a family where others near and dear have secure employment and can help with the expenses of daily living. While happy to do a range of things on an honorary basis, it nonetheless surprises me how many employers and professional bodies, as well as charities, employment agents and others seem to think *they are doing you a favour*, so naturally you will dispense your knowledge, skills, and experience for nothing.

A serious anti-slavery law for Australia would have these issues at its heart, alongside the question of whether the operation of government policies (like the NDIS) leave some of our most vulnerable citizens lost in a quasi-slave jurisprudential position. With lives controlled and funded by NGOs, it is unclear to me (as a disabled man) how much my State or Commonwealth Government wants me to continue as a public citizen (or even acknowledges my claim to such a status). After all, many of the services I continue to rely on used to be in public hands, accountable to a Minister, Parliament and, the public. Now, while

¹⁸ I discuss this in my submission to the Productivity Commission's Inquiry into Competition and Human Services at http://www.pc.gov.au/data/assets/pdf_file/0003/209748/subpfr356-human-services-identifying-reform.pdf as at 16 April 2017. Note especially footnote 14 and the fact that the reform mentioned has still to be implemented. The Government is very happy to give NGOs billions of dollars, but does not move with anything like the same speed to confirm monies granted reach the intended clients. The most forgiving interpretation of this failure is that it is a Government error or misstep. The least generous view is that the Government is very happy to have the disabled off its hands; so long as money is granted those in power can say obligations are being met. Empowering the Auditor to examine the conduct of NGO spending will only invite problems and controversies all sides of politics would rather not know about.



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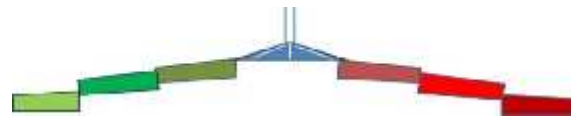
the central money dispensary is public (the National Disability Insurance Agency) those who provide services to clients like me, are not public entities. People can say there are Ombudsman offices and that there is a Quality Framework, but I really don't feel safe or reassured by any of that. There is nothing in the new scheme that is truly commensurate to the large portion of public and parliamentary oversight (not to mention public service infrastructure) dismantled (perhaps more correctly, destroyed) during the 'reform' process. After all, as noted earlier, the NSW Auditor can't even follow the NGO money trail to see that the money meant for me is spent on me.

Despite these significant flaws, the NDIS went ahead and, thousands of people like me had no choice but to sign up. I challenge anyone to argue that there is not a considerable degree of servitude in such a policy.

Yours faithfully,

Adam Johnston





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To: **PRODUCTIVITY COMMISSION INQUIRY INTO INTRODUCING COMPETITION AND INFORMED USER CHOICE INTO HUMAN SERVICES**

From: Adam Johnston, Proprietor, ADJ Consultancy Services

Date: 27 October 2016

Re: **INTRODUCING COMPETITION AND INFORMED USER CHOICE INTO HUMAN SERVICES**

TERMS OF REFERENCE (IN PART)

In the second stage, the (Productivity) Commission will undertake a more extensive examination and provide an inquiry report making recommendations on how to introduce greater competition, contestability and user choice to the services that were identified above.

(a) In providing its recommendations, the Commission's report should identify the steps required to implement recommended reforms.

(b) In developing policy options to introduce principles of competition and informed user choice in the provision of human services, the Commission will have particular regard, where relevant, to:

(i) the roles and responsibilities of consumers within the human service sector, and the service or services being considered;

(ii) the factors affecting consumer use of services and preferences for different models of service delivery, noting the particular challenges facing consumers with complex and chronic needs and/or reduced capacity to make informed choices;

(iii) the role of the government generally, and as a commissioner, provider and regulator, in the delivery of human services;

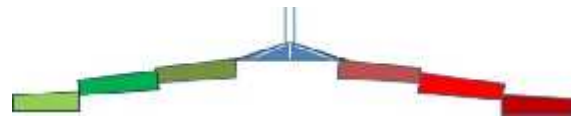
(iv) the role of government agencies in designing policy, commissioning and, in some cases, delivering human services in a client-centred way that encourages innovation, focusses on outcomes and builds efficiency and collaboration;

(v) the role of private sector and not-for-profit providers;

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- (vi) the benefits and costs of applying competition principles in the provision of human services, including improving competitive neutrality between government, private and not-for-profit service providers;
- (vii) how best to promote innovation and improvements in the quality, range and funding of human services;
- (viii) the challenges facing the provision of human services in rural and remote areas, small regional cities and emerging markets;
- (ix) the need to improve Indigenous outcomes; and
- (x) the development of systems that allow the performance of any new arrangements to be evaluated rigorously and to encourage continuous learning.

Dear Commissioners,

All the above words sound good and noble in theory, but they are not anything like that in practical application. As someone with cerebral palsy who has been confined to a wheelchair all my life, I look upon many of the reforms you propose with a degree of horror. This is because personal, first-hand experience says many in the charitable sector are neither noble, nor benevolent. As such, the last thing one wants to see is more collaboration between the NGO or charitable sector and government, regarding the delivery of human services.

I have addressed these issues in a range of submissions, most of which are listed in a submission to a lapsed inquiry of the 44th Federal Parliament into tax deductibility.¹ In short, it is difficult to comprehend how any government can continue to justify cooperation with the NGOs, be it on the grounds of foregone tax revenue (in the form of deductible donations and grants), or the now widely accepted systemic abuse of many vulnerable people which has been exposed by the McClelland Royal Commission into Institutional Responses to Child Abuse and Neglect.²

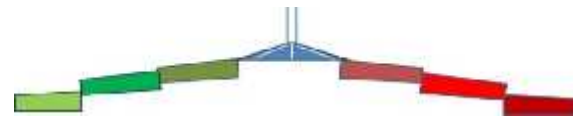
¹ See <http://www.aph.gov.au/DocumentStore.ashx?id=00874c93-07f4-4b37-9403-c50fef481832&subId=407687> as at 26 October 2016

² I attach a copy of my submission to the Royal Commission, with supporting documentation.

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Why would we ever trust or fund any of these NGO care institutions again? I would not and do not endorse the central role of charities in the NDIS rollout. This is emphasized in my submission to the NDIS Discussion Paper on their Safety and Quality Framework.³ Furthermore, an argument can readily be made that moving human service provision to the non-government sector subtly denudes people of their public citizenship, by putting them out of public sight and out of the public mind. This is an argument I have made repeatedly, but most notably before the ALRC's Inquiry into Disability and Capacity before the Law.⁴ You will note that at the beginning of the submission I quote Oscar Wilde who wrote:

But (charity) is not a solution: it is an aggravation of the difficulty. The proper aim is to try and reconstruct society on such a basis that poverty will be impossible. And the altruistic virtues have really prevented the carrying out of this aim. Just as the worst slave-owners were those who were kind to their slaves, and so prevented the horror of the system being (realised) by those who suffered from it, and understood by those who contemplated it...Charity degrades and (demoralises)...Charity creates a multitude of sins.⁵

I do not wish to spend my entire life tethered to the charitable sector by lazy public policy and, it was a relief to see the Commission acknowledge:

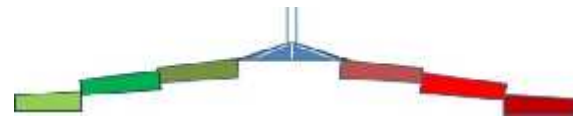
The Commission considers that maximising community welfare from the provision of human services does not depend on adopting one type of model or favouring one type of service provider. Additional benefits — such as those potentially offered by not-for profit organisations — should be considered, but not at the expense of improving outcomes for individuals and their families.⁶

³ See generally, <https://engage.dss.gov.au/wp-content/uploads/2015/05/Submission1.docx> as at 26 October 2016

⁴ See generally, http://www.alrc.gov.au/sites/default/files/subs/12_a_johnston.pdf as at 26 October 2016

⁵ Oscar Wilde, "The Soul of Man Under Socialism." Quotation taken from <http://abetterworldisprobable.wordpress.com/2012/01/01/oscar-wilde-on-the-problems-of-charity/> as at 26 December 2013; Oscar Wilde, *The Soul of Man Under Socialism*, (1891)

⁶ Productivity Commission 2016, *Introducing Competition and Informed User Choice into Human Services: Identifying Sectors for Reform, Preliminary Findings Report*, Canberra, p.7 (17 of 183) Adobe numbering



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As the years' have passed, Wilde's characterization of the charitable sector has increasingly resonated with me, as poor service, poor outcome and a lack of accountability have re-emerged again and again.⁷ This has been my consistent experience with the NGO sector, be it in the provision of disability employment services,⁸ or in my dealings with the National Disability Insurance Agency.⁹

This was an Agency and a reform supposed to be about choice and flexibility, but as my attached complaint to the ACCC shows, it is about an exhausting round of contracts, budgets, red tape and charities trying to gouge money out of you.¹⁰ As I said to a recent conference at the Consumer Directed Care conference at the Northside Conference Centre in Crowsnest NSW,¹¹ I doubted many of us with disabilities were as economically savvy as we were now expected to be. As many of us are both high dependent and living on fixed

⁷ I proposed the NGOs who undertook any public functions should be called before Parliament like any other Department of State. However, NSW did not proceed with recall election reforms; see

http://www.dpc.nsw.gov.au/_data/assets/pdf_file/0008/131120/06_Johnston.pdf as at 26 October 2016

⁸ See my submission to a Senate inquiry into employment services at

<http://www.aph.gov.au/DocumentStore.ashx?id=a6fa4e6a-eb31-49de-bb0f-c9f11849c86c>, and see also

<http://www.aph.gov.au/DocumentStore.ashx?id=b0e07f8c-3f2b-43f0-b6de-3e7f0ceaf38e&subId=301892> as at 26 October 2016

⁹ My becoming a participant in the scheme was forced by the Baird Government's decision to transfer all NSW Homecare clients to the NDIS. I would not have done so, had the State retained its (in my view, proper) role in the direct delivery of disability services. This view is strengthened when considering the words of the Liberal Party's founder Sir Robert Gordon Menzies, when he said:

The country has great and imperative obligations to the weak, the sick, the unfortunate. It must give to them all the sustenance and support it can. We look forward to social and unemployment insurances, to improved health services, to a wiser control of our economy to avert if possible all booms and slumps which tend to convert labour into a commodity, to a better distribution of wealth, to a keener sense of social justice and social responsibility. We not only look forward to these things; we shall demand and obtain them. To every good citizen the State owes not only a chance in life but a self-respecting life. (Source: Petro Georgiou, *Menzies, Liberalism And Social Justice*, Sir Robert Menzies Lecture Trust, 1999 Lecture (1999), 3, quoting as at 13 March 2012, quoting Robert Menzies in a 1942 radio broadcast (citation omitted) <<http://www.menzieslecture.org/1999.html>>; the source of the broadcast is: Robert Menzies, *The Forgotten People: Chapter 5 - Freedom from Want*, 10 July 1942, The Menzies Foundation, Menzies Virtual Museum <<http://menziesvirtualmuseum.org.au/transcripts/the-forgotten-people/63-chapter-5-freedom-from-want>>.)

I suspect Sir Robert would have had many misgivings about Premier Mike Baird's policy choices, particularly with regarding to human services. As a service recipient, even though the quotation is dated, I place greater faith in the judgment of the older, wiser Menzies.

¹⁰ See my attached complaint to the ACCC

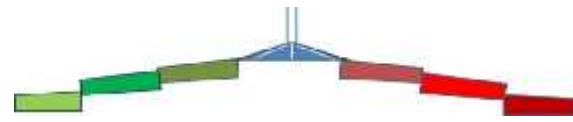
¹¹ See conference details at Care and Support Directed by the Consumer Forum,

<http://sydneynorthhealthnetwork.org.au/consumer-forum-care-support/> as at 26 October 2016

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incomes (i.e.: pensions) the notion that we are anything but price-takers was laughable.¹²

Equally, the notion that there is a market in many human services is also laughable; NGO welfare agencies, be they in child-care, disability care, employment services or aged care, are heavily subsidized by government, devoting much energy to maintaining that subsidy.¹³ Meanwhile, service recipients lose key access to public oversight bodies, when human services are outsourced.¹⁴ This is certainly my experience of the VET sector, where I completed a small business certificate, on the recommendation of disability employment agent who is long gone. I am left with a qualification few seem to recognise and a complaint mechanism that proved to be a disinterested, “toothless tiger”, which I had to pursue via the Commonwealth Ombudsman to have the Australian Skills Quality Agency¹⁵ even respond to my complaint.¹⁶

The push to make human services contestable and market-driven miss several key issues. The first is that many consumers cannot be regarded as customers; we don't have the money to select from a wide range of providers, and the products we seek do not lend themselves to a great deal of differentiation, so is there any great need for “choice”? Further, did we *really* ask for choice, or was this another concept foisted upon many of us, whether we wanted it or not?

And what does it achieve? Those who are providers have great market power because they are often large agencies with a large caseload, alongside an administrative set-up aimed at maintaining relationships with, and subsidies

¹² Find my Powerpoint presentation to forum attached

¹³ See e.g., my submission to the McClure Review of Welfare at <https://engage.dss.gov.au/wp-content/uploads/2016/06/Welfare-review-1.pdf> (as at 26 October 2016) and, also note my 2015 Pre-Budget Submission, attached

¹⁴ The NSW Baird Government is yet to empower the Auditor General to look at the accounts of NGOs, despite outsourcing all disability services to them and, having a clear recommendation from the Public Accounts Committee that reform was needed – The Report <https://www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/5507/Efficiency%20and%20effectiveness%20of%20the%20Audit%20Office%20o.pdf>; my submission <https://www.parliament.nsw.gov.au/committees/inquiries/Pages/inquiry-submission-details.aspx?pk=48395> as at 26 October 2016

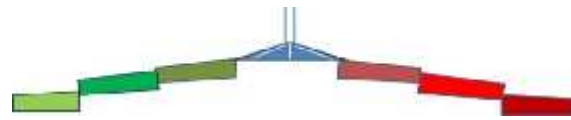
¹⁵ See <http://www.asqa.gov.au/> as at 27 October 2016

¹⁶ See my attached submission to the VET review

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from, government.¹⁷ You can choose another agency, if you have the time, energy and inclination for research, as well as the preparedness to have the rhythms of your life disrupted. So, is it better to “stick with the devil you know?” More often than not, the answer is: “Yes”.

Therefore, in many respects, the NDIS, for all the claims of reform, is little different from the system it is supposedly replacing. As noted above, all the NDIS has brought me is stress and, as my conference presentation argues, while we waste money on rolling out this bureaucracy, what scientific and technological opportunities are we foregoing? There is an opportunity cost to every policy decision and, I would much rather be cured than indefinitely cared for. Additionally, if we were serious about tax reform¹⁸ more people with chronic illnesses and disabilities will find it economically advantageous to work¹⁹ and, we will have the revenue to fund innovation and research, rather than prop up an outsourced care system.

Trying to reinvent the human services sector as an efficient, customer-focused business invokes in my mind the rather blunt terminology of former Queensland Senator and NRL star Glen Lazarus’s rather infamous reference in a press conference to ‘polishing a turd.’²⁰ If needy, vulnerable people are truly citizens, then they deserve to know the State will not abandon them. One of the ways the State can arguably show good faith and maintain the ‘social contract is by being a direct provider of services. Again, while we can complain about public service and efficiencies, it has clearer “chain of command” reporting and accountability lines than say, an industry ombudsman (if you can

¹⁷ I have previously recommended to the State Government that all churches and charities should be registered as lobbyists, if they wish to lobby Government. As far as I know, this has yet to be acted upon; see my submission at

http://www.dpc.nsw.gov.au/_data/assets/pdf_file/0005/170753/ADJ_Consultancy_Services_Submission_on_Lobbying_Regulatory_Impact_Statement.pdf and, a further submission made on reforming political

donations (which covers many similar issues) at

http://www.dpc.nsw.gov.au/_data/assets/pdf_file/0003/166008/Submission_19_-_Adam_Johnston.pdf as at 27 October 2016

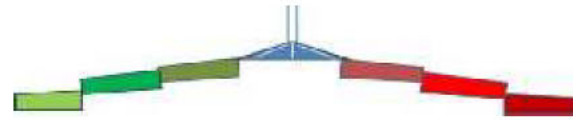
¹⁸ See e.g. my submission to the *Rethink Tax Review* at <https://engage.dss.gov.au/wp-content/uploads/2016/06/Rethink-submission-1.pdf> as at 27 October 2016

¹⁹ See e.g. my submission to the Human Rights Commission inquiry, *Willing to Work*, attached

²⁰ See e.g.: *Brick with eyes: Budget “unpolishable turd”*

By Houses and Holes in Australian budget, Featured Article at 7:20 am on January 22, 2015 | 64,

<http://www.macrobusiness.com.au/2015/01/brick-with-eyes-declares-budget-unpolishable-turd/> as at 27 October 2016



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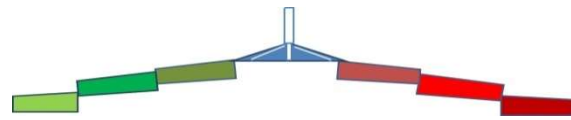
find them). As such, I am far from convinced about the reform of human services and, the introduction of supposed competition.

Yours faithfully,



Adam Johnston

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ADJ Consultancy Services

To: Senate Community Affairs References Committee and;
Joint Standing Committee on Foreign Affairs, Defence and Trade

From: Adam Johnston, Proprietor, ADJ Consultancy Services

CC:

Date: 28 February 2017

Re: Design, scope, cost-benefit analysis, contracts awarded and
implementation associated with the Better Management of the
Social Welfare System initiative and;

Delivery of outcomes under the National Disability Strategy 2010-
2020 to build inclusive and accessible communities and;

Inquiry into establishing a Modern Slavery Act in Australia

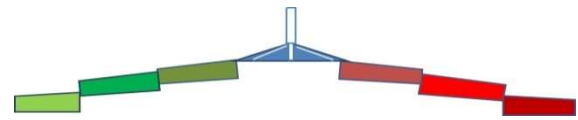
Dear Sir,

Introduction

As a current disability pensioner, who is attempting to run his own one man consultancy, study and, receive work (resulting in sitting fees) from a variety of ad hoc tribunal and committee appointments,¹ I have had plenty of experience with the *Better Management of the Social Welfare initiative* (hereafter *Better Management* initiative). I will make clear, in the course of this submission, why the consideration of *Better Management* should run alongside the consideration of a new Disability Strategy and whether there should be modernized anti-slavery legislation in Australia.

¹ See for example

https://law.mq.edu.au/current_students/higher_degree_research_students/adam_johnston/ as at 25 February 2017



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One keeps an ever-growing list of documents in both electronic and paper form, as well as scanning various pay-slips, receipts, and other forms onto the MyGov system. It is true that *Centrelink* has accused me of being overpaid and/or failing to declare income at various times. An examination of the claims consistently found that my reports or declarations were in *Centrelink's* system, but that they had already made payments.

Two points need to be made here. The first is that *Centrelink's* MyGov portal has been very unreliable for many years. In the latter years of the first decade of this century and, into the second decade, the portal has been so unreliable that I have readily resorted to using the department's reply paid Canberra mail-box; if that didn't accord with the department's pay-weeks, then so be it.

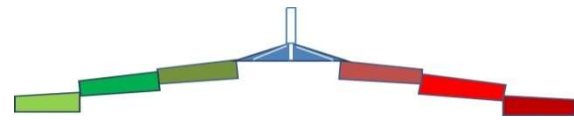
Context

The second issue is that the department has known about these problems for decades and, failed to do anything substantial about them. As a Parliamentary Intern in 1996, the Senate Regulations and Ordinances Committee asked me to review a constituency complaint.

A single mother complained that the then Department of Social Security kept retrospectively clawing back Family Payment amounts as her former husband was less than reliable in making child support payments. When a large amount of arrears arrived in her bank account, the department would rush to claim its share. The constituent was left unable to budget and, would go with virtual no money in her account some weeks.

I recommended the pay-weeks for Family Payment and child support needed to be harmonized. Equally, the Department needed to pay child support itself and then recoup any debts from the ex-husband itself; mothers and children should not be left with these problems, nor the consequences of over or underpayments. As stated, this was all laid out in a report in 1996,² but as far

² "An S.O.S. to the D.S.S. : reform the F.P." / by Adam Johnston. [Canberra : Australian National Internship Program, ANU], 1996. Author [Johnston, Adam Australian National Internship Program \(Australian National University\) Australia. Department of the Senate. Procedure Office](#) Date 01-01-1996 - Physical description 25 p. ; 30 cm. Series [Research report \(Australian National Internship Program \(Australian National University\)\)](#)



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as I'm aware little has been done to change the system legislatively or administratively to implement the recommendations. If it had, we may not need yet *another* inquiry into the social welfare system.

The real intent of all governments

However, governments of all political hues (and the bureaucrats under them) seem content to maintain a transfer system designed to confuse, bemuse, humiliate, and frighten. Closely tied to this is the notion of getting disability pensioners (and others) into work, therefore justifying making the welfare system as punitive and complex as possible. Firstly though, we must establish whether there is work out there to do and, even if we apply for it, whether employers want us, the unemployed. Beyond this, you need to ask what work is available and the answer is temporary, casual, and part-time.³

Furthermore, in my own case, I know the percentage of disabled people in work is low, compared to the wider population and, that this figure has been rather static, over many years.⁴ This has all happened in the face of government throwing billions of taxpayer dollars at various "job ready", "make work" and vocational education schemes. Most of these are run by highly

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<http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;adv=yes;orderBy=date-eFirst;page=2;query=%22Adam%20Johnston%22%20Decade%3A%221990s%22;rec=0;resCount=Default> as at 25 February 2017

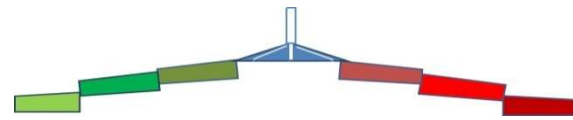
³ I laid out my own experience in the Human Rights Commission's *Willing to Work* inquiry at http://www.pc.gov.au/_data/assets/pdf_file/0004/209749/subpfr356-human-services-identifying-reform-attachment1.pdf. I also made extensive comments to the McClure Review at <https://engage.dss.gov.au/wp-content/uploads/2016/06/Welfare-review-1.pdf> as at 25 February 2017. As these two submissions argue, it is time for government to acknowledge that what it does in the employment space is throw good money after bad, and the only people who gain ongoing (the new word for 'permanent') employment are the dubious NGO providers; who earn their keep by sending unsuspecting clients to vocational courses which produce qualification few employers in the real economy (that is, production not subsidised by government and resulting in a good or service with a market demand) recognise as legitimate. Refer to footnote 5 for further information.

⁴ See ABS, 4433.0.55.006 - Disability and Labour Force Participation, 2012 Latest ISSUE Released at 11:30 AM (CANBERRA TIME) 05/02/2015 First Issue, <http://www.abs.gov.au/ausstats/abs@.nsf/0/C7C72D7706E9BED0CA257DE2000BDC60?Opendocument> as at 25 February 2017. In particular, the webpage says: "Although there have been improvements in anti-discrimination legislation, Survey of Disability, Ageing and Carers (SDAC) data show that people with disability are still less likely to be participating in the labour force than other Australians. According to data from SDAC, there has been little change in the labour force participation rate for people with disability aged 15-64 years between 1993 (54.9%) and 2012 (52.8%)."

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dubious for-profit (or equally questionable not-for-profit) providers, of which I have had direct personal experience.⁵ Any rational policy maker would have declared these schemes abject failures and closed them a long time ago. But no, the dubious rent-seekers of the NGO-world continue to ride on their taxpayer-funded gravy train.⁶

Their clients by contrast, receive very different treatment. Government continues to cross-reference various computer systems, wanting to pull billions from individuals and families. My strong recommendation is to abandon the *Better Management* initiative and instead, work on real and lasting tax reform, for a start. None other than the former Head of Treasury, Dr Ken Henry, has castigated the 'political class' for their lack of will, action and bipartisanship when it comes to public policy reform.⁷

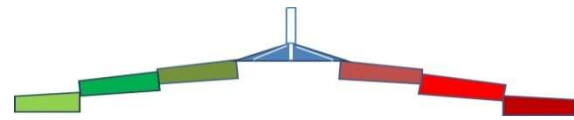
I thoroughly endorse Dr Henry's reported comments⁸ and, they relate directly to these inquiries in as much as the *Better Management* initiative should be known as the *Easy Pickings by Lazy Bureaucrats and Politicians* initiative. The Government is content to recoup debts from people on fixed incomes, by whatever means possible, to avoid dealing with the fact that the past ten years has been a reform and policy free zone in many key areas, to the detriment of all Australians.

⁵ See part of a submission I recently sent to the Productivity Commission. Attachment 2 related specifically to vocational education: http://www.pc.gov.au/_data/assets/pdf_file/0005/209750/subpfr356-human-services-identifying-reform-attachment2.pdf It was part of a wider submission about competition in the non-government sector available at http://www.pc.gov.au/_data/assets/pdf_file/0003/209748/subpfr356-human-services-identifying-reform.pdf as at 25 February 2017

⁶ Comments I have made in this area include a submission to *An inquiry into the Social Security Legislation Amendment (Strengthening the Job Seeker Compliance Framework) Bill 2014* at <http://www.aph.gov.au/DocumentStore.ashx?id=b0e07f8c-3f2b-43f0-b6de-3e7f0ceaf38e&subId=301892> as at 25 February 2017

⁷ See e.g.: Former treasury head Ken Henry attacks political system in Canberra conference By political editor Chris Uhlmann, Updated Thu at 4:49pm, <http://www.abc.net.au/news/2017-02-23/former-treasury-head-ken-henry-attacks-political-system/8296692> as at 25 February 2017

⁸ My submission to Dr Henry's review of the tax system is available at http://taxreview.treasury.gov.au/content/submissions/pre_14_november_2008/Adam_Johnston.pdf as at 27 February 2017. I stand by remarks in this document and, would argue that tax reform will generate far more revenue (and likely cost less to administer) than trying to recoup debts off welfare recipients.



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Various politicians, including the current Prime Minister Malcolm Turnbull, have blamed the Opposition, the economy, Budget pressures and the Senate, amongst other things, for this failure. However, Ken Henry does not find this compelling and, neither do I. In a submission about Senate reform my argument was that it was doubtful the changing Senate voting procedure would stop a disenchanted electorate finding ways to curb the Executive. One pointedly attached several documents to that submission, which were contributions to other inquiries relating to urgent but failed economic, structural, and institutional reforms.⁹

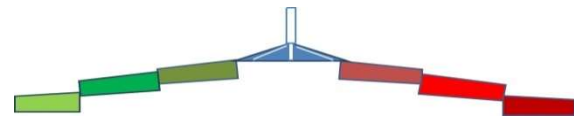
A few legal issues

This brings me back to the question of the euphemism known as *Better Management*. If a business sent out debt collectors to recoup money, some of which is not actually owed, this could be regarded as unconscionable conduct and regulators would be involved. Similarly, if a business did the same to an individual, State police, Fair Trading, or both, could take a variety of civil or criminal actions, dependent on the severity and elements of the behaviour. If the dispute was between private individuals, police would still have discretion to act on a complaint of assault, demanding money with menaces, theft, and the like. When the Federal Government behaves in the same fashion, it is called *Better Management*.

This provides a convenient segue to questions of the Disability Strategy and slavery in Australia. Firstly, one has been consulted on enough disability strategies (and written submissions to enough of them¹⁰) to be prepared for the banal final documents, full of glossy photos, interspersed with politically

⁹ See my submission to the Joint Standing Committee on Electoral Matters, dated 29th February 2016, regarding the *Commonwealth Electoral Amendment Bill 2016* at <http://www.aph.gov.au/DocumentStore.ashx?id=46843386-896e-4e6a-8f0d-5aae67fd40c4&subId=409662> as at 25 February 2017

¹⁰ See for example, *Living Life My Way, Putting people with disability at the centre of decision making Outcomes of statewide consultations May – August 2012*, http://www.adhc.nsw.gov.au/_data/assets/file/0018/262530/Stage_3_consult_report_Aug2012.pdf; see also *Ageing, Disability and Home Care | Disability Inclusion Bill 2014 Your feedback, our response* at https://www.adhc.nsw.gov.au/_data/assets/file/0011/300152/3291_ADHC_DIB_ConReport_WEB.pdf and my submission to the process at https://www.adhc.nsw.gov.au/_data/assets/pdf_file/0010/296254/Adam_Johnston.pdf as at 26 February 2017



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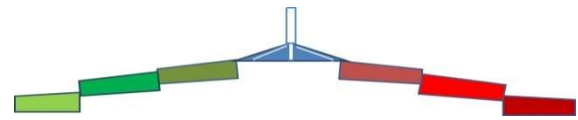
correct motherhood statements about inclusion, diversity, and support. As one advised a prior Senate review, a reason for this nauseating policy approach was that:

(t)he 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 (is) as a study of extremes. We are either portrayed as extremely needy and vulnerable (e.g.: service provider appealing for charitable donations) or as exceptionally praiseworthy and courageous (e.g.: Para Olympians). Depending on whose statistics you accept, up to 20% of the Australian population has a disability. We do not all live life in the extremes popularly depicted.¹¹

If you seek from an ideological or dogmatic standpoint to enforce views about what is “normal,” it is then easier to make declarations about what “normal” people should do; including notions of how, when and why they should work. This brings into sharp focus concepts of welfare and work and, more particularly programs like the Howard Government’s *Welfare to Work* scheme. As documented by the attachments included with my submission to the Senate inquiry into ‘*The administration and purchasing of Disability Employment Services in Australia,*’ you will see that I used to be a fervent supporter of the concept.

However, over the years, I saw a lot of third rate service delivery from a ‘third sector’ being paid handsomely by the taxpayer to provide employment support

¹¹ Submission to Senate Legal and Constitutional Affairs Committee: Proposed Amendments to the Disability Discrimination Act, p.2, <http://www.aph.gov.au/DocumentStore.ashx?id=52150cdb-cecf-4337-bb59-17c1497066c9> as at 26 February 2017



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which was either not well directed, not needed or non-existent (usually at a point at which some help would have been handy).¹² Many of the jobs it directed me towards were transient, non-existent and, at times, offered little or no remuneration. My own profession, the legal fraternity, is a prime example of both an institutionalized monopoly which has failed to adapt to multiple pressures of an over-supply of graduates, alongside the contradiction of undersupply of legal services, a loss of female talent and, a general ageing of the profession; while leaving younger and mid-career lawyers (like me) either under-employed or unemployed. I have tried repeatedly to call on the legal profession to conduct 'root and branch' reform upon itself and, have *not* been surprised by my singular lack of success.¹³

It is also noteworthy, that despite 'competition' being the policy watchword of the past 20 or 30 years, the legal profession has held onto its training, admission, discipline, and court advocacy monopoly, with few external incursions. This is a disservice to the public, business and, a growing number of practitioners, yet our politicians at State and Federal level (many a lapsed lawyer among them) consistently fail to act to curtail the legal monopoly. This is yet another monument to the failure of reform that the likes of Ken Henry have identified

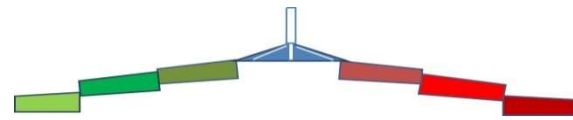
Consequences: the failure of reform

This failure of reform has real consequences, as desperate, indebted governments look for money.¹⁴ For example, you can look to Disability Strategies to determine what the policy aspiration may be, but then look at an

¹² See generally, my submission to 'The administration and purchasing of Disability Employment Services in Australia,' at <http://www.aph.gov.au/DocumentStore.ashx?id=a6fa4e6a-eb31-49de-bb0f-c9f11849c86c> as at 26 February 2017

¹³ See for example, my two submissions to the Productivity Commission's *Access to Justice inquiry* at <http://www.pc.gov.au/inquiries/completed/access-justice/submissions/submissions-test2/submission-counter/subdr164-access-justice.docx> (Submission 1); <http://www.pc.gov.au/inquiries/completed/access-justice/submissions/submissions-test2/submission-counter/subdr297-access-justice.pdf> (Supplementary Submission) and Transcript from Sydney hearings, pp. 203-209 <http://www.pc.gov.au/inquiries/completed/access-justice/public-hearings/20140603-sydney-access-justice-transcript.pdf>; I also spoke to the Law Society's FLIP (Future of Law and Innovation in the Profession) Commission of inquiry at <https://youtu.be/KYLMmLddZzo> as at 27 February 2017

¹⁴ I will not enter the argument of whether debt can be serviced or not. I will merely work off statements made by the Treasurer and Prime Minister that Australia has a spending problem.



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initiative like *Better Management* to determine what governments will do in practice. This is because, in truth, if you wanted to make the community (and the world of work) more accessible to people with disabilities, the first order of business is to change the tax and superannuation systems. However, policy reform is difficult and, going after the sick, disabled, poor and elderly for money is easier; few of them will fight back (most can't afford legal help¹⁵) and presenting them as welfare cheats plays well in the tabloid press.

This does not alter my view that the biggest "cheats" in the welfare system are the NGOs¹⁶ which government, corporates and others are complicit in continuing to fund. Governments seem happy to transfer responsibility for many of the most needy and vulnerable in our society to a third rate third sector, courtesy of large grants, tax-free and charitable gift status. But, if the same governments want to recoup lost revenue and, make the disabled feel more like members of the community, I recommend such largesse to the church and charitable sector must stop.¹⁷ Corporate and household largesse

¹⁵ And this has been known for a long time; see for example,

Schetzer, L. & Henderson, J 2003, *Public consultations: a project to identify legal needs, pathways and barriers for disadvantaged people in NSW*, *Access to justice and legal needs* vol. 1, Law and Justice Foundation of NSW, Sydney. I told this inquiry that:

"...one accepts the notion that formal litigation is not a realistic option, in considering how I might solve any legal or para-legal problem. Indeed it could be argued, that any issue [that] is seen as legal can also be viewed from an administrative or political context.

The formal justice system is out of my price range and, there are an ever-growing range of administrative, consultative and political forums in which one may seek redress..." (Ch 5. Participation in law reform)

<http://www.lawfoundation.net.au/report/consultations/57ACAB8603D4F279CA257060007D4F29.html> as at 27 February 2017

¹⁶ I served on the Board of a major NSW charity for a brief period. [REDACTED]

[REDACTED]; see generally, Appendix 1, attached.

¹⁷ See for example, my submission to the Treasury Review of Governance in the Not-For-Profit Sector at

<http://www.treasury.gov.au/~media/Treasury/Consultations%20and%20Reviews/Consultations/2011/Review%20of%20not-for-profit%20governance%20arrangements/Submissions/PDF/Johnston%20Adam.ashx>; also

note my submission to the Lavarch Review of Tax Concessions for the NFP sector at

http://www.treasury.gov.au/~media/Treasury/Consultations%20and%20Reviews/Consultations/2012/Tax%20concessions%20for%20the%20not-for-profit%20sector/Submissions/PDF/001_Adam_Johnston.ashx as at 27

February 2017. It was and is a matter of great disappointment to me that an Inquiry into Tax Deductibility (in

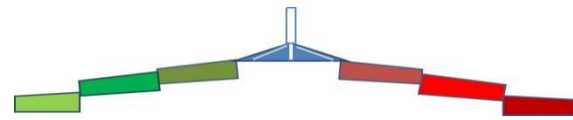
the last Parliament (see: [http://www.aph.gov.au/DocumentStore.ashx?id=00874c93-07f4-4b37-9403-](http://www.aph.gov.au/DocumentStore.ashx?id=00874c93-07f4-4b37-9403-c50fef481832&subId=407687)

[c50fef481832&subId=407687](http://www.aph.gov.au/DocumentStore.ashx?id=00874c93-07f4-4b37-9403-c50fef481832&subId=407687)) has not been revived. Despite the inquiry being listed as current, the website

also says: "This inquiry lapsed when the Standing Committee on Economics ceased to exist at the dissolution of the Senate and the House of Representatives on Monday 09 May 2016. Submissions cannot be received."

http://www.aph.gov.au/Parliamentary_Business/Committees/House/Economics/Tax_deductibility as at 27

February 2017



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must also cease, by bringing an end to tax deductions and tax expenditures,¹⁸ so that revenue streams are more straightforward (with less leaks) and, government has to take direct responsibility for all outlays, through direct expenditure. Then, as argued in the earlier cited Pre-Budget submission, governments could more readily afford goods and services for the citizenry, as well as being truly accountable for their delivery.

This sounds familiar...

These are issues I have been taking up for years, since the *Henry Review*. This is because, in my own experience, entry-level, temporary employment does not make much economic sense and, nor does it do anything positive to health of someone with chronic illnesses and disability.¹⁹ The only people who seem to win are the charities, regardless of whether we, their clients think the NGOs are competent, honest, or not.²⁰ *Centrelink* legally obliges clients to deal with these organisations, unless you are someone like me who returns to study and tells the Secretary of the Department that you have neither the time, money nor inclination to deal with an NGO employment service, many of which are clearly interested in you so long as your presence on their books signifies “easy money” and, you don't make too many service demands as a client.²¹

Beyond this, there seems to be a view in the Department that *Centrelink* can contact clients at any time and insist on information. When I found that this included Saturday morning, rather than spending Saturday afternoon with the newspaper, I was drafting yet another email to [REDACTED].²² It is acknowledged that the Department sent a letter, dated 10th May 2016,

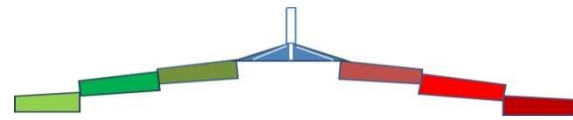
¹⁸ I discussed these issues at length in my above cited submission to the House Economics Committee regarding tax deductibility, and also during the *Better Tax (ReThink) System* inquiry at <https://engage.dss.gov.au/wp-content/uploads/2016/06/Rethink-submission-1.pdf> as at 27 February 2017

¹⁹ See generally, my submission to then Treasurer Joe Hockey, during the 2015 Pre-Budget process at http://www.pc.gov.au/_data/assets/pdf_file/0006/209751/subpfr356-human-services-identifying-reform-attachment3.pdf as at 27 February 2017

²⁰ See generally, my submission to *An inquiry into the Social Security Legislation Amendment (Strengthening the Job Seeker Compliance Framework) Bill 2014*, at <http://www.aph.gov.au/DocumentStore.ashx?id=b0e07f8c-3f2b-43f0-b6de-3e7f0ceaf38e&subId=301892> as at 27 February 2017

²¹ See Email to Kathryn Campbell, dated 29 September 2016, entitled “Complaint - Employment Services Assessment,” attached

²² See Cold call.pdf, attached



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apologizing for any distress caused and affirming I was not obliged to take calls, particularly on the weekend or out of hours.²³

While I appreciated receiving the letter, had one not complained, I would not have known about my ability to rebuff unwelcome, untimely, and unwarranted callers, even if they are from *Centrelink*/Human Services. In my view, the Department trades on fear and financial leverage far too readily and, while it knows it can't frighten me (for I will access the Secretary's and Ombudsman's email in-box), few others will have my professional background or training and, even if they do know of appeal mechanisms, fewer still will be prepared to exercise them. *Better Management* shows the Department's willingness to use such strategies and in my opinion, this is the true explanation of forces behind the initiative. As stated earlier, if anyone else behaved similarly, they would likely be subject to legal sanction.

Furthermore, the Productivity Commission conducted an inquiry into NGO employment services in 2001,²⁴ which found that:

(i) individual jobseekers with complex needs were being excluded from services as providers focused on those clients most likely to find employment and, ensure a contractual return for the service provider. In what the Commissioner labelled 'parking' and 'creaming' the system perversely encouraged assistance to go to those who needed it least, while rationing support for those who needed it most.²⁵

It would not surprise me to find *Better Management* performing a variant of the creaming and parking move. Only, this time it is cream the poorest and

²³ See Scan.jpg attached

²⁴ Refer to Commonwealth of Australia (2002), Independent Review of Job Network: inquiry report; available online at http://www.pc.gov.au/data/assets/pdf_file/0018/54333/jobnetwork.pdf. Accessed 21/7/09.

²⁵ Siobhan O'Sullivan, Mark Considine and Jenny Lewis, *John Howard and the Neo-liberal Agenda: regulation and reform of Australia's privatised employment services sector between 1996 and 2008 – Presented at the Australian Political Studies Association (APSA) Conference* (September 2009) Macquarie University, 10 http://ssps.unimelb.edu.au/sites/ssps.unimelb.edu.au/files/John_Howard_and_the_Neoliberal_Agenda_Sept_2009.pdf as at 6 January 2016, cited indirectly for my comments on page 10 of my submission concerning tax deductibility at <http://www.aph.gov.au/DocumentStore.ashx?id=00874c93-07f4-4b37-9403-c50fef481832&subId=407687> as at 27 February 2017



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park them in poverty, knowing most won't or can't resist. Such an outcome would conform with my experience of, and expectation of, *Centrelink*.

Why questions of Modern Slavery are relevant

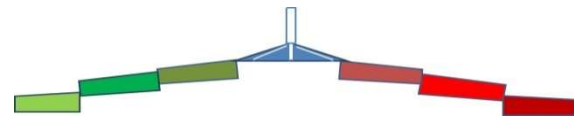
Therefore, I link an inquiry on the *Better Management* to a question of a Modern Slavery Act for Australia. The requirements of *Centrelink* (and its related enforcement bodies, including its NGO service providers) can be so demanding, the paperwork so ridiculous, time consuming and tiring, that an argument for enslavement can be readily made. Governments shouldn't just look to visa fraud and international human trafficking, but also domestic, bureaucratically orchestrated trafficking in their own agencies.

To my mind, I've been on this 'official [REDACTED] treadmill' many times, [REDACTED] or bounced between NGO providers (for *their* payment), and subject to demands for information either by letter or via the questionable phone call mentioned earlier; or issued with instructions to attend a mandatory meeting. Many other disabled people less fortunate than me are [REDACTED] by Special Business Enterprises and paid a pittance, yet this [REDACTED] continues to be subsidized by government.²⁶

Where is Bill Shorten's or Malcolm Turnbull's confected outrage, concern or grandstanding when it comes to extraordinary low pay for the disabled? It is as absent as my own legal rights of redress, when I discovered I had gone through an extensive application process with an NGO job placement firm, only to find after detailed preparation, the job had been cancelled. When I complained to the relevant Department, I was promptly told:

It is important that employers are not discouraged from seeking to employ people with disability by requiring them to be penalized if their fluctuating business concerns cause them to cease a planned recruitment process. When an employer places a job vacancy into the public domain there is always the risk that the employer's (needs) will

²⁶ See generally, my submission to the Australian Law Reform Commission - REVIEW OF EQUAL RECOGNITION BEFORE THE LAW AND LEGAL CAPACITY FOR PEOPLE WITH DISABILITY, attached. This document discusses the very dubious policy of paying people under the BSWAT. See, in particular, pages 1-5.



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change and that the recruitment may have to be deferred or stopped
(Letter from [REDACTED]
[REDACTED], to Adam Johnston, dated 24 November 2006)²⁷

Again, when one is put in one's place so succinctly, you appreciate the difference between disability strategy and actual policy. You also wonder how far away the social welfare and related 'activity schemes' really are from slavery, particularly when a Government can say that legally enforceable contracts would discourage employment. As such, I don't believe Australian welfare policy and slavery are that distant; indeed, they are getting closer every day.

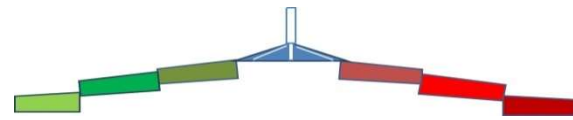
Over the years, I have dealt with an ever more prescriptive, ever more punitive, and ever more complex *Centrelink*; the same can be said of the [REDACTED] taxpayer-funded NGOs who have increasingly entered the welfare and employment arena under contract. When you add the National Disability Insurance Scheme (NDIS) to this environment (an arrangement at once drowning in bureaucratic individual planning documents and yet, heavily dependent on NGOs for service delivery), you begin to wonder whether you are still a citizen, or have been unilaterally outsourced to NGO sector, as little more than a piece of property?²⁹

Amid these changes, governments continue to complain about spending overruns and revenue downturns, even as they rush to give responsibility for everything (and everyone) that isn't "nailed to the floor" to non-government bodies. At the same time, politicians refuse to confront tax reform; as you will see, I wrote to Minister Tudge, about the lack of coordination between the tax

²⁷ Ibid., p.5

²⁹ See generally, my submission to the ALRC concerning Review of Equal Recognition Before the Law and Legal Capacity for People With Disability at https://www.alrc.gov.au/sites/default/files/subs/12_a_johnston.pdf as at 28 February 2017. Pointedly, I open the submission with a quote from Oscar Wilde, which applies to describe the errors of contemporary welfare policy:

But (charity) is not a solution: it is an aggravation of the difficulty. The proper aim is to try and reconstruct society on such a basis that poverty will be impossible. And the altruistic virtues have really prevented the carrying out of this aim. Just as the worst slave-owners were those who were kind to their slaves, and so prevented the horror of the system being (realised) by those who suffered from it, and understood by those who contemplated it...Charity degrades and (demoralises)...Charity creates a multitude of sins. Oscar Wilde, "The Soul of Man Under Socialism"



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and transfer system.³⁰ An official in Minister Porter's Department responded, insisting that the welfare and tax systems had two very different aims.³¹ Yet, it is in part this policy thinking that perpetuates many difficulties. Why should citizens have to file tax returns, when many get the same money returned to them in transfers? Why should people keep copious records, to inform government of matters the State can find out quite readily (and does) by other means? Why does the State continue to fund/subsidise NGOs and other bodies, forgoing billions in revenue? If this stopped, would we finally have a Budget that could afford the direct delivery of decent goods and services; rather than chasing the sick and vulnerable over debts? And, in such circumstances, would State, Federal and local governments *finally* admit that we the poor, elderly, sick and disabled are their citizens and, not someone else's "problem" or "special project"?

These are the policy reforms I seek from these inquiries.

Yours faithfully



Adam Johnston



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³⁰ See Email to [REDACTED], "Reform needed to avoid tax, income and welfare churn" 28 August 2016, attached

³¹ See MC16-009256



Thank you



Thank you Adam Johnston. Your complaint has been submitted on 27/3/2019

Business/Trader Identified

ILS

Details of your problem

I asked for an NDIS quote on replacement armrests from company ILS. Quote received February, ILS paid by plan manager in early March but parts not available until mid-April

Service Expectations

(http://www.fairtrading.nsw.gov.au/ftw/About_us/Our_services/Customer_service_charter.page)

Further information on how your complaint is handled can be found on our website: how your general complaint is handled

(http://www.fairtrading.nsw.gov.au/ftw/About_us/Our_services/Resolving_issues/General_complaint_handling.page?)

You will be contacted within 14 days.

[Back to Fair Trading](#)

Adam Johnston

From: Adam Johnston <adamdj1@optusnet.com.au>
Sent: Monday, 19 July 2021 10:39 AM
To: 'DRC Submissions'
Cc: 'complaints@humanrights.gov.au'
Subject: FW: Complaint: Commission needs to review Services Australia, Centrelink and the NDIS and the combined pressure they are putting on people
Attachments: Formal request for a review of Decision; Response to consultation paper- Home and Living; Lucky me; The curse of faith based lobbyists; Some emails and articles; 0251a Mr Adam Johnston.pdf; 0251 Mr Adam Johnston (partially confidential)_Redacted.pdf; ahrc_complaint_form_2017-06.doc

Dear submissions team,

The combined demands of Centrelink and the NDIS are becoming far too much. I don't know how anyone is coping because both are telling on me. The old Homecare NSW used to run itself and give me few major problems. My major bogie or monster was Centrelink – periodically this Dragon would emerge from its cave, accuse me of not telling it something (or having the temerity to gain employment). I would invariably shoot back, pointing to the documents I placed on the MyGov portal. The Dragon would lose a head, and look foolish, before returning to its cave to lick its wounds. Then we do it all again in the next 6 to 12 months.

Then another Dragon lumbered into my life called the NDIS. It is many times more demanding, much like that 'high maintenance' work colleague, friend or relative, who can only be tolerated in small portions. However, the Agency and its NGO Dragons must be dealt with as they provide daily care services. That said, one often does the "fire-breathing" part to have NDIS or NGOs do anything. All Dragons can be found sleeping in the Department of Social Services cave. Centrelink will wake of its own accord, which can be dangerous. The NDIS will be asleep because it is anaemic from the large transfer of public funds to the NGO sector. The NGO Dragons are asleep thanks to the large helping of public money being digested, meaning that at least for them it is Christmas Lunch every day of the week.

At the end of this, we the participants are the turkeys who get eaten. And the service can be significantly underwhelming. This would be funny if it wasn't so serious. I have written to the Human Rights Commission and now formally to your Royal Commission because I think it is time to call the Department of Social Services and, those who seek horrendous rents from it to account. To succeed, this Disability Royal Commission (and the Human Rights Commission) must produce many days of reckoning for governments and NGOs. It must note all their many and continuing failures. Discontinuing charity as a form of civil organisation would also be a substantive and positive reform. I deal with it today under sufferance and have no confidence in its probity or competence. I look forward to its non-existence.

Yours truly,
Adam Johnston

From: Adam Johnston <adamdj1@optusnet.com.au>
Sent: Sunday, 18 July 2021 9:09 PM
To: 'complaints@humanrights.gov.au' <complaints@humanrights.gov.au>
Subject: Complaint: Commission needs to review Services Australia, Centrelink and the NDIS and the combined pressure they are putting on people

Dear Sir,

My complaint form and supporting evidence attached. The complaint is about Services Australia, which runs both Centrelink and the NDIS.

Regards



Adam Johnston

35 Woolbrych Crescent

Davidson NSW 2085

Phone: 9402-0539

Mobile: 0408 471 089

Email: adamdj1@optusnet.com.au or adam.johnston@hdr.mq.edu.au or adam.johnston@students.mq.edu.au

Macquarie University, Macquarie Park, Sydney, Australia:

https://law.mq.edu.au/current_students/higher_degree_research_students/adam_johnston/

You can see my paper on the University of New England (UNE), Armidale e-publications at <http://e-publications.une.edu.au/1959.11/11369> and the Social Science Research Network (SSRN) at: <http://ssrn.com/abstract=1855924>

Libertas inaeestimabilis res est - Liberty is a thing beyond all price. (Corpus Iuris Civilis: Digesta) (Latin-English Phrase)

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Public Involvement in Health Service Research – International Symposium

**Thursday February
21st, 2019**

The University of Sydney,
Faculty of Health
Sciences

Symposium organising team:

[Redacted names of the symposium organising team]

University of Sydney, Centre for Disability Research and Policy
Public Involvement in Health Service Research
International Symposium
Program
Thursday February 21st, 2019

75 East Street, Lidcombe NSW 2141, Faculty of Health Sciences, The University of Sydney

Time/Location	Program Sessions
8.30am – 9.00am B Block foyer	Registration
9.00am – 9.30am B020	Opening address – [REDACTED] [REDACTED] [REDACTED]
9.30am – 10.15am B020	Morning Panel - Wellbeing, Health & Youth Panel: Making 'Healthy Publics' Together Chair: [REDACTED] Introduction and Overview [REDACTED] [REDACTED] [REDACTED] Adolescent Health Research Commission [REDACTED] Health Literacies [REDACTED] Knowledge Translation [REDACTED] Ethics of Engagement [REDACTED] People, Places and Platforms [REDACTED]
10.15am – 10.45am B Block foyer	Morning tea * Following Morning Tea, Walk to T Block, approximately 300 metres. Map included below
10.45am – 11.45am T203	Parallel Session 1: Chair [REDACTED] Health Consumers' Experiences of Involvement in Health and Medical Research [REDACTED] A snapshot of consumer and community involvement in translational health research – where are we now and where can we go next? [REDACTED]

	<p>Inclusive consumer-driven health services research – Enhancing public involvement in test result management, communication and follow-up</p> <p>██</p> <p>████████████████</p>
<p>10.45am – 11.45am T207</p>	<p>Parallel Session 1: Chair: ██████████ Co-designing a text message program to support women’s health after breast cancer treatments</p> <p>██</p> <p>What’s our experience really worth? Finding a middle ground between “tokenistic” versus “used & abused” consumer contribution</p> <p>████████████████</p> <p>Patient participation in health research: Biocitizenship and the perpetual politics of knowledge</p> <p>██</p> <p>██████████</p>
<p>10.45am – 11.45am T208</p>	<p>Parallel Session 1: ██████████ Occupational Therapists’ perceptions of consumers providing feedback to learners completing practice education</p> <p>██</p> <p>Identifying and integrating patient and caregiver perspectives in clinical practice guidelines for percutaneous renal biopsy</p> <p>██</p> <p>Pathways to Preventive Care for People with Severe Mental Illness: An Innovative approach to co-design</p> <p>██</p>
<p>11.45am – 12.45pm T203</p>	<p>Parallel Session 2: ██████████ Workshop: From aspiration to implementation: What does it take to embed authentic engagement in research practice? A panel presentation and dialogical workshop</p> <p>██</p> <p>██</p> <p>██████████</p> <p>██</p>
<p>11.45am – 12.45pm T207</p>	<p>Parallel Session 2: Chair: ██████████ What would grandma say?</p> <p>██</p> <p>Families are first responders</p> <p>██</p> <p>Enabling action? Participatory action research with women with disabilities in the Philippines and Australia</p> <p>██</p> <p>██████████</p>
<p>11.45am – 12.45pm T208</p>	<p>Parallel Session 2: Chair: ██████████ Nothing about us without us: consumers shaping research</p> <p>██</p> <p>Agents of Change: Public Involvement in Dementia Research</p> <p>██</p>

<p>11.45am – 12.45pm T110</p>	<p>Parallel Session 2: Chair: [REDACTED] Filling the Gap- Improving Oral Health Outcomes for People with Cerebral Palsy [REDACTED]</p> <p>STELLER: Supporting the translation into everyday life of lived experience research [REDACTED]</p> <p>The importance of patient and public involvement across the continuum in health technology decision-making [REDACTED]</p>
<p>12.45pm – 1.30pm T107 (ground floor)</p>	<p>Lunch</p>
<p>1.30pm – 2.30pm T109</p>	<p>Afternoon Panel: Consumer-Led and Co-Produced Research in a World That is Not Used to it. The Community Led Research Network</p> <p>Chair: [REDACTED] [REDACTED]</p>
<p>2.30pm – 3.30pm T203</p>	<p>Parallel Session 3: Chair: [REDACTED] Reflecting on research and lived experience [REDACTED]</p> <p>The insights from two types of expertise on disability: scientific and lived [REDACTED]</p> <p>Collaboration with consumers, carers and other stakeholders: Lessons for mental health policy, services and research [REDACTED]</p>
<p>2.30pm – 3.30pm T207</p>	<p>Parallel Session 3: Chair: [REDACTED] Choice or coercion in childbirth: a room with a view [REDACTED]</p> <p>How to engage with consumers to reduce medication errors and harm? [REDACTED]</p> <p>The Patient's Voice. A qualitative study embedding person centred care with outpatients in chronic and complex care [REDACTED] a</p>
<p>2.30pm – 3.30pm T208</p>	<p>Parallel Session 3: [REDACTED] Listen! Exploring why the character trait of 'listening' is absent from virtue ethics mental health practice frameworks [REDACTED]</p> <p>CP Quest: Community and researchers together for cerebral palsy research [REDACTED]</p> <p>Public involvement in dementia research in Australia: personal reflections and political realities [REDACTED]</p>
<p>2.30pm – 3.30pm T110</p>	<p>Parallel Session 3: Chair: [REDACTED] The SWASH survey of lesbian, bisexual and queer women's health: How community shaped and sustained a 22-year collaboration. [REDACTED]</p>

	<p>What instructions are available to health researchers for writing lay summaries? A Scoping Review.</p> <p>Consumer & Community Involvement at Telethon Kids Institute: our journey – our success</p>
3.30pm – 3.45pm T107 (ground floor)	Afternoon tea
3.45 – 4.45pm T203	<p>Parallel Session 4: Chair:</p> <p>Organisational approaches to public involvement in health research – perspectives from a local health district and medical research institute.</p> <p>Successfully Participating in General Societies when Living with a Neurological Disability</p> <p>We want to be part of the solution, not just be the problem – why patients need to be involved in research and scientific conferences</p>
3.45 – 4.45pm T207	<p>Parallel Session 4: Chair:</p> <p>Principles and strategies for involving patients in research in chronic kidney disease: report from national workshops</p> <p>Using video-reflexive methods to optimise infection prevention and control: A collaboration between researchers, patients, family members and healthcare professionals</p>
3.45 – 4.45pm T208	<p>Parallel Session 4: Chair:</p> <p>Sharing power with communities in health research priority-setting: Developing a ethics toolkit for engagement practice</p> <p>A shock to the system: service-user lead research using lived experience knowledge to inform ECT practices</p>
3.45 – 4.45pm T110	<p>Parallel Session 4: Chair:</p> <p>Consumer and community involvement in health research – what do consumers say about how to do this?</p> <p>Lived Experience Evaluation – Keep It Real!</p> <p>Consumer and Community Engagement in Research in South Western Sydney: Insights from the SWSLHD Consumer and Community Participation Unit</p>
4.45pm – 5.30pm T109	<p>Wrap up & Conference close</p> <p>Chair:</p> <p>Sydney and Edinburgh organising team</p>

Public Involvement in Health Service Research - International Symposium Abstracts

Morning Panel - Wellbeing, Health & Youth Panel: Making 'Healthy Publics' Together

Introduction and Overview

[REDACTED]

Adolescent Health Research Commission

[REDACTED]

Health Literacies

[REDACTED]

Knowledge Translation

[REDACTED]

Ethics of Engagement

[REDACTED]

People, Places and Platforms

[REDACTED]

What are the possibilities and tensions of public involvement in adolescent health research for the digital age? What might it mean to shift away from individualistic concepts such as 'consumer', 'user' or 'beneficiary' - toward the more collaborative notion of 'healthy publics' (Hinchliffe et al, 2018)? In this panel researchers and young people present key aspects of the Wellbeing Health and Youth Centre of Research Excellence. This spans the following areas: the increasing imperative and evolution of public involvement in adolescent research; the role of young people and how they envision their involvement in a proposed Adolescent Health Research Commission; the vital role of health literacies and knowledge translation; the challenges and opportunities associated with an ethics of engagement; plus the the role of technologies in relation to personal, public and planetary health. Framing our presentation and discussion are the perspectives and values of a Youth Engagement Declaration generated by young people, researchers, and representatives from health service and youth organisations. The supporting framework highlights six key areas: a common language, youth centredness, shared responsibility, ethical practices, digital capacities, and mutual benefit. The purpose of this panel is to highlight areas for opportunity and collaboration for public involvement in adolescent health - but to also grapple with the complexities and challenges of how this can be achieved. This requires not only bringing together the expertise and knowledge of young people, communities, researchers, policymakers and organisations - but also a diversity of ideas, approaches and methods. While products and services aim to meet essential needs, the notion of 'healthy publics' is a meeting place for intergenerational action and holistic change.

Reference

Hinchliffe, S., Jackson, M. A., Wyatt, K., Barlow, A. E., Barreto, M., Clare, L., Depledge, M. H., Durie, R., Fleming, L. E., Groom, N., Morrissey, K., Salisbury, L., Thomas, F. (2018) Healthy publics: enabling cultures and environments for health, *Palgrave Communications*, Volume 4 (57).

Parallel Session 1:

Health Consumers' Experiences of Involvement in Health and Medical Research

There is a growing interest increasing the involvement of health consumers in health and medical research. However, little is known about the health consumer experience of being involved in medical research, beyond participation as a research subject, in order to increase the capacity for consumer involvement.

In late 2016, Health Consumers NSW and Research4Me held a joint workshop with health consumers with experience in the co-design of health and medical research, to understand their experience and what's needed from a consumer perspective to be involved in health and medical research.

Over the course of a few hours, it became clear that the consumers involved in the workshop had a very sophisticated understanding of the value of health and medical research, and the challenges experienced by researchers. Workshop attendees brought a diversity of illness and types of research experience, and overwhelmingly gave their time to researchers because of the value they believe they added to the research process, and in achieving better research outcomes that are more relevant to consumers and the community.

The following themes were identified to be impacting on the level of involvement of consumers in research:

- Types of research;
- Consumer availability and experience;
- Funding consumer involvement;
- Finding the 'right' consumer;
- Consumer training and support;
- Researcher beliefs and culture;
- Researcher training;
- Clarity about roles and responsibilities;
- Language.

Enablers that help support increased consumer involvement in research were also identified:

- Appropriate selection processes and training for consumer representatives;
- Flexibility in working with consumers and respecting the value of their contribution;
- Training of researchers to better partner with consumers;
- Increased/better use of plain language by researchers;
- Funding consumer involvement in research;
- Support materials and structures for both consumers and researchers.

There was consensus amongst the workshop attendees on most issues, however there were a few contentious issues, including:

- payment to consumer representatives (beyond reimbursement of out-of-pocket expenses);
- payments or incentives for completion of high-risk procedures for clinical trial participants;
- What information is appropriate to share with researchers about potential consumer representatives, and how should that information be handled/protected;
- Whether or not there is a need for community education about clinical trials;
- Whether there should be any type of accreditation for consumer representatives.

Over a very short space of time, the depth of knowledge and experience shared by the consumer workshop attendees was surprising and gave valuable insights into the infrastructure and support needed to increase consumer involvement in research, from the consumer perspective.

A snapshot of consumer and community involvement in translational health research – where are we now and where can we go next?

Background

The Australian Health Research Alliance (AHRA) comprises 7 NHMRC-accredited Advanced Health Research Translation Centres and 2 Centres for Regional Health. These 9 centres represent approximately 70% of health care delivery and 90% of translational research across Australia. Strengthening consumer and community involvement (CCI) in research is one of four national priority areas addressed by AHRA.

Objectives/Methods

- To undertake a targeted review of published literature about CCI in health research
- To review 4 agencies recognised as leaders in CCI in health research
- To survey AHRA members about current CCI activities and resources
- To conduct a national workshop to review the findings and make recommendations to AHRA.

Results

Approximately 80 published papers and the websites of four agencies were reviewed (INVOLVE in the UK, the Strategy for Patient Oriented Research (SPOR) in Canada, the Patient Centred Outcomes Research Institute (PCORI) in the US, and the Consumer and Community Health Research Network in Western Australia). The AHRA survey included responses from 868 researchers, health professionals and consumer and community members. The workshop was attended by 40 people including AHRA members, and consumer and community advocacy groups.

Together, these activities affirmed a growing support for CCI in health research; recognition of the benefits of CCI for the relevance and use of research; and the availability of a wide range of tools and resources; but the need to systemically embed CCI as a requirement and expectation of health research; and to undertake more rigorous evaluations of tools and resources as well as the impact of CCI on research.

Recommendations submitted to AHRA included:

- embedding CCI in translational research
- developing minimum standards for good practice in CCI
- sharing existing resources and expertise to support CCI
- evaluating the effects of CCI in translational research

Inclusive consumer-driven health services research – Enhancing public involvement in test result management, communication and follow-up

Public involvement in health services research can lead to more efficient and effective health services and care delivery. Despite advances in co-creation of clinical research with consumers in the last decades, consumer engagement remains inconsistent in health services research and is often treated as a tick box exercise or a mere token effort at best. These inconsistencies and shortcomings exist despite research and health care policies outlining the importance of consumer involvement. In this paper, consumers and researchers share the practical strategies and outcomes of a program of work designed to enhance the contribution of consumers in all stages of a health services research study on test-result management, communication and follow up.

Collaborating with NSW Health Pathology, the Australian Commission on Safety and Quality in Healthcare and Health Consumers NSW, researchers employed three major strategies. First, seeking the advice of consumer representative organisations during the development of the research proposal and providing opportunity for diverse interest groups to shape the direction of research in a forum at the launch of the project. Second, utilising the insights gained from the Forum we conducted semi-structured interviews with clinicians, radiology and laboratory staff, and patients within three NSW Emergency Departments to trace and compare work processes and patient experience in the test management cycle. Third, establishing a Consumer Reference Group (CRG) to select relevant topics and participate in qualitative interview analysis in an interactive workshop under the guidance of researchers. The workshop allowed consumers to generate key themes related to consumer-selected topics 'transitions of care' and 'access to information' in relation test-result management. The CRG is involved in disseminating findings through academic and public outlets and will drive practice change via policy briefs promoting the translation of research findings and contributing to the establishment of person-centred, safe and effective test-result management systems. In this way, consumer involvement forms a foundation of this translational research study, research is done *with* not just for consumers thus moving away from tokenistic to genuine inclusive research.

Parallel Session 1:

Co-designing a text message program to support women's health after breast cancer treatments

Background: More than 15,000 Australian women survive breast cancer treatments each year. After treatments, many women find it mentally and physically difficult to manage their health independently. Research shows that improving one's confidence with health management skills can increase health-promoting behaviours. Moreover, supportive text message programs may offer a simple and scalable strategy for people living with chronic diseases, however such programs have not been tested for women after breast cancer treatments.

Aim: To understand lived experiences of women recovering from breast cancer treatments and to co-design a consumer-led text message program with breast cancer survivors, researchers and health professionals to support clinical and psychological health outcomes within the first year after treatments.

Method: An established iterative mixed-methods process was used to design the program structure and content. Consumer representatives and experts (medical staff, health researchers) attended a workshop to determine program specifications (message frequency, timing) and key message content themes. Co-designed messages were developed, then reviewed by 14 consumers and 14 experts; ranked for appropriateness, usefulness and clarity on a 5-point Likert scale as well as written and oral feedback. The message bank was revised accordingly.

Results: Workshop participants agreed on four text message themes: 1) social/emotional well-being 2) general breast cancer information 3) physical activity/nutrition and 4) medication adherence/side effects. The program will be delivered one-way (no replies), where messages will be sent four times/week, at random times and days, to increase engagement. One-hundred-and-ninety co-designed messages were reviewed, resulting in 130 evidence-based text messages.

Conclusions: Evidence-based text messages were co-designed with consumers to support women's health after breast cancer treatments. The text message program will now be tested for effectiveness in a randomised controlled trial.

Translational significance: If effective, the program can be easily scaled-up to support post-treatment care for breast cancer survivors nationally and internationally.

What's our experience really worth? Finding a middle ground between "tokenistic" versus "used & abused" consumer contribution

There's no doubt health consumers' experience, expertise and unique perspective brings much value to research, committees and working parties. Yet as a health consumer you are often left querying the nature of your contribution, whether it be tokenistic or "used and abused".

The tokenistic approach is where it's obvious you were simply a tick to an obligatory "consumer involvement" box. The health professionals or researchers involved made their decisions well before you were even invited to participate. They may scribble down your ideas on some butcher's paper, to be recycled once you leave, never to be thought of again. What a waste of precious time.

At the other end of the spectrum, perhaps you were actively involved in processes and your input is really valued. Yet after writing multiple emails, paper revisions and attending countless meetings at some stage you wonder "was it worth it". You may feel taken for granted, with no compensation for the time or services given. In doing so, little consideration is given to the burden placed upon the health consumer.

Is it fair health consumers' contributions are for free, or even left with out of pocket expenses? What are the ethical considerations around financial reparations?

Patient participation in health research: Biocitizenship and the perpetual politics of knowledge

Biocitizenship refers to political identities forged via people's biological conditions, such as genetics or experience of illnesses, which extend beyond the political rights bestowed by the state. By identifying and belonging to a collective community by virtue of a shared health condition or healthcare experience, patients are no longer just the sick. Non-government advocacy groups, patient networks and charities have emerged to lay claims to rights and legitimacy in accessing treatment, information and healthcare ('therapeutic citizenship'), or indeed demand choice and quality of services as discerning 'consumers' in the healthcare free-market.

The involvement of patients in medicine and healthcare delivery has become ever more expansive. Patients' role in leading or co-creating research from the outset, such as study conceptualisation, named applicants on grant funding, and in study analysis and dissemination, signals the next bastion of biocitizenship. Having a voice and representation in scientific research, the 'experiential knowledge' of patients through the embodiment of illness is increasingly legitimised. Indeed, emerging hybrid notions such as 'expert patients' attempt to blur the boundaries between 'expert' and 'lay' knowledge taken for granted by the scientific establishment.

However, concerns should be raised about this new shift: Firstly, there is limited reporting or research on the selection and demographic make-up of patient representatives in the myriad of research that goes on. Biocitizenship is often said to be stratified, when biology is privileged, if not fetishized, over other forms of identities and suffering, such as socio-economic status, level of education, gender, race, and class. Thus representation based on biology may produce new forms of elitism, and limit research involvement to patients who are deemed scientifically and politically 'literate'. Secondly, given the perpetual privileging of scientific and political literacy in the research participation process, the true extent of collaboration and legitimising of 'lived experience' requires more scrutiny. Caution is needed to ensure patient involvement does not inadvertently become co-opted to reinforce the dominance of the medical paradigm.

Parallel Session 1:

Occupational Therapists' perceptions of consumers providing feedback to learners completing practice education

Introduction: Consumer involvement in the education of occupational therapy learners has been primarily 'campus' based. Engagement of consumers in course work varies across the Australian education context, with consumers being consulted in course design, providing on-campus lectures and more recently completing assessment of learners. However, consumers remain a recipient of services when an occupational therapy learner completes practice education. During practice education, the registered occupational therapist supervises and provides formal assessment of the learners' performance using a national assessment form. The assessment tool method requires the assessment to be completed using the professional's expert opinion then grading the learner's performance.

Objectives: The objective of this paper is to describe preliminary findings of a national questionnaire exploring Australian occupational therapists' perceptions of consumers being asked to contribute direct feedback to occupational therapy learners while they complete practice education.

Methods: A purpose designed questionnaire was developed to collate Australian occupational therapists' perceptions on the consumers contributing feedback directly to students as they complete practice education. Snowballing technique was used to distribute the questionnaire. Data will be analysed using descriptive statistics to describe the respondent population, and qualitative content analysis to uncover themes from the open-ended responses. The research is the first study of the author's PhD to co-design and test a feedback system for occupational therapy learners to use during practice education.

Implications: We need to understand the perspectives of the profession about consumer involvement in learner practice education prior to new systems being developed and introduced. The results from this research will assist with understanding the professions expectation and assist with developing education and tools to prepare professionals for formally including consumer feedback into learners practice education assessments.

Conclusion: Formalising the involvement of consumer's in occupational therapy learners practice education assessment may continue to assist the profession in striving towards enhanced consumer centred practice.

Identifying and integrating patient and caregiver perspectives in clinical practice guidelines for percutaneous renal biopsy

Background: Percutaneous renal biopsy is often essential for providing reliable diagnostic and prognostic information for people with known or suspected kidney disease. However, the procedure is invasive and can lead to complications and concerns among patients.

Aim: To identify and integrate patient priorities and perspectives into the Kidney Health Australia – Caring for Australasians with Renal Impairment clinical practice guidelines for renal biopsy, to ensure patient-relevance.

Methods: We convened a workshop, consisting of three simultaneous focus groups and a plenary session with patients who had undergone a renal biopsy and their caregivers. Participants were selected using a purposive sampling strategy. Topics and outcomes prioritised by patients and their caregivers were compared to those identified by the guideline working group, which was comprised of seven nephrologists. Transcripts and flipcharts were analysed thematically to identify the reasons for participants' choices.

Results: Ten patients and seven caregivers attended the workshop. In total, 48 topics/outcomes were identified; 34 (70%) by patients/caregivers and 28 (58%) by the guideline working group. Only 14 (29%) topics/outcomes were identified by both groups. Most of the topics identified by the patient/caregiver group related to communication and education, psychosocial support and self-management. We identified five themes underpinning the reasons for topic and outcome selection: alleviating anxiety and unnecessary distress, minimising discomfort and disruption, supporting family and caregivers, enabling self-management, and protecting their kidney. As a result of this workshop, a new topic on patient care and education was added to the guideline.

Conclusions: Patient and caregiver involvement in developing guidelines on renal biopsy ensured that their concerns and needs for education, psychosocial support, and self-management were explicitly addressed; enabling a patient-centred approach to renal biopsies.

Pathways to Preventive Care for People with Severe Mental Illness: An Innovative approach to co-design

This presentation will showcase an innovative approach to research applying a co-designed asset-based approach. The study explores the access of people with severe mental illness (PWSMI) to primary health care (PHC). PWSMI have poorer physical health and a 13-30-year shorter life expectancy than the general population, so improved access to preventive health care is needed. The study uses an asset-based framework (strengths of the person, community and agencies), underpinned by Relational Coordination Theory to explore what PWSMI value in their relationship with their GP.

The importance of consumer and carer involvement in mental health program and service evaluation is increasingly being considered in research and evaluation as best practice. Studies have found that including academics with a lived experience of mental illness in research design and execution enhances relevance, validity and consumer ownership of results. The inclusion of consumer academics on the research team ensures that research is sensitive to the needs, concerns and desired outcomes for consumers and, consequently, consumers are more likely to participate in the study and action recommendations.

This presentation will demonstrate how the project applies a co-design process from the proposal development stage, starting with an investigator team that includes people with lived experience, medicine, public health, social sciences, and service management to design more relevant, effective, useful research.

The 'Asset-based' approach focuses on what is working rather than what is not. This approach, based on the concept of Appreciative Inquiry, creates a sense of safety for those who have the most potential to contribute new and relevant knowledge – practitioners and consumers – bridging gaps from knowledge to practice by supporting the coproduction of knowledge to advance practice.

This presentation will demonstrate how an asset-based approach will privilege the voice of PWSMI in the framing of the research question, data collection methods and knowledge exchange activities.

Parallel Session 2:

Workshop: From aspiration to implementation: What does it take to embed authentic engagement in research practice? A panel presentation and dialogical workshop

A presentation by researchers, engagement staff and community partners about the engagement activities currently being implemented by the Sunshine Coast Mind and Neuroscience Thompson Institute. The majority of the workshop is a series of dialogical activities designed to maximize information sharing between participants about their current practices for involving end users of research in decision making across the research cycle. It is envisioned that sharing practice stories will enable the group to collectively explore to what extent engagement is authentically embedded in research practice.

Parallel Session 2:

What would grandma say?

In both Australia and the United Kingdom over the past several years, services for people with disabilities have increasingly been outsourced from the public sector to the non-government or charitable sector. If the Western welfare state can still be presumed to exist, we need to ask the question as to why governments have seen fit to retreat from direct service delivery. We also need to scrutinise the rationale often cited that funding non-government organisations (NGOs) is more cost effective than public provision and provides individuals with more choice and control over the services they use. Arguably, people should be able to make further choices to restore and repair the neurological and physical incapacities of their bodies. This is the next logical step, given the development of technology, particularly if you accept the hypothesis that in this modern age, all people should be able to expect something more from their lives beyond dependence on charity.

This should involve facilitation of opportunities to participate in research, with the potential to augment, improve and amend the broken bodies we currently live within. The conception behind supposedly historic government policy was perpetual impairment and disability, as well as continued and growing dependence of people with disability on charity. The absence of a research focus, or any apparent public debate on the lack of a research focus, is telling. It suggests much about the Australian public's view (or lack thereof) of their place in research, some people with disabilities view of themselves and what their lives can mean, not to mention the Parliament's view.

Families are first responders

A presentation of an extract from a memoir-in-progress which follows one family's lived experience of psychosis and addiction over several years. Details of interactions with various health services are documented, including mental health services, emergency departments, mental health crisis teams, intervention into psychosis programs, private hospitals and rehabilitation services, among others. The story also illustrates the common outcome of a serious mental health problem that continues untreated: homelessness, encounters with law enforcement and incarceration. This recounted experience of one young person's crisis and its impact on the family will help to demonstrate the way in which thousands of families suffer as a result of mental ill health and substance abuse. The voicing of these stories is made more difficult, and often impossible, by the deep shame felt by the families involved.

Enabling action? Participatory action research with women with disabilities in the Philippines and Australia

For several decades formally trained researchers have worked with peer researchers to undertake participatory action research in relation to health and social development. Increasingly, researchers who practice community engaged research are critically reflecting on the potential for these approaches to facilitate positive outcomes and social change for the (often marginalised) communities involved. However, reflective accounts of community engaged research are rarely told from peer researchers' perspectives and often do not discuss the post-research impact on the peer-researchers involved. University-based researchers are often drawn to participatory approaches because of their action-orientation, potential for 'impact' and promise of contributing to social change. Peer researchers may be highly motivated to make concrete changes to their circumstances or those of their communities, seeing participation in research as an opportunity to address disadvantage. Despite the promise of 'action' inherent in participatory action research, there is considerably more guidance available on the participatory elements of such an approach than there has been consideration of action. University-based researchers, under pressure to demonstrate their impact, may see 'action' as change in policy and/or practice, but does this constitute action from the perspective of peer researchers? What is the role of peer researchers in policy and practice making, and how can this be supported? Does peer research and peer researchers make a difference to the real world circumstances of disadvantaged communities, and if so how? This chapter will examine these questions by drawing on participatory research endeavours with women with disabilities in the Philippines and Australia.

Parallel Session 2:

Nothing about us without us: consumers shaping research

Cancer Voices (CV) recognises the value of consumer involvement in both research and research funding decisions. CV advocated for and developed in partnership with Cancer Council NSW (CCNSW), a Consumer Involvement in Research (CIR) Program which matches trained consumers to interested researchers. The first program of its kind in Australia, the service facilitates electronic access by researchers to informed, trained consumers. The process has been documented by four peer reviewed publications with a formal evaluation being published in 2015.

The Consumer Research Training Program comprises four online modules followed by a half-day face-to-face workshop. This training gives participants a basic idea of the kinds of cancer research, the stages of research and funding cycles and what is expected of both the consumer and the researcher in working together.

Studies have shown that the quality and content of research benefits a great deal from consumer engagement – in its direction, its applicability to community needs, and its end value for people affected by cancer. Most research funders now require evidence, that funding applicants have engaged in a meaningful way with informed consumers.

The consumer is able to consider issues from a broad and objective viewpoint. For example, is this a valuable research objective for people affected by cancer (or a specific cancer)? Could its focus be better directed? The consumer's role is not to act as a mini scientist, but as someone who can bring a broad, informed view to the project as a patient or carer, and who can keep community needs at the forefront of researchers' minds. The specific roles will vary depending on the type of project the consumer has been nominated to. Increasingly these roles are focused on the development of 'patient led' research, and consumers are being recognised and valued as part of the investigation team.

Agents of Change: Public Involvement in Dementia Research

The Agents of Change: Creating National Quality Collaboratives to Improve Dementia Care is a translational research project which has been designed to involve people living with dementia, family care givers and members of the public at all levels of the research. The contribution of members of the public is expected to be of benefit in designing the intervention, in conducting the research and in the success of the implementation of clinical guidelines. The Agents of Change research project is funded by the NHMRC Partnership Centre for dealing with Cognitive and Related Functional Decline in Older People and the NHMRC National Institute for Dementia Research to assess the efficacy of a quality collaborative in improving adherence to key recommendations from the *Clinical Practice Guidelines for Dementia Care in Australia*.

Taking the slogan “*nothing about us without us*” seriously, the Agents of Change research project has involved people with lived experience of dementia, family caregivers and members of the public in writing the submission, in deciding priorities, on steering committees, in developing training content and in collaborating with clinicians in developing implementation plans.

This presentation will be co-presented by one of our expert advisors with lived experience of dementia and a researcher to describe the process, roles and evaluation plans for the public participation in this research. We will draw on the themes identified so far to identify the skills that researchers need to learn, the need for collaboration at the beginning of developing a research project and the supports needed to enable members of the public to contribute their expertise.

The evaluation of the public involvement in this national research project will be completed in 2020 and will provide a cost benefit assessment of the value of public involvement in dementia research.

Parallel Session 2:

Oral Health Outcomes for People with Cerebral Palsy: A Scoping Review to Inform Future Research and Oral Health Policy

Cerebral palsy (CP) describes a group of permanent but not unchanging disorders of movement and posture resulting from injury or insult to the developing brain.⁽¹⁾ Cerebral Palsy is the most common physical disability of childhood (2 per 1000 live births in developed countries) and is a lifelong condition. The causal pathways to CP are complex and not yet completely understood. There are however several recognized risk factors such as male gender, multiple birth pregnancy, low birthweight and preterm birth.⁽²⁾

Cerebral Palsy may increase an individual's susceptibility to oral health issues due to the reported dental implications associated with pre-term birth, a known risk factor for CP. Dental implications include but are not limited to, delayed tooth eruption, developmental enamel defects, and trauma to the enamel. These dental problems coupled with the neuromuscular effects of CP have been shown in some instances to cause changes to the oro-facial structures, negatively impacting nourishment, oral hygiene and result in parafunctional habits of the mouth, jaw and tongue.^(1,3,4) At present, there are no documented systematic reviews reporting on the oral health outcomes of people of all ages with CP. Subsequently there are no clear guidelines, frameworks or detailed oral health recommendations for people with CP in Australia or globally.

This scoping review will draw together the currently limited research base and examine the associated oral health related concerns experienced by people with CP. In addition, data from this scoping review will be utilised in a Delphi survey to form a consensus with consumers, clinicians and researchers to report on the oral health outcomes experienced by people with cerebral palsy. These studies combined with a mixed methods survey on oral 'home-care' practices of people with cerebral palsy and their caregivers aims to provide targeted and specific oral health recommendations to inform policy and improve oral health outcomes and well-being for people with CP.

1. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Martin B. A report: the definition and classification of cerebral palsy April 2006. *Developmental Medicine and Child Neurology*. 2007;49(109):8-14
2. Smithers-Sheedy H, McIntyre S, Gibson C, Meehan E, Scott H, Goldsmith S, et al. Australian Cerebral Palsy Register Group & The Australian Cerebral Palsy Register Group 2016. A special supplement: findings from the Australian Cerebral Palsy Register, birth years 1993 to 2006, *Developmental Medicine & Child Neurology*, 2016;58:5-10.

STELLER: Supporting the translation into everyday life of lived experience research

Lived-experience research in mental health illuminates the perspectives and experiences of people who live with mental illness and is conducted in teams that include people with their own lived experience. The findings from lived-experience research have the potential to help consumers in their recovery journeys, for example by imparting wisdom and inspiring hope. However, little is known about how useful consumers might find lived-experience research, nor what the best formats are to bring it to their attention. We used a design thinking approach to develop a translation strategy for lived experience research. In stage 1 we consulted with consumers to understand their perspectives on lived experience research. Stage 2 involved identifying the design aim and the research questions. Stage 3 was ideation – we generated ideas via a workshop with consumers and mental health professionals. We received grant funding from One Door Mental Health to implement stages 4 and 5. In Stage 4 we will develop a suite of resources based on the ideas generated from the workshop and in consultation with the peer workers who will implement stage 5. In stage 5 peer workers will present a range of prototypes to consumers and we will evaluate their accessibility and usefulness. This study will provide evidence about a potentially important source of information and inspiration that consumers can use to facilitate their recovery journeys.

The importance of patient and public involvement across the continuum in health technology decision-making

Health technology assessment (HTA) is an evaluation activity that synthesises evidence of benefits, harms and costs of new technologies and services for decision making. At the broadest level ‘health technology’ includes any intervention used to prevent, diagnose or treat disease, including vaccines, diagnostic tests, medicines, devices, surgery, as well as models and organisation of healthcare services. HTA spans from the development of these ‘technologies’, to decisions about access and funding, through to disinvestment. In Australia, national health technology committees include the Pharmaceutical Benefits Advisory Committee (PBAC), the Medical Services Advisory Committee (MSAC), the Prostheses List Advisory Committee (PLAC) and the MBS Review Taskforce.

While the remit of each committee is different, all include mechanisms to incorporate patient and/or public perspectives into the decision-making process. Gaps however remain in how patient and public involvement occurs across the health technology continuum. Three case studies (new medicines for treatment of hepatitis C, non-invasive prenatal testing and new surgical treatments for weight loss) will be presented to highlight some of the process and methodological challenges in this area and what successes have been achieved. Issues that will be raised include the differing role of patients and the public in health decision-making, approaches to engagement beyond patient advocacy representation and understanding what are the patient centred reported outcomes and research questions that matter most.

Increasing the involvement of patients and public in health care decision-making is slowly becoming embedded in the way we conduct research and make decisions. We have moved from debating why we should include patients and public to more nuanced questions as to how, when and what we should be doing to better involve and improve outcomes for patients and the wider community.

Afternoon Panel: Consumer-Led and Co-Produced Research in a World That is Not Used to it. The Community Led Research Network

Parallel Session 3: Reflecting on research and lived experience

As a researcher whose career was interrupted by mental illness, and who is now working as a peer worker, my personal and working history straddles research and lived experience. Also, in my academic life, just prior to the onset of serious mental health issues, I spent twelve months at the University of California Berkeley as a visiting fellow in disability studies. Although their origins are separate, the disability studies movement in the US was an intellectual and political predecessor of the lived experience movement in mental health. In this paper I connect elements of my lived experience and working life to some of the broader issues around to the growth of lived experience in mental health and connections with research.

I begin as a storyteller, recounting my lived experience of mental illness and its impacts on my capabilities as a researcher. I trace my interest in the interaction of these two domains, lived experience and research, to the way the symptoms of my illness, including memory loss and performance anxiety, disrupted my capacity to function as a researcher, while leaving me just about able to function in everyday life.

I reflect on how being a researcher, compares to the learning process I have gone through during the last few years of my recovery, learning to use my lived experience in telling my story as a community educator, and more recently as a peer worker.

I then discuss my experience of peer work, as a newcomer to this area. I conclude that, while peer work has the potential to make a real difference for people with mental illness, the way it is set up and seems to be operating, it looks more like a way to provide a cheap and flexible source of labour. I suggest that continuing critical examination is needed for peer work to fulfil its promise.

The insights from two types of expertise on disability: scientific and lived

The NHMRC Centre of Research Excellence in Disability and Health (CRE-DH) is an interdisciplinary research initiative that is developing a new monitoring framework and indicator set that will be used to report baseline data and to track change over time in health-related inequities experienced by working age Australians with disabilities. Data reported against the indicators will inform policy by identifying where action is needed and by highlighting issues on which there is progress, regress, or no change.

Given the importance of this framework to the long-term health and well-being of people with disabilities, the CRE-DH is forming an expert panel of advice comprising up to 40 participants who either have a disability themselves or have a family member with a disability. Panel participants will give their views on the draft monitoring framework and indicators through two rounds of consultation. This input will be vital to ensure that all health, social, economic and wellbeing issues that are important and meaningful to people with disabilities are included in appropriate way. Input from the expert panel of advice will be brought together with input from researchers with expertise in indicator construction and disability data analysis. Incorporating the expert panel of advice as a central component of the development methodology recognises the unique expertise that comes from living with a disability.

This presentation explains why the CRE-DH chose to draw on the insight of an expert panel of advice, describes the process of forming the panel, and outlines its contributions to development of the monitoring framework. It also explores the challenges and benefits that arise from the need to explain (and translate) the technical parameters of a monitoring framework into language accessible to non-scientists with different but equally important expertise.

Collaboration with consumers, carers and other stakeholders: Lessons for mental health policy, services and research

As the academic sector recognises the importance of real world impact alongside academic metrics, collaboration with stakeholders to achieve the best impact is vital. ACACIA: The ACT Consumer and Carer Mental Health Research Unit was established in 2013 to facilitate the active involvement of consumers and carers in mental health research, and ensure research, services and policy in the ACT are driven by consumer and carer needs. The Unit is led and staffed by researchers with lived experience of mental health issues and collaboration with consumers, carers, service providers and policy makers is embedded in our core research design.

This presentation will showcase collaborative projects undertaken in partnership with a range of mental health stakeholders. All projects addressed issues on a research agenda developed by consumers and carers. The design and methods were developed with the guidance of a consumer and carer advisory group, together with service providers and decision makers in services where relevant.

The projects demonstrate the rich diversity of issues that mental health consumers and carers consider of importance for research, and the opportunities for a collaborative approach to addressing these issues. The presentation will describe evaluations of mental health programs, developed and conducted with representatives of the services that were the focus, and innovative projects to address the nature and value of participation in policy, services and research processes. The presentation will reflect on the lessons learned about collaboration in addition to research findings.

Parallel Session 3:

Choice or coercion in childbirth: a room with a view

In the last century, the role of fathers in the birth has changed exponentially. Before the 1970s, the principal view was that birth was a female business and not a man's place. Changing cultural and professional attitudes around the emotional bond between a man and a woman, family structure and the more proactive involved role of men in the family have encouraged fathers' attendance at birth. There is evidence that fathers' support can make birthing less traumatic for some women and can make couples closer. This has made some clinicians to believe the fathers should be more involved throughout the birth process. Some clinicians even go further and ask the fathers to watch the medical procedures, such as inserting vaginal speculum, forceps or vacuum, episiotomy and stitches.

Although birth can unfold like a beautiful picture captured by birth photographers, with fathers massaging women's backs by candle light and the miraculous moment of birth, it can be overshadowed by less attractive images of cervical mucous, emptying bowels and the invasive medical procedures. What happens in birth room and the fathers' reaction to the graphic experience of birthing can be unpredictable. Despite the fact that most men are absolutely thrilled to be in the delivery room, for some men, a very intimate body part can become completely desexualised and they can experience psychological and sexual scarring. They see someone they cherish dramatically sliced open, can then associate their partners with a disturbing scene, and it can dramatically affect their relationships.

While most women want the expectant fathers by their side for this life-changing event, not all of them may be happy for their partners to watch the perineum to be cut or stitched or when large blades of forceps are inserted inside the vagina. Anecdotal reports have shown that consent is not sought from the labouring women as to whether they want their partners to watch these procedures.

The majority of research focuses on women's retrospective attitudes towards their birth experience. But, what about the effect of witnessing invasive procedures during childbirth on a man's attraction to his partner, while she is most vulnerable, and also an increased risk of post-traumatic stress disorder in fathers? No research has ever investigated whether women need to be asked for their consent before inviting their partners to closely watch medical procedures during childbirth. Future research is required to provide a basis for better awareness and involve the consumers to understanding the men's and women's experience and their expectations for labour and birth.

How to engage with consumers to reduce medication errors and harm?

The Government's Quality Use of Medicine's Strategy recognizes the consumer as playing both a central role in attaining the quality use of medicines and learning from the wisdom of their experience. Yet many consumers consider there are significant barriers to communicating with key stakeholders, particularly as individuals. As a consumer-led association, we collect stories and data from consumers, for the purposes of providing a consumer voice on medicine safety. We have developed a methodology for engaging with consumers that:

- Makes it safe for them to communicate
- Enables them to tell stories of the consumer in their own reality
- Provide views about stakeholder proposals or points of view
- Asks them what they want the stakeholder to know
- Keeps them focused on themselves as a consumer of medicines.

These consumer stories and data enable engagement with stakeholders as they:

- Cannot be changed to suit the stakeholder and enable the focus to be kept on the consumer
- Can be used to enable the stakeholder to engage emotionally with the statistics to avoid complacency
- Can also be used to empower stakeholders who have solutions that meet consumer needs for improved medicine safety.

In the brief period of time since our incorporation, we have had made significant progress in raising the consumer's voice. This includes the recent NSW Health Inquiry concluding that medication errors are a very big problem in Australia, and securing recommendations that if implemented, will dramatically transform medicine safety.

We are also currently working on three other projects. We will present:

- The main barriers consumers perceive to communicating with each key stakeholder
- The methodology we use to facilitate consumer communication that has led to hundreds of stories (and growing quickly)
- We will present one case study of how our consumers' stories have been used to illuminate statistics and empower stakeholders around medicine safety.

The Patient's Voice. A qualitative study embedding person centred care with outpatients in chronic and complex care

This translational study's objective was to answer the research question of 'How is person-centred care (PCC) embedded in planning and treatment for outpatients?'. The aim was to explore how to capture the views of the participants to produce workable solutions to support healthy relationships between patients and clinicians in the clinical areas of Geriatric, Rehabilitation and Chronic Pain. Recommendations were made to further embed PCC within the services and improve the patient experience.

Methods This qualitative study had an exploratory research design. A total of 20 participants were recruited across the three clinical areas in outpatients. There were two groups :-patients and carers (13 in number) and clinicians (7 in number). Focus group discussions (FGD) and interviews were the data collection method using a semi-structured design with reference to the domains of PCC from the literature. The FGD and interviews were recorded, transcribed, thematically analysed.

Results Three main themes were :-

- *Continuous Planning and Treatment* – clinicians partnered with patients during their journey to give treatment choices and enhance autonomy. Treatment planning was reported by the patients outside of the case conference within other contexts of the patient journey.
- *Emotional Support* including social aspect of care. Patients valued the ongoing relationship with the team and other patients. This provided motivation for engagement in treatment
- *Experimental Learning and Empowerment*. Learning in groups facilitated self-management of chronic health issues using simple directions.

Conclusion

PCC was embedded within these services in the domains of emotional support; education, communication, information and patient preferences and values. Barriers to PCC in the current model of care in MDT care were identified and possible facilitators suggested to improve PCC. A number of innovations were suggested to further embed these domains of PCC within the health service.

Parallel Session 3:

Listen! Exploring why the character trait of 'listening' is absent from virtue ethics mental health practice frameworks

Virtue Ethics allows us to understand which character traits are needed to live a flourishing life. However, in over 2000 years of discussions in what makes one's life ethical, the character trait of 'listening' seems absent. This is problematic, especially when we speak to the obligations needed to fulfil our work as mental health practitioners. There is an increasing amount of peer reviewed and grey literature, as well as reports, that have surveyed what service users want from practitioners. They emphasise - and almost prioritise - the importance of listening in mental health practice. Listening allows the practitioner to be attentive and focus on the unique experiences of people going through acute psychological distress whereby they can then make ethical judgements and decisions about treatment and support for the individual. Further, listening has been reported to empower people in their recovery as well as provide a space for their full narrative to be unpacked. From this paper's perspective, listening is fundamental in mental health practice and should be recognised as such in the conversations on virtuous clinical practice traits in virtue ethics.

This paper will systematically examine the field of virtue ethics in mental health practice to explore what the literature is saying about the character trait listening. The paper will also critique the use of the term listening to gauge what context the term is being used – whether it is listening to explore or listening to implement standard clinical practices. I postulate the reason why an important and obvious trait like listening has been missing, is that the authors of these virtue ethics frameworks have not been asking service users what they think makes a virtuous practitioner. As such, this paper also encourages ethicists, academics and clinicians to implement co-production in their work when designing and scaffolding ethical theories and character traits.

CP Quest: Community and researchers together for cerebral palsy research

Aim: CP Quest aims to integrate the experiences and expertise of people with cerebral palsy (CP) and their families into research activities by supporting these individuals to work in partnership with CP researchers to ensure that 1) valid research is conducted and 2) ideas from the CP community are integrated into future research. Here we describe the development and outcomes of this program to date.

Methods: Research Partners are families and people living with CP. To join CP Quest individuals completed a short online questionnaire and formally volunteered with Cerebral Palsy Alliance. The level of commitment, frequency and type of involvement was subject to the availability and interests of each individual Research Partner.

Results: Over the last two years, CP Quest Research Partners have been involved in CP Research through different mechanisms. Partners (n=30) set CP Research priorities, were involved in the Australia and New Zealand CP Strategy consultation, and participated in reference and advisory groups to provide expert advice (n=21). Our first research 'buddy' partnership has been established, eight Research Partners have become co-investigators and six co-authors helping to shape research. Research Partners and Researchers have attended training (n=42) to better understand how to be involved in research and how the lived experience can improve the quality of research. The main impediments for people with CP and their family members to be involved has been lack of time. In our experience, most people are very busy, and for this reason we need a large pool of Research Partners. A future strategy will be the implementation of a "train the trainer" model to offer more flexible training opportunities for families.

Conclusion: People with CP and their families are eager to be involved in research but need formal support, flexible arrangements and mechanisms to facilitate their involvement.

Public involvement in dementia research in Australia: personal reflections and political realities

My experience of caring for my husband who died of Alzheimer's disease was a powerful motivator to get involved in dementia research as a public contributor.

There is a growing movement for public involvement in dementia research in Australia. This is the result of the activism of people with dementia and carers, and, the leadership and commitment of some institutions. There have been challenges and public involvement is not embedded within our dementia research culture to the extent that it is, say, in the UK. Attempts here to implement models based on those working well, such as the UK Alzheimer's Society Research Network, have not been supported long term.

Nonetheless, there are good examples of public involvement in dementia research in Australia. At the organisational level, the NHMRC Cognitive Decline Partnership Centre has been a leader and supported the active involvement of people with dementia and carers in its work. At the project level, one of the Centre's projects was to develop clinical practice guidelines for dementia for Australia. Alongside researchers and service providers, people with dementia and carers were involved in this. Our involvement ensured their relevance; use of appropriate language; appropriate referencing, and, that they were underpinned by the Principles of Dignity in Care. Further, we were involved in producing a companion guide to the guidelines adapted for patients and the public. It uses accessible dementia friendly language to provide practical advice about key elements of the guidelines.

There is a growing evidence of the value of public involvement in research. But, to capitalise on this we need strong leadership ('bottom up' and 'top down'); infrastructure - including pathways for people to get involved; training opportunities for both researchers and the public; and, appropriate support - including funding. This applies not just to dementia research but universally.

Parallel Session 3:

The SWASH survey of lesbian, bisexual and queer women's health: How community shaped and sustained a 22-year collaboration.

SWASH is a periodic survey of the health and wellbeing of community-connected lesbian, bisexual, queer (LBQ) and other non-heterosexual identifying women in Sydney. It is run in collaboration with ACON Health, where members of LGBTQ communities work in and for LGBTQ communities. SWASH has been running biennially since its inception in 1996, largely without funding. In the absence of a 'mainstream' evidence base, SWASH has provided critical health indicators for LBQ women, and driven and informed action. SWASH is an interesting and unusual case study of public involvement in health research.

In this presentation I will tell the SWASH story from my perspective as a researcher. I will reflect on how the lived experience of LBQ women (and more recently non-binary people) has shaped and sustained the collaboration and profoundly influenced the way we research. The community has a strong sense of ownership over the project; I will talk about the accountabilities and challenges this produces for the researchers and for ACON. In producing scientific evidence, SWASH makes LBQ women and their health needs visible to the mainstream (and by extension, becomes a demand for action). But I am also interested in thinking about how it acts to tell LBQ women about their health, and construct the very notion of common health interests.

What instructions are available to health researchers for writing lay summaries? A Scoping Review.

Consumer & Community Involvement at Telethon Kids Institute: our journey – our success

Telethon Kids Institute (Institute) with the School of Population Health at The University of Western Australia established a joint Consumer and Community Involvement Program (Program) in 1998. The aim of the Program was to enable involvement to become standard practice in research across both organisations. This Program is now part of the Western Australian Health Translation Network which offers a statewide service and is recognised nationally and internationally as a good practice model for involvement. Telethon Kids Institute, a founding partner of the Program, has implemented a range of organisation wide strategies to enable their commitment to greater involvement. This 20-year journey has seen enormous cultural change with widespread consumer and community involvement activities now embedded as standard practice. The driver of this innovative Program has been to give a 'voice' to consumer and community members to ensure their lived experiences inform the Institute's research programs.

Our presentation will focus on how this organisation wide Program has raised awareness and changed attitudes and behaviours. We will showcase research programs that have implemented a diverse range of models for involvement which include:

- Consumer steering panels

- Research buddies
- Community conversations
- Open days
- Community grant reviewers
- Priority setting partnerships

We will discuss the benefits of having:

- A suite of bespoke training workshops available for researchers and community members
- Audit tools
- Resources
- Standards for consumer and community involvement
- Dedicated positions to support partnerships between researchers, consumers and community members

The presentation will demonstrate how a positive change in culture can be achieved through support, training and positive experiences of researchers, consumers and community members working together.

Parallel Session 4:

Organisational approaches to public involvement in health research – perspectives from a local health district and medical research institute.

In light of the movement towards greater public involvement in health research and the obvious need to engage meaningfully with health consumers and community members throughout the entire process, it is imperative that organisations take a systematic and coordinated approach to consumer and community engagement. Anything less carries a high risk of tokenistic involvement, public disengagement, and compromised research impact, leading to limited improvements to the health of the population. A comprehensive evidence review, including a search for existing resources, combined with expert advice, has identified organisational frameworks and strategies that enable and facilitate the meaningful involvement of the public in health research. These strategies, along with the principles behind them (including addressing the barriers and enablers to public involvement) and potential measures for monitoring and evaluation, will be shared with the aim of raising awareness and generating discussion about what organisations can do to effectively support the engagement of consumers and community members in health research.

Successfully Participating in General Societies when Living with a Neurological Disability

The purpose of this research is to understand how individuals participate in general societies when living with a neurological disability, such as epilepsy. This being when anticonvulsive medications alone are unable to fully control seizure activity. One in twenty of the world's population will experience a seizure at some point in their lives. One in two-hundred will experience regular seizure activity and be prescribed an anticonvulsive medication. A multiple case study approach of five Australian men with a history of adult-onset epilepsy provided their personal stories and this was adopted as a research instrument in this study. The data validation was based on the triangulation technique, which included information gained from the in-depth interviews, the observation of social and personal perceptions, and the reflective journal. The results showed that when living 'the normal life', each of the participants found it difficult to fully hide their condition. This would often negatively influence their subjective wellbeing (SWB). The data suggested that by implementing the three Rs model, which are Routine, Restructuring, and Reflecting, this can help individuals to adjust to 'the normal life' whilst living with a disability. By following the First R: Daily routine, this helped the participants to organise their activities similarly to the average person. The Second R: Restructuring the way to participate with others outside of face-to-face contact. Using new technological devices, such as smart phone, internet, email, and different applications for sending messages and contacting people. The Third R: Reflective journal, allowed them to further understand their behaviours and decisions made during the seizure period. This overall lowered the social burden of their disability and increasing their SWB.

We want to be part of the solution, not just be the problem – why patients need to be involved in research and scientific conferences

Patient involvement in all stages of research is widely endorsed by global organisations such as the WHO, however evidence and understanding of the value and potential impact of this involvement remains limited. My experience as a patient research partner demonstrates the role we can play as key figures in research design, delivery, implementation and dissemination:

- Design, development and implementation of the “Norm Bourke Box” – a patient toolkit valued at ~\$300 to assist with the proper and hygienic delivery of peritoneal dialysis, helping to reduce infections and improve adherence.
- Design, development and implementation of a water delivery service to assist rural patients on home dialysis in times of drought.
- Coordinating accommodation solutions close to treatment for rural dialysis patients.
- Co-chair of the BEAT-CKD Consumer Advisory Board - shaping and informing the direction of BEAT-CKD research activities, as well as contributing directly to specific research activities.
- Plenary speaker and session co-chair at the Australian and New Zealand Society of Nephrology Annual Scientific Meeting - I brought a patient voice and perspective to a meeting of medical professionals and bridged the gap between patients and researchers through chairing knowledge translation sessions for patients and authored an invited editorial on my experience for a biomedical journal.
- Conception, development and dissemination of a short film dedicated to patient stories to inform the research community of the power and capacity of patient contributions to research (<https://www.youtube.com/watch?v=MFFpYP5SkxY&feature=youtu.be>).

Our stories alone are powerful enough to help shape the direction of research, funding and government policies, but we are more than our disease. We have experiences and skills both as patients and from our personal and professional lives that can we contribute to research efforts - initiating ideas, providing feedback, answering surveys and prioritising research agendas to align research with problems that are important to patients.

Parallel Session 4:

Principles and strategies for involving patients in research in chronic kidney disease: report from national workshops

Background: There is widespread recognition that research will be more impactful if it arises from partnership between patients and researchers, but evidence on best practice for achieving this remains limited, particularly from the patient perspective.

Aims: To understand and describe patient and health professional perspectives about patient involvement in research in chronic kidney disease, and to identify practical solutions to engage and involve patients in research.

Methods: 105 patients and caregivers and 43 clinicians and researchers participated in three workshops in Sydney, Adelaide and Brisbane. In facilitated breakout groups, participants discussed principles and strategies for patient involvement in research. Transcripts were analysed thematically.

Results: Five major themes emerged. *Respecting consumer expertise and commitment* involved valuing unique and diverse experiential knowledge, clarifying expectations and responsibilities, equipping for meaningful involvement, and keeping patients ‘in the loop’. *Attuning to individual context* required a preference based multipronged approach to engagement, reducing the burden of involvement, and being sensitive to the patient journey. *Harnessing existing relationships and infrastructure* meant partnering with trusted clinicians, increasing research exposure in clinical settings, mentoring patient-to-patient, and extending reach through established networks. *Developing a coordinated approach* would facilitate power in the collective and united voice, a systematic approach for equitable inclusion, and streamlining access to opportunities and trustworthy information. *Fostering a patient-centred culture* encompassed building a community, facilitating knowledge exchange and translation, empowering health ownership, providing an opportunity to give back, and cultivating trust through transparency.

Conclusions: Patients want to be involved in research to take ownership of their health, however they are unaware and uncertain about potential opportunities for involvement. Collectively, these strategies may support active, sustained, and effective involvement of patients and caregivers as partners in research for improved care and outcomes.

Using video-reflexive methods to optimise infection prevention and control: A collaboration between researchers, patients, family members and healthcare professionals

Patient safety research has, to date, offered few opportunities for patients to be actively involved in the research process. We describe two studies, aimed at increasing patient involvement in infection prevention and control (IPC), where patients, family members and clinicians were invited to collaborate as co-researchers in the design, data-creation, interpretation and/or dissemination of the research.

In these studies, we were interested in investigating and advancing alternative ways of involving patients, family members and clinicians in patient safety research in a way that placed less emphasis on pre-determined research roles and knowledge gathering and focused more on co-generation of safety awareness with frontline actors at the point of care. Moreover, we wanted to enable the formation of relationships between people, environments and systems that were dynamic enough to grasp and deal with the complexity of IPC *in situ*.

Video-reflexive ethnography (VRE) is a methodology that embraces the ideology of *in situ* learning and takes an interventionist, collaborative approach to optimising patient safety practices. VRE holds that through collaborative reflexive viewing of videoed work practices, everyone involved can become more aware of the complexity and taken-for-granted aspects of work practices and relationships, as well as strengths and opportunities for change. In our studies, researchers, patients and clinicians collected video recordings of IPC activities. These were then used in one-on-one reflexive sessions with patients who scrutinised the footage to explore how they experience, understand and enact IPC. Patients' insights were then fed back to the clinicians who cared for them, who were then able to devise local strategies for supporting patients to become more actively involved in IPC.

In this presentation, researchers, former patients and clinicians will describe the opportunities and challenges encountered when designing, implementing and disseminating these collaborative studies.

Parallel Session 4:

Sharing power with communities in health research priority-setting: Developing a ethics toolkit for engagement practice

Public engagement is a key means of setting research priorities of relevance to those considered disadvantaged and marginalised. Yet without attention to power and difference, their engagement can often lead to presence without voice and voice without influence. This paper presents a novel ethical framework for designing engagement processes in health research priority-setting where power is more evenly shared with the public, particularly those from disadvantaged and marginalised groups. Here, priority-setting refers to the selection of health research projects and programmes' topics and questions.

Different components of engagement and dimensions of power relevant to each of them were first identified by analysing six key bodies of literature. Ethical considerations and guidance relating to those dimensions of power were characterised for the health research priority-setting context. These initial conceptual findings were then tested against the knowledge and experiences of public engagement practice. 29 in-depth, semi-structured interviews and one focus group were undertaken with researchers, ethicists, community engagement practitioners, and staff of community-based organisations. Relevant dimensions of power, ethical considerations, and guidance relating to them have been revised in light of the empirical findings.

Based on the conceptual and empirical work, an ethical "toolkit" was developed for use by health researchers and their partners when designing engagement processes for priority-setting for health research projects. It is a reflective project planning aid to employ *before* priority-setting is undertaken for health research projects. It consists of three worksheets and a companion document detailing how to use them. Using the toolkit to design priority-setting will facilitate processes where hierarchies of privilege and subordination that marginalise voices are less likely to be reproduced. This, in turn, will help generate health research priorities that encompass and more accurately reflect the health needs and knowledge of those considered disadvantaged and marginalised.

A shock to the system: service-user lead research using lived experience knowledge to inform ECT practices

ECT is a topic of great controversy and consumer voices continue to be predominantly excluded from ECT focused research. This presentation will report on two innovative, consumer-led research projects focus on ECT. The "ECT Let's talk about it!!" project was led by people with a lived experience of ECT (electro-convulsive therapy) and involved collaboration with a number of mental health services. Consumers directed all aspects of the project: from funding application, project management and data collection through to data analysis. By interviewing 17 people about their experiences of ECT, we identified what consumers needed prior to and during any ECT experience. We also identified an almost non-existent body of knowledge around living life after ECT; the ways people are impacted and the ways they successfully manage in their daily lives. This is being addressed in my Masters research: What is the lived experience of people who have had or continue to have ECT as they participate in daily life? How do people perceive and adapt to the consequences of ECT for their daily lives? Rich narratives of consumers in both studies will

hopefully result in better practice, greater support and lived-experience informed recommendations for living life post ECT.

Parallel Session 4:

Consumer and community involvement in health research – what do consumers say about how to do this?

Background/Aim Widespread, systematic embedding of consumer involvement in health research is lacking in Australia. Sydney Health Partners (SHP), a major collaboration between the University of Sydney, four public health services and nine medical research institutes, wanted to better understand what consumers think about how to involve them in health research.

Methods SHP liaised with the managers of patient advisory committees in its four partner health services (Northern Sydney, Sydney, and Western Sydney Local Health Districts, and the Sydney Children's Hospital Network (at Westmead)). Three focus groups (n=16 participants) and four one-on-one interviews were held. Participants included patients, carers and health consumer representatives, with a mixture of genders, ages, socio-economic and cultural backgrounds, and health care conditions and experiences. Discussions focused on two questions:

- How can we better engage patients and other health care consumers in the development of research questions that address priority issues from a patient/consumer perspective?
- How can we best communicate with patients and other health care consumers the importance of participating in research? What information do patients and health care consumers need to have?

Results The following themes emerged from the consultations:

- Marketing and education strategies are needed to promote greater public awareness about health research
- If you ask us, be prepared to listen to us and respect what we say
- Honesty and transparency about research, its purpose, risks and benefits, etc. are essential
- Different engagement processes may be needed for some patient and population groups
- Make involvement in research a positive experience (logistics, communications, etc.)

Conclusions There is growing evidence that consumer involvement improves the quality, relevance and application of research. To do it well requires researchers to invest time and resources to genuinely attract and involve community members, and to adapt their research in response to this engagement.

Lived Experience Evaluation – Keep It Real!

Health Research that authentically values lived experience expertise and embeds this skillset in evaluation co-design fosters greater transparency and understanding of service user data and offers unique insights, providing access to enhanced positive service user outcomes. As early adopters of co-design in an evaluation process, Brisbane North PHN recognised the importance and value of utilising the expertise of lived experience evaluators in the design, delivery and interpretation of qualitative data of the Partners in Recovery (PiR) program.

The Partners in Recovery program was designed to promote a community-based recovery model, supporting better outcomes and collaborative care responses for individuals experiencing severe and persistent mental illness. It is essential to highlight the knowledge, experience, expertise and value drawn from the lived experience community in contributing to health research, as equally important contributors to *creation, implementation* and the *interpretation* of results as other stakeholders. This presentation seeks to 'Keep It Real' and explore how the Principle – 'Nothing About Us Without Us' underpinned the implementation of the evaluation.

As a small team of lived experience evaluators, during the implementation phase of the evaluation we made time to reflect back and support one another within the broader context of the PiR team. Some of the key questions we explored and we will unpack include:

What worked, what didn't and what we did about it?

- Our skill sets
- The work environment
- Resources
- Processes

What does value mean to the:

- person
- service
- system

An interactive mixed media presentation will engage the audience by highlighting the journey of lived experience evaluators of the Brisbane North Partners in Recovery program.

Consumer and Community Engagement in Research in South Western Sydney: Insights from the SWSLHD Consumer and Community Participation Unit

South Western Sydney is one of the fastest growing regions in NSW, with the population projected to reach approximately 1.16 million people by 2026. The rich diversity of the area, including large migrant and Aboriginal and Torres Strait Islander communities, a vast range of socio-economic backgrounds, and a significant youth demographic, stands this region apart from the rest of NSW. While such a distinct population presents challenges to health service delivery, it also offers a unique opportunity for consumer-driven approaches to healthcare. Consumer, carer and community representatives are valued participants in the South Western Sydney Local Health District (SWSLHD) organisational and strategic processes that guide the planning, design and evaluation of health services in South Western Sydney. These representatives, via a coordinated network of local Committees, are afforded ongoing opportunities to contribute to the development of health service strategic plans for research and health service delivery for a broad spectrum of clinical disciplines. Active Links with research groups, recognition of the importance of Evidence-based care, clear Governance structures within the organisation (with the overarching Consumer and Community Participation Council comprising members of and reporting directly to the SWSLHD Board), and a culture of valuing community members Opinions, have been the building blocks for integration of research into community activities and vice versa (termed the Community Engagement in Research “*LEGO principles*”). To date, this has resulted in a significant number of novel community and clinician co-designed models-of-care, and improvements to service delivery (largely via quality improvement projects).

Public Involvement in Health Research

“What would Grandma say?”

*Adam Johnston**

Introduction

My late maternal grandmother, Margaret “Jill” Branagan (better known as Jill because her brother’s name was Jack) had an interesting if difficult life. Born in 1914, she would see the Great Depression, another World War and, raise two daughters as a War Widow in East Coburg, Melbourne. Later moving back to her childhood home, Manly, Jill’s daughters grew, and one would marry and have two children. One of these children, me, would be born three months prematurely and, was not supposed to live. A humidicrib and some inspired 1970s intensive care treatment at Manly Hospital would see me through. Grandma would say of me, regarding my resulting disabilities: “at least he was born in the right age”. She also related to me a dream she constantly had during the difficult days, weeks and indeed months, after my birth. It was a dream where the two of us were walking along the famous Manly Corso, a humidicrib alarm light flashing above my head.

Some may find this funny, or even naïve, but as one gets older and is yet to stride The Corso, you

begin to ask: how do I find and promote the policies and people who are needed to deliver on

Grandma’s vision? One caught a glimpse of such people in 2003, when then NSW Premier Bob Carr

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invited world famous paralysed actor Christopher Reeve, his doctor Professor Wise Young and many other experts, to the *Making Connections Forum* at Sydney's Convention and Exhibition Centre.¹

Suddenly, there was reason for renewed hope; a childhood marked by repeated orthopaedic surgical interventions of indifferent therapeutic benefit, might give way to something better from Mr. Reeve's vision for cellular research, the forerunner to organ, nerve, and tissue regeneration. It could also see the end of other treatments like occupational therapy, physiotherapy, and hydrotherapy, all of which in my experience have a similarly negligible long-term therapeutic benefits to the invasive orthopaedic options. Perhaps I could begin to dream, ever so faintly, of life without disability, just as Grandma had done for me so many years ago?

Definitions

The first issue however, is to establish: what is health? According to *Black's Law Dictionary*, health is:

¹ See e.g.: Christopher & Dana Reeve Foundation, *Matthew Reeve Flies Down Under for Spinal Cord Injury Research: Continues Superman's Legacy*, July 05, 2012 10:23 ET, <http://www.marketwired.com/press-release/matthew-reeve-flies-down-under-spinal-cord-injury-research-continues-supermans-legacy-1676923.htm> as at 31 December 2018; Christopher Reeve's speech to the *Making Connections Forum* is available at: Christopher Reeve, *Keynote Speech*, 'Making Connections' NSW Premier's Forum on Spinal Cord Injury & Conditions, Monday 27 January 2003, <http://www.daretodo.asn.au/pdf/keynote.pdf> as at 31 December 2018

State of being hale, sound, or whole in body, mind or soul; well-being. Freedom from pain or sickness. See Healthy...free from disease, injury or bodily ailment, or any state of the system particularly susceptible or liable to disease or bodily ailment.²

What the term health means in the early 21st century as against what it meant in the late nineteenth or early 20th century is also important. The Australian Institute of Health and Welfare (AIHW) has noted a shift in mortality from communicable diseases, to mortality due to non-communicable illness, alongside a consistent drop in mortality, but an increase in the number of years people are forced to live with chronic illness.³ People are living longer, but it is far from clear that we hale or whole. Not that it can be claimed Australia spends that much on research, with the same AIHW Report suggesting this was just 3 percent of health outlays.⁴

Why so little spending?

This should be a national scandal, while the fact that it is not shows the vital importance of more public involvement in, and more promotion of public participation in, health research. One hastens

² Joseph R. Nolan and Jacqueline M. Nolan-Haley (eds.), *Black's Law Dictionary*, 6th ed., West Publishing Company, 1991, 721

³ See Australian Institute of Health and Welfare, *Australia's health 2018*, Australia's health series no. 16. AUS 221: Canberra: AIHW., 2018, 94-102, <https://www.aihw.gov.au/getmedia/7c42913d-295f-4bc9-9c24-4e44eff4a04a/aihw-aus-221.pdf.aspx?inline=true> as at 29 December 2018

⁴ *Ibid.*, 58 (Figure 2.2.6: Proportion of total health expenditure, by broad area of expenditure, 2015–16)

to add that this is not a new idea, with consumer bodies,⁵ consumer, advocacy and industry collaborations,⁶ and clinicians all realising their need to enact such policies.⁷ While movements for the public to be actively involved and responsible for their own health and wellbeing is positive, we need to examine where this came from.

A driving force behind this trend were reforms in both healthcare and the wider social services sector, emphasising a market-based approach where patients or clients suddenly became consumers of marketable products, rather than passive recipients of treatment, care or welfare. From the 1980s onwards, citizens of western liberal democracies were governed by a political consensus around small governments, free markets and individual choice and responsibility.⁸ The active, informed health consumer, is not dis-similar to the consumer in the free market of classical liberal thinkers like Adam Smith, transplanted into the late 20th and early 21st century. It is not my intention to argue the merits any more widely, other than to say it provides a context for further comments on public

⁵ See e.g.: Research4Me, Health Consumers NSW, (2017) *Involving Health Consumers in Health and Medical Research: Enablers and Challenges from a Consumer Perspective*, Health Consumers NSW and Research4Me, https://research4.me/wp-content/uploads/2017/11/Consumers_in_Research_Rpt_24Feb17.pdf as at 29 December 2018

⁶ See e.g.: Janelle Bowden, Lisa Briggs (2018) *Searching for Clinical Trials: What Patients Want*. Research4Me Report from a Think Tank Exploring the Issues Finding and Providing Information About Clinical Trials, and How They Might Be Solved., https://research4.me/wp-content/uploads/2017/11/Consumers_in_Research_Rpt_24Feb17.pdf as at 29 December 2018

⁷ See e.g.: Todd AL, Nutbeam D. *Involving consumers in health research: what do consumers say?* Public Health Res Pract. 2018;28(2):e2821813. <http://www.phrp.com.au/issues/june-2018-volume-28-issue-2/involving-consumers-in-health-research-what-do-consumers-say/> as at 30 December 2018

⁸ An example describing the ideological, political and procedural changes in the Australian Government's delivery of unemployment services in the 1990s and 2000s can be found at: Siobhan O'Sullivan, Mark Considine and Jenny Lewis, *John Howard and the Neo-liberal Agenda: regulation and reform of Australia's privatised employment services sector between 1996 and 2008*, (Presented at the Australian Political Studies Association (APSA) Conference) (September 2009) Macquarie University, http://ssps.unimelb.edu.au/sites/ssps.unimelb.edu.au/files/John_Howard_and_the_Neoliberal_Agenda_Sept_2009.pdf as at 6 January 2016.

involvement in health research. It should also provide researchers with even more motivation to involve the public, accepting that neither party can passively rely on government at any level.

If researchers sought public participation, all reports cited said that to do this researchers had to be easy to find, be transparent about the work they were doing, really listen to the feedback participants were giving them and, if researchers were serious about co-designing their work with the public, making the consultations early and extensive enough so that a study could truly be changed, entirely redesigned or even stopped, based on consultations. And consumers are very interested in results, with Todd and Nutbeam noting:

Several volunteers also emphasised the importance of study participants receiving feedback about a project, even if it was some years later, so that they can see the value of their contribution. Tellingly, none of our participants who had been involved in research had ever received feedback about the results.⁹

People want to know they added some real value and, how this contributed to the outcome. This desire should be obvious; even more so when bodies like the Australian Commission on Safety and Quality in Health Care (the Commission) release standards like the National Safety and Quality Health Service Standards, the second standard of which is *Partnering with Consumers*.¹⁰ Some

⁹ Above n. 7

¹⁰ See Australian Commission on Safety and Quality in Health Care, *National Safety and Quality Health Service Standards*. 2nd ed. Sydney: ACSQHC; 2017, 13-20, <https://www.safetyandquality.gov.au/wp->

researchers may complain that this risks making research design and implementation less 'scientific' and more transactional, like a free market economy. Studies, included those cited, suggest this is not the case and project quality is not degraded but improved, by public involvement in health research.

This has to be balanced with the reality acknowledged by the Commission, that only about 40 percent of Australians have the knowledge required to follow prescriptions and other clinical directions, warning or messages, as intended.¹¹ Alternatively, this figure could be cited as an argument for more public participation in health research, to build health literacy.

So, what is the real understanding of and, appetite for public involvement in medical research? I have been around the argument for years trying to inform both scientific¹² and popular opinion¹³ about ways each needs to serenade the other. One still cannot gauge success, but if you want public opinion to move, you must go out and both inform it and change it yourself. Notably, Dr. Daniella Goldberg, said this of me in a *LinkedIn* article at a 2015 Stem Cell Conference

One key answer is advocacy - a passionate stem cell advocate that delivered an insightful talk about the important role of advocacy in driving the progress of regenerative medicine, is

[content/uploads/2017/12/National-Safety-and-Quality-Health-Service-Standards-second-edition.pdf](https://www.safetyandquality.gov.au/wp-content/uploads/2017/12/National-Safety-and-Quality-Health-Service-Standards-second-edition.pdf) as at 2 January 2019

¹¹ See Australian Commission on Safety and Quality in Health Care, *Health Literacy National Statement*, August 25, 2014, <https://www.safetyandquality.gov.au/wp-content/uploads/2014/08/Health-Literacy-National-Statement.pdf> as at 2 January 2019

¹² See Stem Cells Australia, *Stem Cells in the Hunter Valley*, 20 November 2015, <http://www.stemcellsaustralia.edu.au/News---Events/News/Stem-Cells-in-the-Hunter-Valley.aspx> as a 2 January 2019; also see *ibid*, *Program: Stem Cells in the Hunter Valley 2015 – Hunter Valley – Lorne page 1*, <http://asscrs3.asnevents.com.au/assets/Uploads/Program-and-posters.pdf> as at 2 January 2019; also see

¹³ See *Equipping patients as partners in trials: A workshop hosted by Dr. Norman Swan*, Hilton Hotel, Sydney, 15 October 2015, https://www.ctc.usyd.edu.au/media/1485286/equipping_patients_21jul2015.pdf as at 2 January 2019

Adam Johnston, who lives with cerebral palsy. With advocacy in place, the stem cell community shall become united, with one voice, to tell the story to the public.¹⁴

A warning about advocacy

It is at this point there should be a warning delivered about advocacy bodies. Some can become the mouthpiece of a person or small group of people,¹⁵ Harold Scruby and his Pedestrian Council being the classic example of a person and organisation both seeming to delight in generating public angst as a media device¹⁶ and, watching it grow.¹⁷ Other organisations grow, accept public funding and fundamentally change, leaving some of their members wondering what has happened; the organisations which were once volunteer-run by parents for the support of their children with disabilities are now the province of professionally paid managers, causing Vern Hughes to observe:

¹⁴ Daniella Goldberg, *The Business of Stem Cells in Australia*, November 12, 2015, <https://www.linkedin.com/pulse/business-stem-cells-australia-daniella-goldberg?articleId=6070407645519425536#comments-6070407645519425536&trk=prof-post> as at 2 January 2019

¹⁵ See e.g.: Mike Stevens, *What Grinds My Gears: The Pedestrian Council*, *The Motor Report*, Aug, 11 2008, <https://www.themotorreport.com.au/car-article/what-grinds-my-gears-the-pedestrian-council-67220.html> as at 2 January 2019; see also The Pedestrian Council, *Structure*, ABN 18 075 106 286. © 2019 Pedestrian Council of Australia. <http://www.walk.com.au/pedestriancouncil/page.asp?PageID=105> as at 2 January 2019

¹⁶ See e.g.: Caroline Tang, *Pedestrian Council chairman Harold Scruby called "un-Australian" after Mosman resident spots him using Council "dobbing" app*, *Mosman Daily*, July 22, 2016 9:42am, <https://www.dailytelegraph.com.au/newslocal/mosman-daily/pedestrian-council-chairman-harold-scruby-called-unaustralian-after-mosman-resident-catches-him-using-council-dobbing-app/news-story/460f1ac7d1d9d99416e965b5170dabda> as at 2 January 2019

¹⁷ There is a Facebook page: *Pedestrians against Harold Scruby* https://www.facebook.com/pg/haroldscruby/community/?ref=page_internal (accessed: 2 January 2019). It has 596 Total Likes and 589 Total Followers. By contrast, the Facebook page: *Pedestrian Council of Australia*, <https://www.facebook.com/pedestriancouncilaustralia/> (accessed: 2 January 2019) only has 436 Total Likes and 444 Total Followers. About the only thing that can be reasonably concluded from these small numbers, is that more people like to hate Harold Scruby and his organisation than support it.

Today many...parents find themselves referred to, in the annual reports of the bodies they created, as "stakeholders" in the welfare of their sons and daughters. They appear alongside key stakeholders such local governments, suppliers and corporate partners. Many shake their heads in disbelief at the entity they unknowingly created. "We gave birth to a monster," some say.

Managerialism – in public, private and community sectors – is the prevailing ideology of our time. It has trumped entrepreneurship in the private sector, and perverted notions of service in the public sector. But in the non-profit sector it has swept all before it.¹⁸

The National Disability Insurance Scheme (NDIS)

I agree with Mr Hughes and, the biggest example of his point about managerialism is the NDIS itself. It was supposed to be a ground-breaking generational change. Instead, a centralised Commonwealth bureaucracy was created to dispense personalised budgets and individual plans to those it judged permanently and significantly disabled. As one of the people deemed permanently and significantly 'unsound of body' (to invoke the dictionary definition) to qualify for the NDIS, I was 'assisted' by a charity to become an NDIS participant by preparing an individual plan. Contained in this plan were

¹⁸ Vern Hughes, *Not for Profits Lose Sight of Volunteer Heritage*, Thursday, 10th February 2011 at 10:22 am, <https://probonoaustralia.com.au/news/2011/02/not-for-profits-lose-sight-of-volunteer-heritage/> as at 2 January 2019

the details of other non-government organisations who would now provide me with disability support services and, be funded by the NDIS.

Other than being the source of funds to be dispersed when individual plans approved by the central bureaucracy, State and Federal Governments have largely excised themselves from the public provision of many social services related to disability. While the prevailing opinion was that this provided me with greater 'choice and control' over who would provide me with support services, my conclusion (and that of a few other brave dissenters¹⁹) was and is that the NDIS is little better than a retreat into dependence on charity. Charitable dependence was the informal system that existed for centuries, until the large-scale development of the welfare state, post the horrors of World War II. And, we are going back to it?²⁰

At the same time, the NDIS presents itself as the epitome of the laissez faire economics which is going to help me and thousands of others with disability find and maintain employment, because that is what the Act says. Section 4 talks quite specifically about people with disabilities making a

¹⁹ See e.g.: Heike Fabig, *NDIS: rights-based paradigm shift or same old charity?*, Ramp Up 11 Apr 2013, <http://www.abc.net.au/rampup/articles/2013/04/11/3734962.htm> as at 11 January 2019; see also Damian Palmer, *Let's be honest, there's more wrong with the NDIS than just 'teething problems'* October 25, 2017 10.23am AEDT, The Conversation, <https://theconversation.com/lets-be-honest-theres-more-wrong-with-the-ndis-than-just-teething-problems-86225> as at 11 January 2019; see also Mark Bagshaw, *The NDIS – A Personal Perspective*, LinkedIn, Published on March 11, 2018, <https://www.linkedin.com/pulse/ndis-personal-perspective-mark-bagshaw/?published=t> as 11 January 2019

²⁰ See e.g.: Adam Johnston, *The NDIS: The Mark of Pre-War or Post-War Public Policy Making?*, Humanity – NewMac Postgrad Journal 2018 Special Issue: Making a Mark, A collection of articles from the 2017 NewMac Conference <https://nova.ajs.newcastle.edu.au/hass/index.php/humanity/article/view/63/58> as at 3 January 2019

social and economic contribution by being employed.²¹ Again, the market-based model of individual ‘choice and control’ in disability services meets the quasi-market (but truly political imperative) of having people with disabilities employed. However, we have all seen this employment story before and, we know how it ends. Despite all the initiatives, all the money and the often-punitive measures,²² Australian Bureau of Statistics figures show that nearly half of Australia’s disabled people of working age are not in the workforce, and only 27 percent have full time work, as compared to 53.8 percent of able-bodied workers.²³

The disparity is complex and beyond the scope of this paper. However, it raises three questions, at least. Why does Australia’s arguably cruel welfare policies continue to push the disabled, chronically unwell and unemployable through training and employment schemes that just do not work? Why has no one in government asked: don’t you need to make someone well (read: healthy) before you can expect them to work, or be a good prospective employee? Finally, would not any number of people with disabilities welcome an opportunity to participate in research? Regardless of whether it

²¹ See *National Disability Insurance Scheme Act 2013*, No. 20, 2013, Compilation No. 9, 1 July 2018, <https://www.legislation.gov.au/Details/C2018C00276> as at 3 January 2019. For example, section 4(2) and (11)(c) of the Act states:

4 General principles guiding actions under this Act

....

(2) People with disability should be supported to participate in and contribute to social and economic life to the extent of their ability...

(11) Reasonable and necessary supports for people with disability should:

(a) ...

(b) ...

(c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the community and in employment.

²² See generally, above n 8.

²³ See Australian Bureau of Statistics, *4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015, Employment*, Latest ISSUE Released at 11:30 AM (CANBERRA TIME) 18/10/2016, <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4430.0main+features202015> as at 4 January 2019

improves their experience or condition, as cited earlier research participants are often very interested in study findings, even if they emerge many years hence.²⁴

The research vacuum that is the NDIS

You can imagine what a deflating experience it was to realise that the *National Disability Insurance Scheme Act 2013* (the Act) contains only six references to research.²⁵ All the references to research

²⁴ See above n 9

²⁵ See above n 21. The references to research are:

Chapter and Part	Section and Sub-section
Chapter 1 – Introduction Part 3—Simplified outline	8 Simplified outline The Agency also has more general functions, such as: (a) developing and enhancing the disability sector, including by facilitating innovation, research and contemporary best practice in the sector; (b) building community awareness of disabilities and the social contributors to disabilities
Chapter 4 – Administration Part 2—Privacy Division 1—Information held by the Agency	60 Protection of information held by the Agency etc. (1) A person may collect protected information for the purposes of this Act... (3) Without limiting subsections (1) and (2), the collection, recording, disclosure or use of information by a person is taken to be for the purposes of this Act if the CEO believes, on reasonable grounds, that it is reasonably necessary for one or more of the following purposes: (a) research into matters relevant to the National Disability Insurance Scheme; (b) actuarial analysis of matters relevant to the National Disability Insurance Scheme; (c) policy development
Chapter 4 – Administration Part 2—Privacy Division 2—Information held by the (Quality and Safeguards) Commissioner	67A Protection of information held by the Commission etc. (1) A person may: (a) make a record of protected Commission information;... (2) Without limiting subsection (1), the recording, disclosure or use of information by a person is taken to be for the purposes of this Act if the Commissioner reasonably believes that it is reasonably necessary for one or more of the following purposes: (a) research into matters relevant to the National Disability Insurance Scheme; (b) policy development.
Chapter 6—National Disability Insurance Scheme Launch	118 Functions of the Agency (1) The Agency has the following functions: (c) to develop and enhance the disability sector, including by facilitating innovation, research and contemporary best practice in the sector;

talk about different parts of the NDIS bureaucracy doing research, largely with the information it already holds. Nowhere are families or NDIS participants seen as active players in proposing, designing, or implementing research. Equally, much of the language used is directed at ‘the disability sector’ or ‘service providers’. This says that the NDIS Agency and its leadership does not see the sector or providers being made redundant anytime soon. And it is not asking its participants or families (supposedly central to its inception) or the taxpaying public who are funding it, what their view of research is? Do NDIS management fear a series of different answers? Would this upset the quiet, convenient and, profitable cartel between the Commonwealth Government, the NDIS and the charitable sector?²⁶

Even before the appearance of the NDIS, the charitable sector was receiving vast amounts of money from all governments, which Peter Kurdi (relying on Productivity Commission figures) putting this

<p>Transition Agency Part 1— National Disability Insurance Scheme Launch Transition Agency</p>	<p>(d) to build community awareness of disabilities and the social contributors to disabilities; (e) to collect, analyse and exchange data about disabilities and the supports (including early intervention supports) for people with disability; (f) to undertake research relating to disabilities, the supports (including early intervention supports) for people with disability and the social contributors to disabilities;</p>
<p>Chapter 6A— NDIS Quality and Safeguards Commission Part 2—NDIS Quality and Safeguards Commissioner</p>	<p>181H Commissioner’s behaviour support function The Commissioner’s behaviour support function is to provide leadership in relation to behaviour support, and in the reduction and elimination of the use of restrictive practices, by NDIS providers, including by: (a) building capability in the development of behaviour support through:… (e) undertaking and publishing research to inform the development and evaluation of the use of behaviour supports and to develop strategies to encourage the reduction and elimination of restrictive practices by NDIS providers;</p>

²⁶ See e.g.: Rod Simms, *Privatising NDIS services could be a repeat of the VET-fee disaster*, Opinion, Sydney Morning Herald, <https://www.smh.com.au/opinion/privitising-ndis-services-could-be-a-repeat-of-the-vetfee-disaster-20170314-guxs7g.html> as at 10 January 2019

amount at \$4 billion dollars in 2013.²⁷ These subsidies, concessions and deductions are part of a much wider framework of growing tax expenditures; these are direct taxes foregone by government and described aptly by some as “welfare by other means”.²⁸

I make these points to show just how many individuals, churches, charities, private businesses and indeed, universities, rely on income from tax expenditures. This includes charitable providers who work with NDIS participants and the NDIS Agency. Widening the administrative echo-chamber of the NDIS bureaucracy and service providers, to involve as many other parties as possible would help prevent the design and implementation of flawed self-congratulatory, self-fulfilling research projects, which simply confirm the NDIS Agency’s view of itself. This can be seen in various pieces of international research where ‘choice and control’ (going by various names including ‘personal budgets’). Initial support among program participants or receipts was questioned by a number of social researchers as relating less to ‘choice and control’ or a personal budget and more to “the impact of having a service with having no service at all”.²⁹

²⁷ See Peter Kurti, *In the Pay of the Piper: Governments, Not-for-Profits, and the Burden of Regulation*, Issue Analysis: No. 139, 23 April 2013, The Centre for Independent Studies, 8, <http://www.cis.org.au/app/uploads/2015/07/ia139.pdf> as at 7 January 2019

²⁸ See Adam Stebbing and Ben Spies-Butcher, *Universal Welfare by ‘Other Means’? Social Tax Expenditures and the Australian Dual Welfare State*, Journal Social Policy, Cambridge University Press 2010, <file:///C:/Users/Adam/Desktop/Francesca/Literature%20Review/0c96053a2976b98f54000000.pdf> as at 7 January 2019

²⁹ See above n 20, 14, citing Colin Slasberg, Peter Beresford and Peter Schofield, *Further lessons from the continuing failure of the national strategy to deliver*, Research, Policy and Planning (2014/15) 31(1), 44 <http://ssrg.org.uk/wpcontent/uploads/2012/01/Slasberg-et-al3.pdf> as at 26 October 2017.

It would not make sense for the Agency or providers to publicise research like this, or anything that suggested people with disabilities and their families wanted something more ambitious than the NDIS; it might threaten their continued funding. Regardless, such work must be done, to challenge the NDIS Agency and expose its many shortcomings.

I expect something better

Beyond this, for \$22 billion annually,³⁰ you might expect a whole lot more from the Agency in terms of its research and how participants, families and the public are involved in such research. The Agency should also have a far more ambitious research agenda, with goals to progressively eliminate or at least ameliorate various forms of disability and chronic illnesses from the human condition. But alas, the day-to-day operational *NDIS Rules* prevent me from exercising a sufficient risk appetite, to chance any real change in my condition, or anyone else trying to do the same thing. This becomes clear when considering the *NDIS Rules*, specifically *Supports for participants*. The conservative and risk-averse nature of the NDIS Agency is underlined by Rules 3.2 and 3.3, which state:

³⁰ Helen Dickinson, *Explainer: how much does the NDIS cost and where does this money come from?*, May 8, 2018 6.16am AEST, The Conversation, <http://theconversation.com/explainer-how-much-does-the-ndis-cost-and-where-does-this-money-come-from-95924> as at 3 January 2019

Effective and beneficial and current good practice

3.2 In deciding whether the support will be, or is likely to be, effective and beneficial for a participant, having regard to current good practice, the CEO is to consider the available evidence of the effectiveness of the support for others in like circumstances. That evidence may include:

- (a) published and refereed literature and any consensus of expert opinion;
- (b) the lived experience of the participant or their carers; or
- (c) anything the Agency has learnt through delivery of the NDIS.

3.3 In deciding whether the support will be, or is likely to be, effective and beneficial for a participant, having regard to current good practice, the CEO is to take into account, and if necessary seek, expert opinion.³¹

Some will claim this is due caution and, exercise of the precautionary principle. However, it does show who is in charge when it comes to dispensing money: the NDIS Agency and its Chief Executive Officer (CEO). A participant or family who wanted to test a new therapy or product, would likely be defeated by this rule; this is particularly when Rule 3.2 (a) seeks not just expert opinion but “any consensus of expert opinion”.³² People will also be declined with the need to show the effectiveness

³¹ *National Disability Insurance Scheme (Supports for Participants) Rules 2013*, https://www.legislation.gov.au/Details/F2013L01063/Html/Text#_Toc358793028 as a 4 January 2019

³² *Ibid*

of a support to others “in like circumstances”.³³ If you are trying something truly different and innovative, then there will not be a comparator.

So, there it is - no venture into stem cell research or therapy, no electronic implants and robotics³⁴ only so far as they might be cost-effective and a disability aid, while not replacing or duplicating an existing or alternative service of lower cost. Cost is such an overriding concern, it has its own Part in the *Rules*.³⁵ And, certainly, nothing will be funded that according to Part 5 of the *Rules*, which state in part:

³³ Ibid

³⁴ I highlight reported developments in these technologies and, ask whether people with disabilities are being short-changed by the NDIS; see Adam Johnston, *From Citizen to Charity Case: Has Contracted Welfare Breached the Sovereign’s Duty to Her Subjects?* (Poster presentation), 2017 Ethical, Legal & Clinical Implications of Neuroscience Research, 14-15 September 2017, https://neuroethicsconference.org.au/?page_id=166 as at 11 January 2019

³⁵ See above n 31, **Part 3 Assessing proposed supports** – which states specifically:

Value for money

3.1 In deciding whether the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support, the CEO is to consider the following matters:

- (a) whether there are comparable supports which would achieve the same outcome at a substantially lower cost;
- (b) whether there is evidence that the support will substantially improve the life stage outcomes for, and be of long-term benefit to, the participant;
- (c) whether funding or provision of the support is likely to reduce the cost of the funding of supports for the participant in the long term (for example, some early intervention supports may be value for money given their potential to avoid or delay reliance on more costly supports);
- (d) for supports that involve the provision of equipment or modifications:
 - (i) the comparative cost of purchasing or leasing the equipment or modifications; and
 - (ii) whether there are any expected changes in technology or the participant’s circumstances in the short term that would make it inappropriate to fund the equipment or modifications;
- (e) whether the cost of the support is comparable to the cost of supports of the same kind that are provided in the area in which the participant resides;
- (f) whether the support will increase the participant’s independence and reduce the participant’s need for other kinds of supports (for example, some home modifications may reduce a participant’s need for home care).

Part 5 General criteria for supports, and supports that will not be funded or provided

General criteria for supports

5.1 A support will not be provided or funded under the NDIS if:

- (a) it is likely to cause harm to the participant or pose a risk to others;³⁶

It is not as if we lack bright, young researchers ready and willing to take research to the public.³⁷

And exciting research is being done; of special interest for this author blighted by cerebral palsy, is work on early stage neural cell and nervous system development.³⁸

What do we need to do?

Do we celebrate our scientists in Australia? In this country, we are more likely to be able to name footballers or cricket stars than scientists, but as stated earlier, there are people trying to change

³⁶ Ibid

³⁷ See Tamara Treleaven and Bernard E Tuch, *Australian Public Attitudes on Gene Editing of the Human Embryo*, *Journal of Law and Medicine* update: Vol 26 Pt 1, <http://sites.thomsonreuters.com.au/journals/2018/10/08/journal-of-law-and-medicine-update-vol-26-pt-1/> as at 7 January 2019

³⁸ For someone with cerebral palsy like me, following a bright, young researcher studying early brain and nervous system development provides a vital ray of hope for restoration; see Rachel Adina Shparberg, *L-proline-mediated neural differentiation of mouse embryonic stem cells*, Doctor of Philosophy Ph.D., 31-Dec-2017, <http://hdl.handle.net/2123/18653> <https://ses.library.usyd.edu.au/handle/2123/18653> as at 8 January 2019

this. As the general public, we also need to pressure politicians to rationalise the number, extent and value of tax expenditures in the economy.

The tax expenditures prop up a vast charitable network, much of which now provides the service infrastructure for the NDIS. Some would say that is a good thing, but not only are governments losing billions in direct revenue, there is something about the NDIS that needs to be confronted. It assumes lifelong disability and makes its plans from this starting position.

The NDIS webpage makes this clear when it says that:

the NDIS takes a lifetime approach (i.e.: seeks to minimise support costs over a participant's lifetime) by investing in people early to build their capacity to help them pursue their goals and aspirations resulting in greater outcomes in later life.³⁹

While the NDIS Agency may claim it wants people to have 'greater outcomes,' this is done as cheaply as possible and always with the participant remaining disabled; this is unlikely to improve employment outcomes, or any other outcome for that matter. Furthermore, while the Overview just quoted refers to innovation later in the same section,⁴⁰ with the caveats placed on research in the

³⁹ Overview of the NDIS, 4.3 What are the NDIS Insurance Principles?, <https://www.ndis.gov.au/operational-guideline/overview> as at 8 January 8, 2019

⁴⁰ See *ibid*

Act, how it will be conducted and who will be involved, suggests there will be innovation in name only. Equally, the caveats on participant supports in the *Rules* make sure that the NDIS Agency and its coterie of charitable providers perpetuate the need for their existence, at the expense of participants and families, who might want to try experimental supports. Introduce some participants and families and it could change the whole research and health debate in the NDIS Agency.

But the Agency would say it does not fund the provision of health services, pointing to *Rules 7.4* and *7.5*. These relate to health and, while the Agency can make a defensible case that it should not fund GP, hospital care and the like, consider this section:

7.5 The NDIS will not be responsible for:

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

(i) ...

(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;

Despite the Overview talking of goals, capacity, and greater outcomes,⁴¹ improving someone's function after a medical intervention is not within the scope of the NDIS. This shows how 'talk is cheap' with the NDIS and how no greatest outcome will ever be without my disability in tow.

Rule 7.5 must be one of the crudest, most cruel, and most soul-destroying pieces of subordinate legislation written this century. It shows just what a limited scope there is for greater outcomes under the NDIS and how insurance under this model has little or no restorative aim, despite dictionary definitions suggesting that true disability insurance should; as well as incapacity being temporary.⁴²

I would have expected a good NDIS and their collaborators, to set immediately to work on how to do themselves out of a job. But no, the NDIS and charitable partners are content to rest their laurels on a pre-existing, no-real-change lifelong disability model. Isn't that exactly what we had before the NDIS?

Why has this orthodoxy of lifelong suffering and incapacity not been challenged? Arguably, there are billions of dollars and many organisations invested in keeping current arrangements on track. Also,

⁴¹ See above n 39

⁴² See above n 3, 462, where disability insurance is defined as:

Insurance cover purchased to protect insured financially during periods of incapacity from working. Often purchased by professionals.

academics have written a growing amount in the area of critical disability theory busily reconstructing disability not as a functional, medical issue, but as an issue of social exclusion from wider society. As someone with disability, the social exclusion argument is understandable to a certain extent. Until mid-2018 though, I was not aware of "ableism" as a serious academic and social concept, despite having spent all my life living with cerebral palsy, as well as having spent the greater part of my adult life in some form of tertiary study. When people, in the name of ableism, who I would understand as lacking the benefits of hearing campaign actively against the rollout of Cochlear implants,⁴³ it does cause one to pause and reflect on the neurology, psychology, ideology and indeed, sanity of those who would prefer to be disabled.

Robert Sparrow explains that some people who were deaf saw Cochlear as "the desire of a majority (hearing) culture to impose its language and values on the Deaf."⁴⁴ This kind of argument shows the contest between the social concept of disability and the medical construction of disability. The latter view looks at an individual's clinical condition and change it, while the former is internationally accepted and seeks to "accommodate people living with impairment (in the community)".⁴⁵ While this might be the internationally accepted standard, some advocates arguably take it further, to an

⁴³ See generally, Robert Sparrow, *Defending Deaf Culture: The Case of Cochlear Implants*, *The Journal of Political Philosophy*: Volume 13, Number 2, 2005, 135–152, <http://profiles.arts.monash.edu.au/wp-content/arts-files/robert-sparrow/Deaf-Culture.pdf> as at 6 June 2018

⁴⁴ *Ibid*, 135-6.

⁴⁵ People with Disability Australia, *The Social Model of Disability*, <http://pwd.org.au/student-section/the-social-model-of-disability.html> as at 6 June 2018

extremist position known as ableism, where the able-bodied majority are seen, not as a gold standard of health, but as instruments of oppression.

Furthermore, charities, particularly the overtly Christian ones, may also struggle to reconcile their involvement with the NDIS, with the example of a Saviour in Jesus Christ, who reportedly cured many people;⁴⁶ an example of the functional restoration the NDIS will not support.

While it is clearly unrealistic to expect charities staffed by mortals to equal the works of the Devine, some amongst the churches' number here and overseas, should be challenged on the true basis of their opposition to stem cell research and like technologies. Does the prospect of future disability averted or cured, represent that much of an institutional challenge? Is the nature of the challenge financial or doctrinal? Assuming a generous position and saying the objection is doctrinal, can the churches presume their congregations will concur, or will religious leaders, like many professional advocates and other managerial charities, struggle to hold a constituency of opinion together.⁴⁷

How could it have possibly come to this?!

⁴⁶ See e.g.: HealingScripture.com, *The Healing Miracles of Jesus Christ*, <http://healingscripture.com/HealingRecord.shtml#officials> as at 13 January 2019

⁴⁷ See e.g.: *Religious Right*, Pittsburgh Post-Gazette. Diat by USF Inc. <http://bornagainpagan.com/cartoons/014-stem-cell-research.jpg> as at 13 January 2019

Conclusion

I doubt Grandma would have ever understood or accepted ableism as an acceptable explanation for her grandson's condition or his life expectations. Ableism is barely intelligible to me, as is some religious objections to certain types of research. However, they both serve the social construction theory of disability. This in turn serves the NDIS Agency, its charitable partners and, the professional lobbyists who campaigned for the NDIS. In other words, while people with disabilities, their families and the wider public might have thought we obtained something new in the NDIS, to invoke Vern Hughes words, the same bureaucratic managerialists prevailed.

This is particularly obvious in the NDIS Agency's approach to research. Research is something between the Agency and the disability sector; participants, families and the wider public are notable for our absence from this process. This is understandable, because we might demand more from an Agency and, a supposedly enhanced, innovative disability sector. We might also unfavourably critique the lack of ambition in the NDIS, given that supporting a participant's functional improvement is beyond the Scheme's scope. Yet, I suspect functional improvement is what many participants and families might have expected to be an aim of the NDIS. My Grandma had a clarity on this point four decades ago, which is strangely missing now, in this supposedly enlightened, Informed age.

Neither the NDIS, its charitable partners or government 'got the memo' about the public interest or involvement in research. Regardless of how much the NDIS Agency says that participants are central to its work in some areas, we are not central to its research agenda. To invite us there would threaten the fiscal and policy consensus between the institutional arms of government, charity, and professional lobbyists. In the end, where does this leave NDIS participants and our families? On the outer when it comes to research, still disabled and still with a lifetime dependence on charity.

In my view, the second last word on the true nature of this lifelong disability and charitable dependence should go to author Oscar Wilde who said:

But (charity) is not a solution: it is an aggravation of the difficulty. The proper aim is to try and reconstruct society on such a basis that poverty will be impossible. And the altruistic virtues have really prevented the carrying out of this aim. Just as the worst slave-owners were those who were kind to their slaves, and so prevented the horror of the system being (realised) by those who suffered from it, and understood by those who contemplated it...Charity degrades and (demoralises)...Charity creates a multitude of sins.⁴⁸

⁴⁸ Oscar Wilde, *The Soul of Man Under Socialism*. 1891, <http://abetterworldisprobable.wordpress.com/2012/01/01/oscar-wilde-on-the-problems-of-charity/> as at 26 December 2013

Exchange poverty for disability in the quotation and Mr. Wilde has said it all; almost. The last word I reserve for myself – what would Grandma say?

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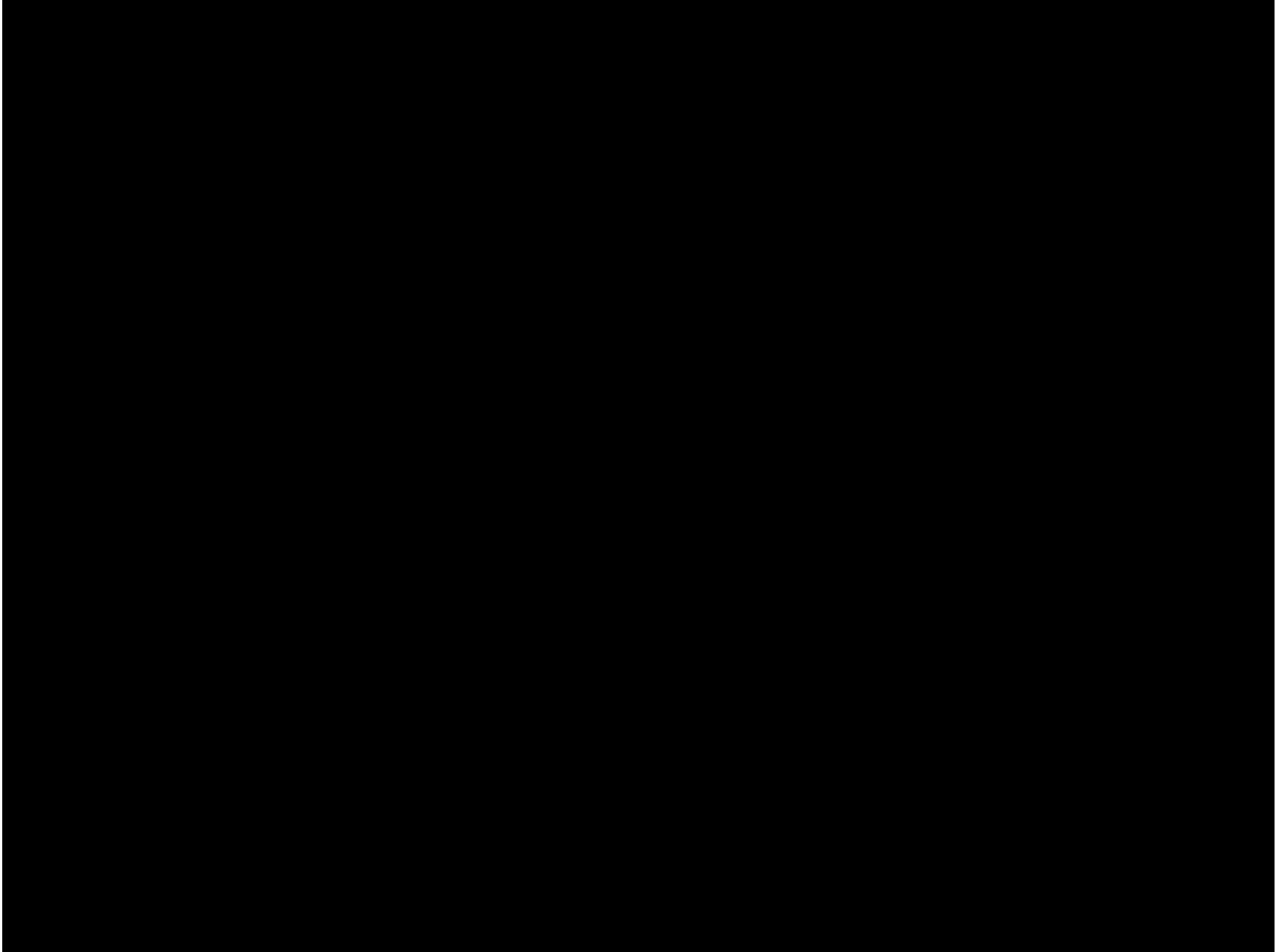
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PUBLIC INVOLVEMENT IN HEALTH RESEARCH



What is health?

State of being hale, sound, or whole in body, mind or soul; well-being. Freedom from pain or sickness. See Healthy...free from disease, injury or bodily ailment, or any state of the system particularly susceptible or liable to disease or bodily ailment

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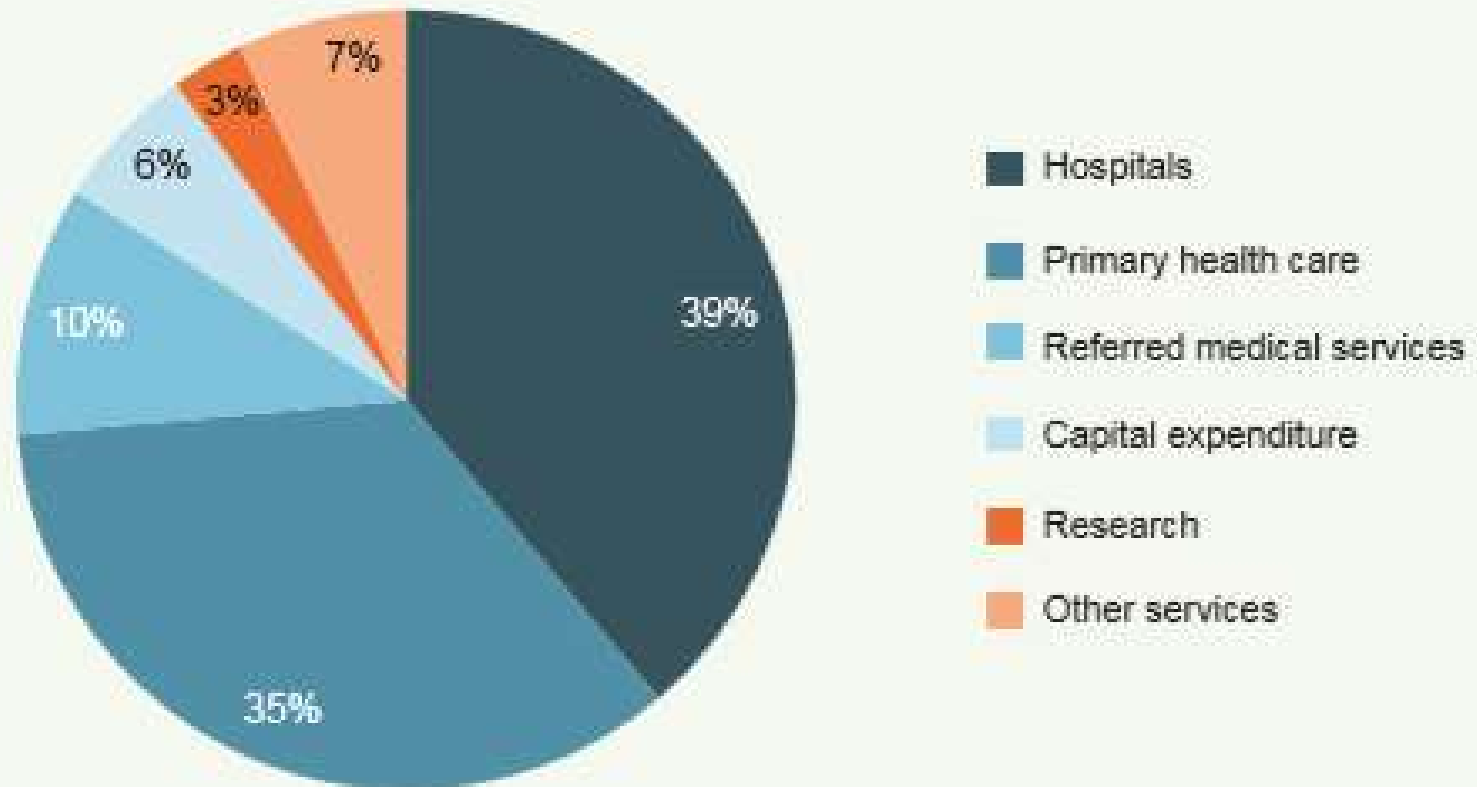
Todd AL, Nutbeam D. *Involving consumers in health research: what do consumers say?* Public Health Res Pract. 2018;28(2):e2821813. <http://www.phrp.com.au/issues/june-2018-volume-28-issue-2/involving-consumers-in-health-research-what-do-consumers-say/>

Researchers need to be...

- Easy to find
- Able to explain their research in plain English
- Ready to listen and adapt research based on participant feedback
- Keeping people informed – WE CARE ABOUT RESULTS

Only 3% on research??

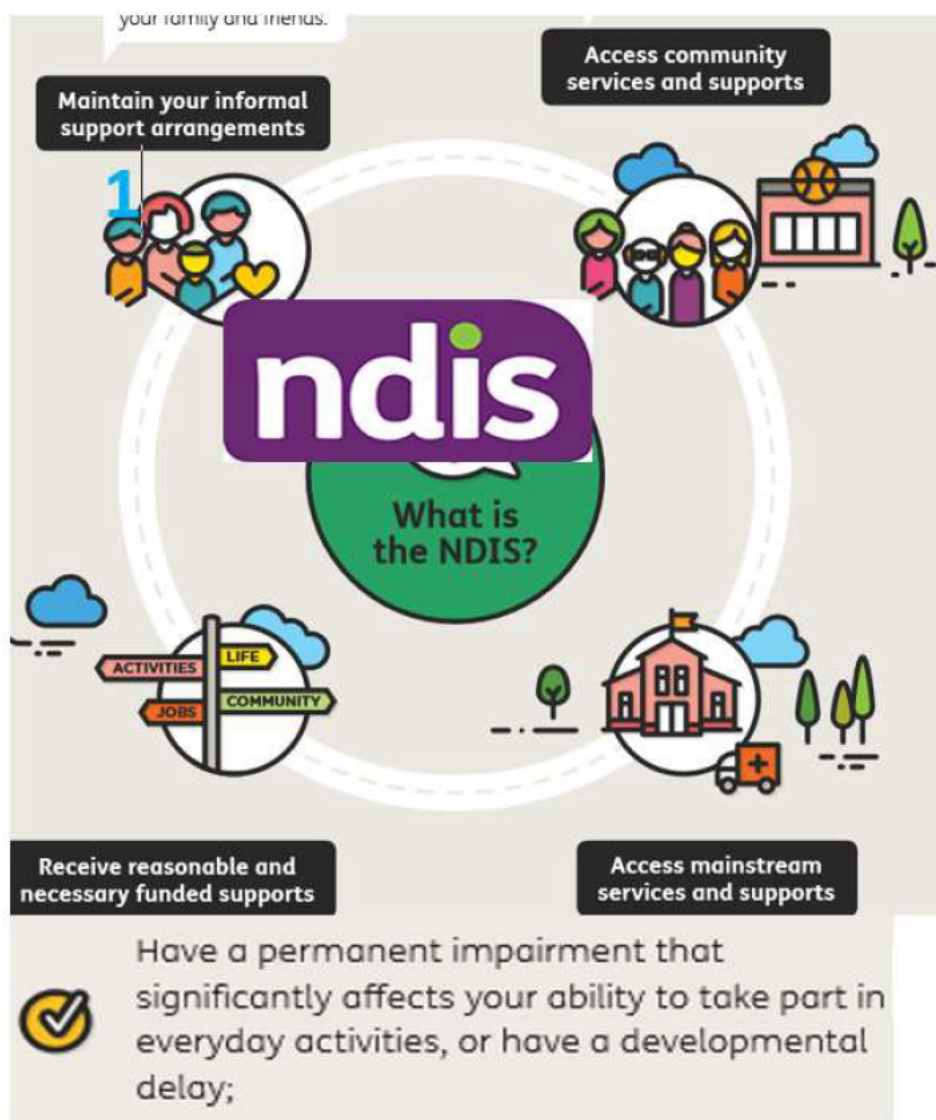
Figure 2.2.6: Proportion of total health expenditure, by broad area of expenditure, 2015–16



Sources: AIHW health expenditure database; Table S2.2.6.

<https://www.aihw.gov.au/getmedia/7c42913d-295f-4bc9-9c24-4e44eff4a04a/aihw-aus-221.pdf.aspx?inline=true>

NDIS in a page – Positive + / Negative -



'So, I nearly choked on my lunch when I read this week that St Vincent de Paul was named as provider of the NDIS pilot. Excuse me?!? NSW hands the first coordinator positions to a charity - the very thing we were trying to leave behind! Wasn't the whole point of the NDIS precisely to get the charity out of disability? To have services provided by independent people who are trained in a person-centred, rights-based approach to disability services?'

NDIS Approach to Research: No Public Involvement

Chapter 6—National Disability Insurance Scheme Launch Transition Agency Part 1—National Disability Insurance Scheme Launch Transition Agency

118 Functions of the Agency

(1) The Agency has the following functions:

(c) to develop and enhance the disability sector, including by facilitating innovation, research and contemporary best practice in the sector;

(e) to collect, analyse and exchange data about disabilities and the supports (including early intervention supports) for people with disability;

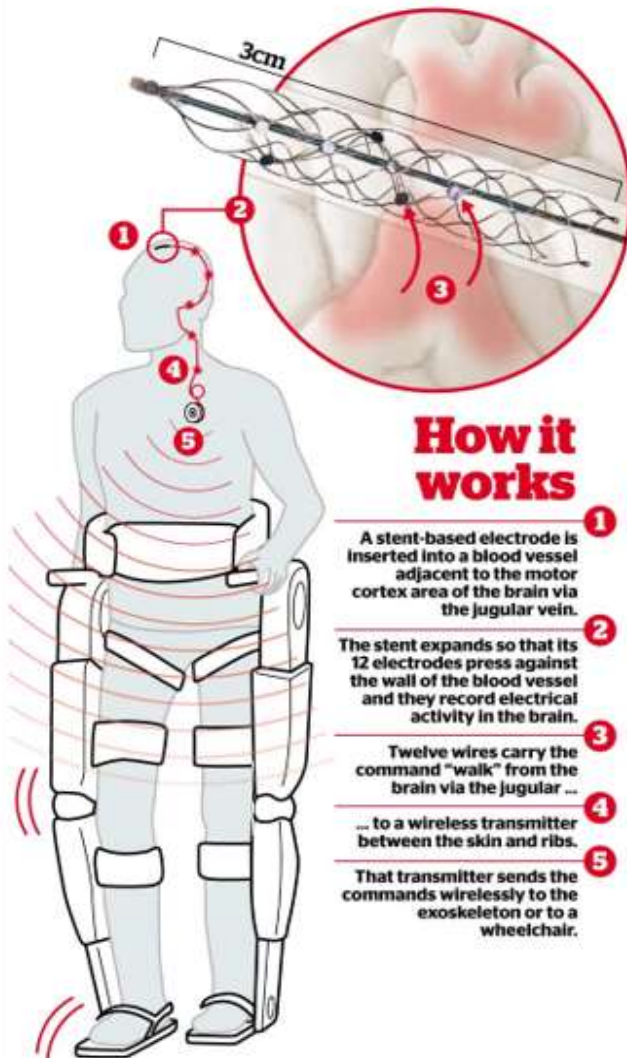
(f) to undertake research relating to disabilities, the supports (including early intervention supports) for people with disability and the social contributors to disabilities;

STAYING DISABLED UNDER THE NDIS

Risk aversion + maintenance of charitable model/
funding = no rise in 'ordinary life' expectations

e.g.: funding for surgery and
exoskeletons unlikely, due to cost,
risk, & the Agency's Rule 7.5 against
funding medical/surgical event,
aimed @ improved functional status

See: Woman with disabilities scores landmark
win over NDIS, 18/6/17, The Age,
<http://www.theage.com.au/victoria/>



How it works

1 A stent-based electrode is inserted into a blood vessel adjacent to the motor cortex area of the brain via the jugular vein.

2 The stent expands so that its 12 electrodes press against the wall of the blood vessel and they record electrical activity in the brain.

3 Twelve wires carry the command "walk" from the brain via the jugular ...

4 ... to a wireless transmitter between the skin and ribs.

5 That transmitter sends the commands wirelessly to the exoskeleton or to a wheelchair.

Defining disability insurance

The NDIS takes a lifetime approach (i.e.: seeks to minimise support costs over a participant's lifetime) by investing in people early to build their capacity to help them pursue their goals and aspirations resulting in greater outcomes in later life.

(NDIS Overview, NDIS webpage)

Insurance cover purchased to protect insured financially during periods of incapacity from working. Often purchased by professionals.

(Nolan & Nolan-Haley, *Black's Law Dictionary*, 6th ed.,)

CARER AWARD

[REDACTED] is a worthy recipient of a NSW Government Local Carer Award. Despite working full time, [REDACTED] has always been the primary carer of her son Adam. Her dedication and care has allowed Adam to be an active community participant.

Talked all things stem cells, gene editing and CRISPR today to the Seaforth Probus Club ...followed by some fancy drinks on the wharf! [REDACTED]

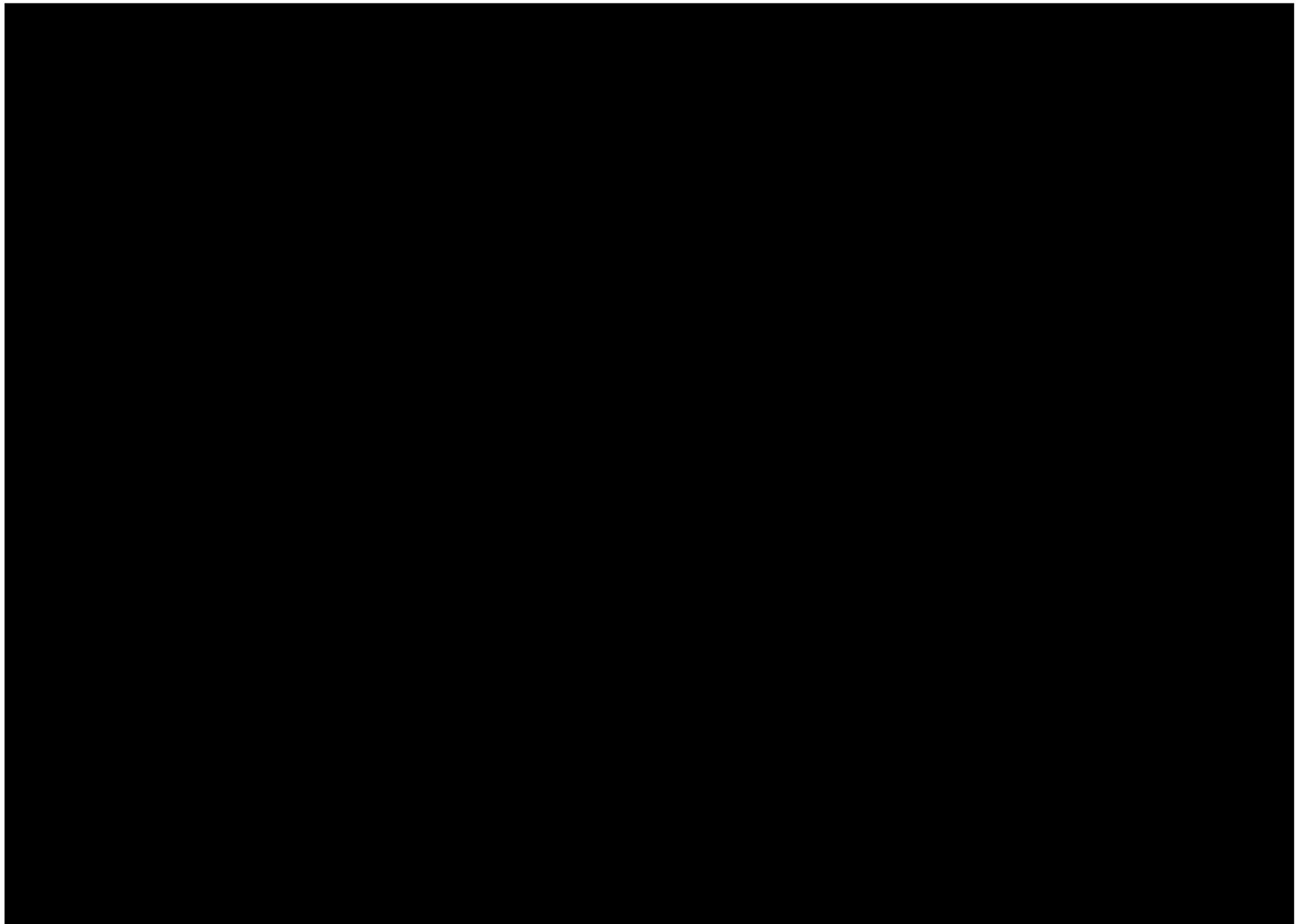
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Conclusions

1. Governments, the NDIS Agency and its charitable partners have a research agenda focused on them and their needs
2. NDIS participants, their families and the public are absent. This is wrong, contrary to public participation principles & peer reviewed literature
3. If the NDIS wants to be taken seriously as an *insurance agency*, it should be working to restore the functional capacity of participants, with medical, surgical and rehabilitation professionals, if this what an individual requires to lead a full and active life
4. A lack of public involvement in disability research allows the NDIS Agency to maintain that “lifetime disability” is acceptable
5. 3 percent of health expenditures on research? That’s never acceptable and, all of us need to demand that more be done

PUBLIC INVOLVEMENT IN HEALTH RESEARCH.



FUNDING NGO DELIVERY OF HUMAN SERVICES IN NSW: A PERIOD OF TRANSITION

A SUBMISSION TO THE INDEPENDENT COMMISSION AGAINST CORRUPTION

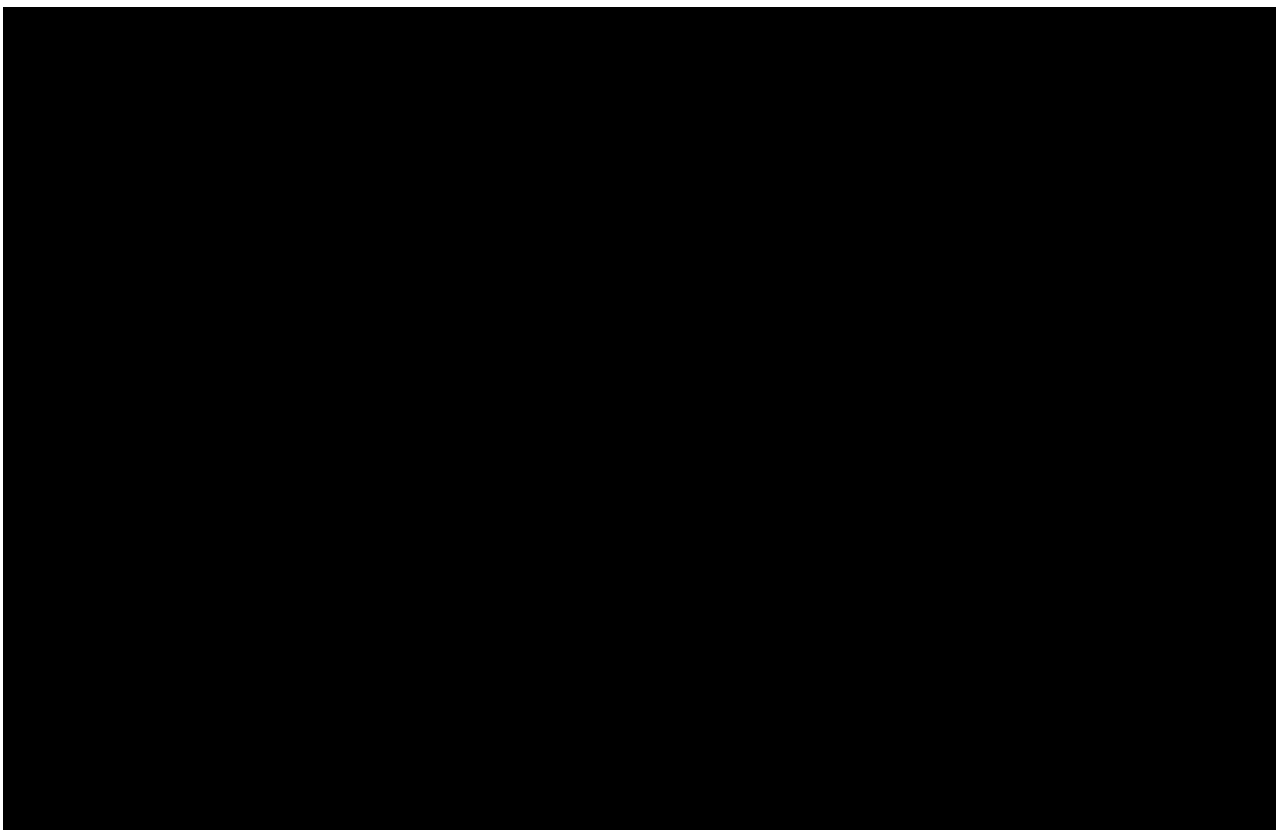
Adam Johnston

5th October 2012

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Annex 1: Submission to the Parliamentary Committee	<p><i>Submission to the Legislative Assembly's Committee on Community Services Inquiry into the Devolution of Human Services</i></p> <p>Appendices to Submission:</p> <p>Appendix 1: Submission to Federal Treasury on Governance in the Not for Profit Sector</p> <p>Appendix 2: Attendant Care Funding Application for wheelchair</p> <p>Appendix 3: Third Submission to the Productivity Commission's Disability Care and Support Inquiry</p> <p>Appendix 4: Email sent to NSW Auditor [REDACTED]</p> <p>Appendix 5: Statement on Resigning as Director of the Spastic Centre of NSW/Cerebral Palsy Alliance and related document</p> <p>Appendix 6: Letter from Australian Institute of Company Directors to Adam Johnston, dated 2 February 2012</p> <p>Appendix 7: Budget Priorities for Treasury - 2012-13 Pre-Budget Submission to the Budget Policy Division, Federal Treasury</p>
Annex 2: The Auditor	<p>Attachment A: Letter from [REDACTED], dated 5th July 2012 (Image1.JPG)</p> <p>Attachment B: Email to [REDACTED] dated 26 July 2012 (Providing funds to allow the Auditor General to prioritise projects in 2013)</p> <p>Attachment C: Response from the Treasurer, dated 3 September 2012 [REDACTED]</p> <p>Attachment D: Letter to [REDACTED], dated 17 September 2012</p>
Annex 3: The Parliamentary Committee	<p>Exhibit 1: RE: Inquiry regarding my submission - sent by email 12 April 2012 - Inquiry into Outsourcing of Community Services (Email sent 11th July 2012)</p>

Annex 4: The National Disability Insurance Scheme (NDIS)	<p>Item 1: Response to the Issues Paper – 1st submission to the Productivity Commission’s Disability Care and Support Inquiry (unedited version)</p> <p>Item 2: Briefing for Minister for Disability Services, the Hon. [REDACTED]</p>
Annex 5: The “problem” that is programmatic funding	<ol style="list-style-type: none"> 1. Letter to the Secretary of the Federal Department of Human Services, 14 September 2012 (Letter to Secretary) 2. Email “Complaint about Centrelink” to the Commonwealth Ombudsman 3. Letter from Centrelink restoring my mobility allowance, dated 21 September 2012 4. Emails to and from SEDS relating to point 3 (all emails entitled “Centrelink” or “Centrelink blinks”) 5. Response from the Commonwealth Ombudsman (Commonwealth Ombudsman 1 and 2) 6. Letter to [REDACTED], Secretary of the Commonwealth Department of Employment and Workplace Relations 7. SEDS declines to meet with me for continuing job seeking support (see email entitled “Declined: SEDS meetings and contrast this with all emails with “meeting” in their title)
Addendum	My email exchanges with [REDACTED]



“In Mum alone I Trust, trusting others only to bring their own agenda.”

The quotation was ‘borrowed’ from: “In God We Trust. All Others Must Bring Data.” - Dr W. Edwards Deming.

Adam Johnston

35 Woolrych Crescent
Davidson NSW 2085
Adamdj1@optusnet.com.au

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

icac@icac.nsw.gov.au

Dear [REDACTED]

I write in response to your *Consultation Paper* regarding the funding of non-government organisations (NGOs) to provide human services, which were previously the domain of the State Government. As someone with a permanent physical disability, who is very likely to be directly affected by these policies, I have numerous concerns about their implementation and, the real rationale that lies behind them. This has direct relevance to the jurisdiction of the Independent Commission Against Corruption (ICAC) for a variety of reasons, which I will demonstrate through my answers to the questions below.

Chapter 2

1. Which control decisions should be (a) centralised and (b) decentralised to the regions or lower level?

If the person centred or client centred policy focus is to mean anything in substance, then we should not be centralising "control decisions". However, in saying this, we need to address the question of who is actually in control. The policy mantra of late has been to put the individual client and/or their family in control. As demonstrated in my first submission to the Productivity Commission's Inquiry into *Disability Care and Support*, the Attendant Care Program (ACP) in NSW promised enhanced and flexible services to both me and my mother as each of us aged.

What emerged over a protracted period was a rigid set of eligibility and program criteria, in which case officers working for various publicly funded NGO service brokers believe they had a ready discretion to reorganise our life based on *their assessment* of what was in the best interests of both me and my mother. Fortunately, we are both strong-willed individuals, well used to confronting the administrative molestation practised by many in the social welfare sector. I specifically draw your attention to these comments provided to the Productivity Commission (the Commission):

I recall taking a telephone call... at work, from my (then) ACP service provider ([REDACTED]). She had just had a conversation with my mother, which ended badly. In short, the enquiry revolved around whether we intended staying with the ACP; the question ending with a reminder of the funding on offer. I quickly explained to her that the terms of

my staying were clear: both my mother and I had one clear message from the beginning – whatever else happened we wished to retain our Homecare service. This was the one thing that, up until [REDACTED] [REDACTED] (a senior official of the Department of Ageing, Disability and Homecare) intervention, was specifically refused. Therefore, I advised that I was very dissatisfied with the ACP initiative and, was prepared to leave the program. Thereupon started the provider's blackmail argument, which was that I had 'failed to consider my mother's future needs' by unilaterally exiting the program.

These comments fitted a pattern of behaviour engaged in by the provider, when it became clear to her that we were not going to say "Yes" to everything she suggested, nor be managed to her funding timeframes. At times when it suited the ACP provider, I was the client; at other times it was my mother. It never seemed to occur to her that the first thing a mother and son would do, was to check with each other as to what had been said to us. A less than subtle 'divide and conquer' strategy failed. After I told the provider that I thought she was little more than a bully (to which she claimed deep offence) putting down the phone only made it ring again. It was Mum, in a very distressed state, after also having been interrupted at work by a call from the ACP provider. From then on, we decided I would be the only contact point for ACP, and that would be by email.¹

While the situation has improved with a new service provider, it is still a fairly rigid arrangement of predetermined hours and support services. While the provision of increased support services relieves my mother of some of the physical burdens of my care, it means that we must both now be conscious to ensure my availability to third party carers, not only first thing in the morning, but also in the evening.

This is no reflection on the individuals themselves; rather, managing increased contact with service providers can put a dampener on one's discretion to attend meetings, public performances and generally, to come and go from one's own house as you might otherwise please.

Over time, I have managed to come to arrangements with individual care staff, to facilitate other aspects of both my and their lives. For example, on occasions it is easiest for all parties to make arrangements to conduct support services (or cancel a specific incidence) at times differing from those on the formal rosters. This is generally convenient to both, because we all have busy lives, multiple commitments and, familial obligations to attend to; some of these arising unexpectedly. Such actions are generally taken on an informal basis, to minimise paperwork and, to ensure that no one ends up out of pocket. Demonstrating a degree of personal flexibility can be advantageous, particularly when relationships are based on a high degree of dependence.

¹ Refer to Annex 4, Item 1, p.3

While I can say with confidence that this has never been used against me personally (as I am too assertive, thanks to the example of my mother, to permit it) the same could not be said for many others. Indeed, one of the reasons for writing this submission is my knowledge that there are many people with disabilities and families of people with disabilities, who are far too frightened to approach a body like ICAC with their complaints and concerns. Their understandable fear is one of retribution, resulting in a loss of support services. Equally, however much some people may feel that what they are receiving currently does not truly meet their needs, their overriding concern is that raising any complaint will put them in a worse position than they are now.

For as long as my mother and I both remain in good health, and I retain sufficient physical capacities to permit her to continue as my principal carer, I retain a luxury of being able to speak with a frankness that many others would dare not exercise. As such, it is important to make two points here. Firstly, it would seem administratively impossible and financially prohibitive to try and police such informal arrangements,² like those discussed above. Secondly, in many instances, the internal administrative procedures of many organisations (government and NGO alike) frustrate staff and service recipients in equal measure, in the act of simply trying to deliver service.

It was these observations that led me to recommend to the Commission that any proposed National Disability Scheme *not* be based on a large, centralised administrative agency.³ Instead, my preferred option all along was for a largely informal *Minder-style* arrangement.⁴

These observations may worry an organisation like ICAC, given my level of apparent indifference to form and procedure. While I understand this concern, it should be remembered that oversight and protocol are not without cost themselves. Agencies, be they government or NGO will seek to recover these costs, either by directly levying clients or by discontinuing (or not experimenting with) models of service provision from which it may be difficult to cross-subsidise.

This does not mean that I deny the need for a level of oversight, particularly when it comes to the outlay of public funds. Indeed, in the NGO sector, proper public scrutiny is something which has been seriously lacking. Politicians of all persuasions have failed to address this issue, largely because it would not be to their political advantage to truly critique the not-for-profit sector. Rather, this sector is all too readily provided with ad hoc grants, tax exemptions and other financial dispensations, because they represent a positive "photo-op" (photo opportunity) for a passing parade of politicians and other minor celebrities. This is where ICAC should

² I made a similar point when appearing before a Legislative Council inquiry into the NSW taxi industry. In response to questioning about a recommendation made by the NSW Taxi Council, that the prohibition against unofficial radio networks maintained by taxi drivers be strictly enforced, I argued that the official radio networks provided poor service. Equally, I wished to maintain access to drivers' private mobile telephone numbers, in the interests of my own safety and security, as well as to be assured of prompt, reliable service. See *Committee Hansard*, Jubilee Room, 4 February 2010, pp. 42 – 43 [http://www.parliament.nsw.gov.au/Prod/parlment/committee.nsf/0/7d5791ac13312a47ca2576c100058c71/\\$FILE/100204%20Uncorrected%20transcript.pdf](http://www.parliament.nsw.gov.au/Prod/parlment/committee.nsf/0/7d5791ac13312a47ca2576c100058c71/$FILE/100204%20Uncorrected%20transcript.pdf) (accessed 1 October 2012)

³ See generally, Annex 1, Appendix 3

⁴ See discussion of this point, Annex 4, Item 1, pp. 9-10

be focusing its investigation and, you will have marked success in finding instances of corruption and malpractice.

2. How can control be streamlined?

In answering this question, an opportunity presents itself to address a number of other issues which are related and need to be confronted as a matter of urgency. Firstly, the Government appears to have taken a relatively uncritical view of the NGO sector; this pattern is repeated at both the State and Federal level. You will note from Item 1 in Annex 4, that I encouraged the Commission to critique the NGO sector in a relatively fearless fashion.⁵

The Commission failed people with disabilities, their families and the wider Australian community, with the insipid, centralist bureaucracy it proposed as a National Disability Insurance Scheme (NDIS). This in no way represents any form of streamlining, but rather was designed like any number of programs and bureaucracies which have come before it. And, service delivery continued to be a matter largely dependent on NGOs, many of whom appeared before the Commission, making their *Oliver Twist* 'pitch' for *more* public money.⁶

In particular, I take issue with the standard "case management formula" where innumerable social workers, therapists and other welfare workers make assessments of a person's disability, and contingent eligibility for support.⁷ Anyone with a permanent disability, or indeed, anyone who has been unemployed, will tell you about the complex and opaque nature of dealing with bureaucracies like *Centrelink*, employment agencies, as well as NGO service providers themselves. They all tend to be based on a "case management" model, which regularly throws up inconsistent and unreasonable results; I have regularly appealed decisions made in and by the State-run bodies, as well as those of NGOs.⁸

⁵ See *ibid.*, p.3; note in particular, these comments: *In making its inquiries, the Commission should not hesitate to both critique and be critical of both the government-run and non-government welfare/social services sector. In my experience with the ACP, it seemed assumed that recipients and their families would automatically be grateful for any service package produced (even if it didn't meet an individual's stated needs).*

⁶ My second submission to the Productivity Commission's *Disability Care Inquiry* is available from http://www.pc.gov.au/data/assets/pdf_file/0016/100726/sub0186.pdf (accessed 3 October 2012). I draw your attention to my comments on page 5: *"(One) could not help but notice that advocacy groups that spoke at the hearing did not miss the opportunity to argue that they should receive funding from the (disability) insurance scheme as well. This should not occur; reform that is worthwhile should be about more than changing a funding source, only to keep 'all the usual (disability) suspects' in their places."*

⁷ See Annex 1, Appendix 3, pp. 5 – 7. In particular, note the commentary under the subheading on page 5, *"Who is really in control?"* The paragraph that precedes the subheading is also deliberately designed to be telling and provocative, in highlighting the nature of the relationship between the National Disability Insurance Authority (NDIA), its staff and, the organisations clients. Again, in many ways, as someone with a disability, I have seen this bureaucratic form so many times before in my life that the prospect of the creation of another one (with the accompanying condescending management, voluminous regulations and general waste of resources) is truly galling.

⁸ See for example, my submission to Professor Julian Disney's Review of the Job Seeker Compliance Regime. I outlined my own personal experience of going for nearly 6 months without a Disability Support Pension appealing Centrelink's denial of payment all the way to the Social Security Appeals Tribunal <http://www.deewr.gov.au/Employment/ComplianceReview/Documents/AdamJohnstonSubReviewFinal.pdf> (accessed 1 October 2012). While acknowledging my disability employment agent (Sydney Employment

And in questioning the processes, not only of government, but of NGOs themselves, one has long ago come to the conclusion that obtaining *the funding* is the ultimate objective; whether the money benefits a client or group of service users is but a corollary or positive externality of the exercise. As I told the Senate's recent review of disability employment services in Australia:

*Any examination of the disability employment sector will demonstrate that it is highly (dependent) on government subsidies. The specialist employment agents/brokers are funded by government and, if a worker is placed in a Special Business Enterprise (SBE or sheltered workshop), their "wage" is pegged to the Disability Support Pension. Add to this the fact that many of the businesses themselves will only be viable because of state subsidies, and you realise just how much money is circulating, but how little of it is really "new money" generated by a multiplier (effect). Most of it is coming from the taxpayer and supporting a noticeable amount of administration.*⁹

I will always acknowledge the Australian taxpayer as being far more generous than a number of Western counterparts (such as the United States) in providing social welfare. As someone who has clearly benefited from that support, I rail against waste and mismanagement, or people treating public funds (or funds donated by the public for an allegedly charitable cause) as if the money was their own *by right*.

From personal observation, this is a belief, manifesting as a broad cultural malaise, in many charities. Indeed, I have lost confidence in the charitable/not-for-profit form and, the thought that more human services may be provided by them, sickens me. This is bad public policy, for a number of reasons. Firstly, the State Government is *stepping back and opting out* of the lives and needs of some of its most vulnerable citizens. The O'Farrell Government claims that its reforms will give people with disabilities greater choice and flexibility in their lives, but I refer you to my earlier comments about the ACP as a counter-weight to such claims.

As Annex 1 demonstrates, it is all too easy to show the inconsistency of the current Liberal Government, with the stated views of the Liberal Party's founder, Sir Robert Gordon Menzies. He said in 1942:

The country has great and imperative obligations to the weak, the sick, the unfortunate. *It must give to them all the sustenance and support it can. We look forward to social and unemployment insurances, to improved health services, to a wiser control of our*

Development Service - <http://www.cerebralpalsy.org.au/our-services/adults/sydney-employment-development-service-seds> [accessed 2 October 2012] provided a letter of support for my appeal, one often wonders how these government-subsidised, charitable "agents" otherwise fill their time.

⁹ Senate Standing Committee on Education, Employment and Workplace Relations: *The administration and funding of Disability Employment Services in Australia*, Submission 60 (Adam Johnston), pp. 28 – 29 (under the subheading "A rent-seeker's paradise")
<https://senate.aph.gov.au/submissions/comitees/viewdocument.aspx?id=a6fa4e6a-eb31-49de-bb0f-c9f11849c86c> (accessed on 2 October 2012)

*economy to avert if possible all booms and slumps which tend to convert labour into a commodity, to a better distribution of wealth, to a keener sense of social justice and social responsibility. We not only look forward to these things; we shall demand and obtain them. **To every good citizen the State owes not only a chance in life but a self-respecting life** (my emphasis)¹⁰*

While Menzies was supportive of charities, it is also noteworthy that he drew a clear distinction between them and social welfare. He said that the latter could never become a discretionary exercise of the former.¹¹ I make this point, not as a matter of political rhetoric, but to draw to ICAC's attention the gravity of the change taking place. The Legislative Assembly is well aware of my view that the Government's proposed policy represents a step back to a "pre-Menzies liberalism".¹²

The fact that the Legislative Assembly chose not to publish my submission told me much about their preparedness to address the issues it raised. Elements of the submission that identified particular NGOs could have been redacted and, an amended version placed on the NSW Parliamentary website. As you will observe from Annex 3, the [REDACTED] advised, on 26 June 2012, that the committee had decided not to publish my submission; he pointedly did not address my offer of providing further documentary evidence to the committee, by virtue of Section 198F (2) of the *Corporations Act 2001*. Nor was there any response to my subsequent e-mail of 11 July 2012, advising that the NSW Assistant Auditor had responded to my e-mail to his office. This was despite the Legislative Assembly holding a copy of the letter I had sent the Auditor.¹³

I admit to being bitterly disappointed in the Legislative Assembly committee's handling of my submission on the devolution of human services to the NGO sector. Examining those submissions that were available on the website, it seemed clear that there was a distinct division of opinion between established care agencies, care workers and, individuals receiving care or support in the community. The service providers/NGOs were generally aligned with the Government's objective of devolving services, while many anonymous care workers, their clients and families expressed deep concerns about loss of service (as well as service quality and accountability) under a devolved model. I concur with the views of care workers and clients, particularly after my experience as a member of the Board of Directors of the Spastic Centre of NSW/Cerebral Palsy Alliance. (the Centre)

As the State's biggest disability charity, it has multiple divisions and a newly completed Headquarters in Allambie. The submission to the Legislative Assembly contained in Annex 1, along with the accompanying Appendix 1 [REDACTED] [REDACTED] After only 19 months, my colleagues could not stand my inquisitorial style and, my willingness to challenge management; the organisation's President and Chief Executive ultimately concluded that I failed to show them sufficient 'respect'.

¹⁰ Annex 1: *Submission to Legislative Assembly Inquiry*, pp. 5 - 6

¹¹ See *ibid.*, p.6

¹² *Ibid*

¹³ Refer to Annex 1, Appendix 4

By the end of my tenure on the Board, neither party was too much concerned for the opinion of the other. [REDACTED]

The Centre would no doubt point to its Finance and Audit Committee (a sub-committee of the Board), its written delegations to senior staff and, the limits this imposed on what individuals could spend without prior approval of the CEO. And, this is all true, in that the forms of proper governance are there. My concerns though, went increasingly to practices betraying true beliefs in the day-to-day running of the Centre.

For example, I was given a *Cabcharge* plastic card to pay for my taxi travel expenses to and from Board meetings, as well as other Centre-related events. My response was to routinely provide the Company Secretary Tony Cannon with my receipts. Accountability for my spending of *other peoples' money* lies at the heart of my ethical obligations as a solicitor, not to mention similar obligations to my then employer, NSW Ombudsman Bruce Barbour.¹⁴

To lose the confidence and trust of either Mr Barbour or his deputy Mr Wheeler was a prospect far more grievous than anything the Centre's Board could ever do to me.

[REDACTED] Board members were expected to complete (at the organisation's expense) to complete a Graduate

¹⁴ I have held a number of positions with the NSW Ombudsman's Office over the past 7 years or so. I owe the organisation much, not the least of which is the fact that its Legal Officers supervised my Practical Legal Training (PLT), leading to my Admission as a Solicitor in 2005. Deputy Ombudsman Chris Wheeler and I have also penned an article together, for the Law Society Journal: Chris Wheeler & Adam Johnston, *Lawyers Encouraging Apologies: Not a contradiction in terms*, Law Society Journal, November 2009, Vol. 47, No. 10, pp. 74-79

<http://www.lawsociety.com.au/resources/journal/archives/Archivelssue/index.htm?issueVolume=47&issueYear=2009&issueMonth=November> (link requires Law Society membership access code)

¹⁵ See Annex 1, *Submission to Legislative Assembly Inquiry*, pp. 13 – 21. Reading from the subheading "Oh Grandma, what big teeth you have?" you will a summary of my experience with the Centre.

¹⁶ [REDACTED]

Diploma Course in Company Directorship, from the Australian Institute of Company Directors (AICD). [REDACTED]

[REDACTED] It is worth remembering that this was all taking place as the Centre's financial investment portfolio was being hit hard by the Global Financial Crisis. Interest from about one million dollars or so that we had under management was supposed to support a variety of client services.

The fact that returns were falling never dented the Board's appetite for seminars, consultants or a hot, catered meal at every Board meeting. Some may accuse me of pettiness, but I had growing difficulties about the Centre presenting a public face as a needy, deserving charity, [REDACTED]

It was this that led me to write Appendix 1, contained in Annex 1. I stand by all recommendations made in that document in its entirety. Equally, charitable tax concessions to donors, or NGOs themselves, undermine State and Commonwealth revenues. Furthermore, only individuals (and not corporations) should be able to donate to charities/NGOs.¹⁸

[REDACTED]

[REDACTED]

¹⁷ I did not attend these seminars. However, I was put under direct pressure by the Board [REDACTED] to comply with the standing Board resolution that all directors undertake the AICD course.

In the end, I relented and completed the course by correspondence, meaning there was a significant cut in fees. Upon my "resignation" from the Board, I had a bank cheque issued in the Centre's favour for the balance of the fees (see Annex 1, Appendix 5, p.16). The Centre refused to accept the money, on the basis that the Board had resolved that the organisation would meet the cost of *directors' education*. Nonetheless, the Centre had to take the bank cheque, process it through the organisation's accounts and, and remit the funds back to me. It was a Pyrrhic victory, but a victory nevertheless. My point about the Board's self-indulgence could not have been lost, as a wheelchair-bound, part Disability Support Pensioner, handed the Company Secretary of a disability charity a cheque for over \$2000 (the offer is still open, if the Centre wants it).

My mother, always True North when the compass-needle of my life is spinning madly, encouraged me to finish the Company Director's course. The photograph on the front of this submission was taken at the Award Presentation on Wednesday 18 July 2012 at The Establishment, 252 George Street Sydney. Meanwhile, Appendix 6 in Annex 1 is the formal letter of congratulations.

¹⁸ See Annex 1, Appendix 1, p.12. In particular, read footnotes 31 and 32.

These and other reforms¹⁹ would do much to improve accountability and transparency in NGOs.

3. What are the advantages and disadvantages of the programmatic approach to service design and delivery?

For the individual service recipient and their family, there are few if any, advantages to programmatic service design. This submission, and everything that comes with it, should be testament enough to that. Furthermore, I had hoped that person-centred care would be the antithesis of programmatic models. If the ACP is any guide, this will not be the case.

Annex 1 and the Submission to the Productivity Commission contained in Annex 4, should speak volumes about the failings of programmatic funding. Should you need more proof, look to Annex 5 and read my recent experience with SEDS. Their failure to submit paperwork to the Federal Department of Employment and Workplace Relations caused *Centrelink* to write and, advise me of its intention to cancel my mobility allowance.

I lodged an appeal which was successful, but as I told the Secretaries of the Departments of Human Services and Employment (as well as the Commonwealth Ombudsman) one is far from pleased with SEDS performance. The most recent email from SEDS²⁰ indicates they won't meet with me until I obtain a treating doctor's report from my GP and have a Work Capacity test at my local *Centrelink* office. This is the exact opposite of what case officer ██████████ said in an email to me dated 11 September 2012.²¹ Furthermore, no amount of bureaucratic nit-picking should obscure the fact that if SEDS had performed properly in the first place, none of what I have just related would have occurred.

4. What would be necessary for both head office and frontline staff to have access to key performance information in a form that would facilitate monitoring of NGO issues?

This question presupposes something akin to the current mishmash of providers and services remaining in place. As I told the Commission in my third and final submission on *Disability Care*, my preferred option would have seen individuals poach preferred staff from existing agencies. This is intended to cause a structural implosion of current hierarchies, giving choice and market freedom to people seeking care and, those offering to provide it.²²

Again, as I said in my *Legislative Assembly* submission, Parliament should never obviate its responsibilities to *all* NSW citizens, including those with disabilities. Parliament should not permit Departments of State to rely on guidelines and, all

¹⁹ See discussion in Annex 1, Appendix 7

²⁰ See Annex 5, and in particular the email entitled "*Centrelink*" (Point 4)

²¹ See *ibid*, meeting email "Declined" from ██████████

²² See Annex 1, Appendix 3, pp. 6 - 7

NGO service providers should be required to enter legally binding contacts with their clients and the Government (if they are seeking State funding).²³

5. How can quality information about client experience be obtained?

I have felt for a long time that real, measurable and binding standards should be set in service contracts. Equally, commercial-in-confidence principles should not apply when NGOs are contracted to provide services on behalf of the Government. On this basis, I wrote to the NSW Auditor, and subsequently the Treasurer, seeking reform of the *Public Finance and Audit Act 1983*.²⁴ Such reform would be aimed at giving the Auditor jurisdiction to examine the finances of NGOs. Currently, he can only look at contracting-out arrangements from the perspective of how the State handles them.

Additionally, Appendix 1 contained in Annex 1 outlines how I believe the marketing, management and fundraising arms of major charities and other NGOs should be forcibly separated from any activity which delivers a service to a client. The former activities would be taxed like any other corporate entity, while the latter would be tax exempt.²⁵ This is because I contend that charities and NGOs are indistinguishable from other businesses. Other commentators, like Vern Hughes, share a similar perspective.

"Chinese walls" should therefore be constructed between the two arms of NGO activity. And where an NGO has benefited from a Government grant, it should be considered as a de-facto State instrumentality. This means, at the very least, that the body needs to table its Annual Report in Parliament.

6. How can the recording of performance information be improved at frontline and head offices?

This question perpetuates assumptions about the continuing hierarchal structure for NGOs. Everything I have outlined above would, if implemented, cause of flattening of management. Hopefully, there would be a significant thinning out of the "bland managerialism" which both I and Vern Hughes believe have infected the sector.²⁶

ICAC should consider whether these structures are compatible with the principles of person centred care. In that arrangement, it would be the client or their family setting the performance criteria in contracts with care staff. As such, the role for head offices is at best unclear; indeed, they are arguably irrelevant.

7. What information should trigger investigations of NGOs?

The first protection against inappropriate, improper or illegal behaviour is public disclosure. Requiring NGO's who accept government money to be directly

²³ See *ibid*, *Submission to the Assembly*, pp. 8 – 12. In particular, please note the analogy drawn with William Wilberforce and, the call to use a Canadian Patriation-style law, to bring the operations of NGOs into the light of Parliamentary scrutiny.

²⁴ See Annex 2

²⁵ See Annex 1, Appendix 1, pp. 2 -5.

²⁶ See *ibid.*, p.4

accountable to Parliament through their annual reports, as well as bringing the Parliament back into the care arrangements for some of its most vulnerable citizens, is vitally important. As stated above, departments should not be allowed to base funding programs on guidelines which never see the light of the Parliamentary Table as Regulations.

There should continue to be a steady stream of audits, community visits and public oversight bodies, like the Ombudsman and the Auditor, who have abilities to take complaints, or launch their own wide ranging investigations. NGOs that contract with government to provide public services should be subject to public scrutiny, as if they were Department of State and, to ensure transparency, commercial in confidence provisions should not apply to NGO contracts.

8. How can an information management system be balanced to evaluate government programs, regions/offices and NGOs?

If an NGO takes on a State function, its information management system should meet all the legislative and regulatory requirements that a comparable State Government Department would be required to meet.

9. What are the key agency skills for the management and control of NGO funding?

[REDACTED]

The corporation has a specific role in risk management and wealth creation, which has been well understood since the Enlightenment and the Industrial Revolution. However, I do not believe the corporation is necessarily benevolent, or should necessarily be adapted to benevolent ends. [REDACTED]

[REDACTED]

[REDACTED]

10. What skills shortages currently exist in human services agencies?

I am sorry to have to say this (and while it certainly does not reflect all people in all agencies) but, it would not be difficult to come to the conclusion that human services

is all too often the refuge of those who could not maintain employment in the private or public sectors.

Whether it is dealing with employment agents, the ACP [REDACTED] I have often been amazed at the inability of many within these organisations, to solve basic problems for their clients. In my case, resolving problems with the ACP involved two ministerial letters, while Annex 5 shows you the links I have had to go to in order to attempt to resolve problems created by SEDS. It is worth remembering that these people are supposed to be helping me find work. Rather than doing that, they have generated paperwork for me, as I had to assure *Centrelink* of my continuing eligibility for the mobility allowance.

11. Is it feasible to have frontline staff undertake generalist roles (for example, in social services) as well as a variety of specialist roles (for example, finance, contracting and procurement)?

Given my answer to question 10, my answer to this question is "no".

12. What specialist skills are required by staff in the head offices of human services agencies?

Please refer to my answer for question 9.

13. What specialist skills are required by staff located near the point of service delivery?

Any staff member providing point of service delivery needs to be a confident communicator, empathic and patient with clients and their families. Care workers also need to be accepting that individuals and their families may have objectives that the workers themselves do not agree with.

I have always resented social workers, teachers, physiotherapists and others, presuming to speak in my best interests. While appreciating that this phraseology exists in many pieces of social welfare legislation, it is nonetheless personally repugnant and, in my view, inconsistent with the ideas of liberal democracy and limited government. Limited government should mean that there is a clear space for private choices and actions, some of which others may believe are deleterious to an individual's well-being or best interests. However, it should not be the third party's view that is determinant. In human services however, this is too often the case.

It is also worthwhile adding that, as a client in receipt services it would be useful for service providers to be responsible for ensuring that all care workers could speak competent, conversational English. This has not always been the case, in my experience.

14. In what circumstances should defunding decisions be at a regional, head office or ministerial level?

Funding should be an open and transparent process, based on a published, competitive tender. If the occasions in which Ministers or departmental staff can gift

NGOs public money can be limited, the transparency of public decision-making will be improved.

Equally, person centred funding should ideally take the funding decisions out of many bureaucrats' hands, regardless of whether they work in the public sector or the NGO sector.

15. Should the funds recovered from a defunded NGO be returned to the relevant region instead of the head office?

The funds should be put out to public tender, with the objective of finding another NGO (or government agency) to fill the void left by the defunded agency. By the same token, if the funds were part of an individual package granted to a service client, the money should be returned to the client. Equally, they should be given a list of alternative service providers, as well as urgent assistance to try and put alternative arrangements in place as soon as possible, so they are not unduly disadvantaged.

The State Government and its Department of Human Services should be responsible for maintaining a database of service providers, to address difficulties of defunded or insolvent service providers. This database should also be publicly available to people looking for service providers to meet their care needs.

16. How can the continuation of services be maintained in a defunding situation?

Please refer to the answer to question 15.

17. Should all NGOs be subject to a government regulator or regulators and, if so, should one regulator or multiple regulators perform this role?

As stated in Appendix 1, contained in Annex 1, what the NGO sector needs is not a new regulator, but a stringent "show cause" test.²⁷ This would be aimed at having NGO agencies periodically prove that their dominant purpose remained charitable.

18. What other initiative might be developed to improve reporting of improper NGO behaviour?

My submission to the *Legislative Assembly* directly addressed the question of whether outsourcing human services delivery so completely, amounted to creating a class of people who were literal "slaves to benevolence".²⁸ I believe it does and, that the proposal to outsource human services delivery to NGOs potentially violates instruments such as the *International Charter on the Rights of People with Disabilities*.

While not generally one to put great weight on international instruments (as I believe their application and legal standing can often be dubious, or politically motivated), it does seem that a group of people are somehow lesser citizens of NSW, simply

²⁷ See Annex 1, Appendix 1, p.4

²⁸ See Annex 1, *Submission to Assembly*, pp. 9 - 13

because they rely on human services. This point was also explored in my unpublished submission to the *Legislative Assembly*, and I draw those remarks to your attention.²⁹ Equally, I remind you of repeated earlier comments in this submission, placing a strong emphasis on the full public disclosure of all activities undertaken by NGOs.

Chapter 3

19. Should a framework be developed for classifying the type of funding agreement necessary for the service being delivered?

As stated previously, all contracts with NGOs should be made public and, commercial in confidence provisions should not apply in any circumstances. Perhaps the only exception to this rule would be to redact the name and personal details of individual clients from publicly disclosed information.

Additionally, as I have also emphasised, any framework should be reliant on legally enforceable contracts which include the client and their family as full legal partners. There should be absolutely no use of unenforceable Memoranda of Understanding (MoUs)

20. Should grants and contracts be separated and managed accordingly and, if so, how should this be done?

In a person centred care arrangement, it should not matter whether the money comes as a grant or a contract. What needs to be demonstrated is that the entirety of the money was handled for the person's benefit by the benevolent side of an NGO; that is, the fund raising and management side of the organisation (the business that would be taxed) had nothing to do with the money that was contracted or granted for an individual's care.

21. In what context should government provide grants to NGOs?

This should only take place after a fully disclosed and publicised competitive tender process. Politicians and bureaucrats should be discouraged from giving discretionary grants from monies within their own departments, or under their direct control. While this will admittedly reduce the opportunity for positive photo opportunities, it will also reduce the likelihood of corruption and nepotism.

22. How can service delivery outcomes be better specified?

Refer to my earlier comments about implementing legally binding contracts and discontinuing any use of unenforceable MoUs.³⁰

²⁹ See *ibid.*, pp. 5 - 6

³⁰ Also see generally, Senate Standing Committee on Education, Employment and Workplace Relations, *op. cit.*, where I write extensively about the failings of MoUs.

23. In what context should “bundling” of funds occur?

There should be determined by the needs of an individual, as part of their person centred care plan. Again, I will always emphasise the needs and wants of the individual service recipient, over the management convenience of a service agency.

24. How can human services agencies better use markets to determine price and value?

I am a supporter of free and open markets and, as stated above, would encourage the use of open and competitive tendering. Additionally however, I would also be inclined to waive commercial in confidence provisions, because of my strong belief that public transparency and accountability should trump commercial interest, particularly if we are speaking about the spending of taxpayers' money.

25. What reform is necessary to develop in-house agency capacity to determine the price of services?

Even with my own experience working in government, I was never entirely convinced that the public sector truly believed it was delivering a service. Certainly, the language used by departments, instrumentalities and agencies suggested that a change had taken place, but the reality is that many who come to government looking for a service, are dealing with a monopoly provider.

On the face of it, this should make the possibility of dealing with NGOs an attractive alternative. Given however, that the funding will come from the government, it will be a case of: *he who pays the piper, calls the tune.*

I again refer you to earlier cited comments of Vern Hughes, on how government funding can radically change the objectives and culture of NGOs. This is broadly supported by comments from [REDACTED].³¹

It is for all these reasons that I believe a high onus of disclosure will force improved performance. If commercial in confidence and other mechanisms can no longer shield waste and mismanagement, both NGOs and government will put a higher premium on ensuring they have competent, well trained staff that are committed to efficient, customer focused service delivery.

26. How can direct negotiations with NGOs be managed to determine a price that reflects the actual cost of delivery?

I draw your attention to the addendum of my submission. It includes a copy of a recent report from the ABC's *730 program* and an article from a Queensland newspaper. It also contains copies of e-mail exchanges between me and [REDACTED]. [REDACTED] Enable is the consolidated agency for the provision of a wide variety of disability care products from wheelchairs, to incontinence products and mechanical limbs for amputees.

³¹ See Annex 1, Appendix 1, pp. 8 - 9

As a member of the Enable Advisory Council I have been raising concerns about the prices charged by domestic suppliers, for various goods and services. The news reports contained in the addendum were useful examples when I sought to raise the issue of overcharging and price gouging.

To her credit, [REDACTED] acknowledges that this is a serious issue and, at the Council's most recent meeting, the price and services provided by a number of domestic suppliers provoked much discussion. I am also encouraged by the example clearly set by Enable New Zealand. They already source supplies internationally, having obtained NZ Government import approvals.

The same should happen here, as a matter of urgency. It will significantly reduce prices, give individuals freedom of choice and, force domestic suppliers to provide efficient services, because purchases are no longer beholden to them.

27. What other steps can be taken to ensure value for money in the provision of services?

Refer to my previous answers.

28. What can be done to minimise corruption risks associated with irregular allocation of funding?

This should not occur, if all funds are committed to individual care recipients, under the person-centred model. Money should always be attached directly to the person receiving care, with an NGO care agency only ever holding the money as a Trustee. And, if it is public money, it would need to be disclosed to Parliament in an Annual Report, and potentially audited by the NSW Audit Office.

29. What changes to the budget processes of human services agencies are required to reduce the practice of end-of-year distribution of surplus funds?

See my previous answer.

30. How are the conflicting duties and community relationships best managed to ensure impartial and effective oversight of NGO funding?

Earlier in this submission, I spoke about the erection of Chinese walls and, the deliberate separation of fund raising and management from care and service delivery. These changes are essential for the NGO sector to take on the roles proposed with any credibility and in order to retain public confidence. Ultimately, I believe that the retention of public confidence requires a continued central role for Parliament and open disclosure. Equally, as stated repeatedly, MoUs must not be used.

This question does give me the opportunity to address the important question of Enable NSW and my acceptance of a position on its Advisory Council. It is acknowledged that this is one of the factors which led to my "resignation" from the Board of the Centre.

However, I have a completely clear conscience about my conduct in relation to this matter. Firstly, one responded to a public advertisement seeking expressions of interest for membership of the Advisory Council. I responded and, after some months, the then Department of Health advised me that I was under the consideration of the Minister for appointment. They requested that I keep this information confidential, as it was Cabinet in Confidence, which naturally, one agreed to do.

In the interim, there was a meeting of the Centre's Board. I of course, said nothing about being approached by the Health Department, as it would have been grossly inappropriate to do so. However, when the appointment was confirmed I made the appropriate declaration of interest to [REDACTED]

In a meeting a week or so prior to my ultimate "resignation," [REDACTED] made clear that she felt I had been disloyal. Apparently, one should have sought her approval before allowing my name to be considered by the Health Minister. She had also previously instructed [REDACTED] to alter Board minutes to show I had declared an interest in Enable prior to my actually advising the Company Secretary. The record thus put me in breach of Cabinet confidentiality, to which I objected without success.³²

31. What changes, within and across government agencies, can be made near the point of service delivery to minimise conflicts of duty and partial behaviour?

This is a very difficult question to answer, because point of service delivery can revolve around very intimate matters. Human nature will be to develop relationships, particularly where one person is reliant on another for sensitive issues of care. While I appreciate the issue ICAC is raising, there does not seem to be any practical solution to it.

Indeed, in a person centred approach, the longevity, familiarity and intimacy of a care relationship may be the determining factors in deciding which carer/s are hired by the client and their family. And, who are we to second-guess that?

Chapter 4

32. What matters should be coordinated centrally?

Given my prior comments, my answer here is "as few matters as possible". With few exceptions, my experiences of "central authorities" as they relate to disability services, are negative. This was why I sought a meeting with (and prepared a Briefing Note for) [REDACTED]

[REDACTED]³³.

My objective was to outline to the Minister my opposition to the proposed NDIS and its "central agency" approach. I argued that this disempowered service recipients,

³² See Annex 1, Appendix 5, pp. 1 -15. The Statement was the address I gave just prior to my "resignation".

³³ See generally, Annex 4, *Briefing to Minister*. My opposition to the proposal is also made clear in Annex 1, Appendix 7.

while also being the antithesis of Coalition beliefs and policies. I urged him to oppose implementation of the NDIS at the Council of Australia Governments (CoAG). There is a risk that if a large “pot of money” is established (called the NDIS), it will become an irresistible “honey pot” for those willing to make “easy money” off the backs of potentially vulnerable people.

33. What matters should be coordinated near the point of service delivery?

Under a person-centred care approach, most if not all matters would be coordinated at the point of service delivery.

34. How is coordination near the point of delivery best achieved?

This would be determined by the contract between the care recipient and the care provider.

35. Should human services agencies specify minimum standards of administrative practice and/or governance arrangements prior to providing funding to NGOs? If so, what should these be?

My previous answers have highlighted a number of structural and governance issues, which really need to be addressed *before* any more human services are handed over to the NGO sector.

If you need any more convincing, I refer you to Annex 1.

36. Where weak administrative capability is identified, should NGOs be required to outsource their administrative functions to larger, more capable NGOs, or to shared services provided by government?

Given the earlier cited comments of Vern Hughes and Arthur Mudry, I do not support giving more public financial succour to “bland managerial types” in the NGO sector. If an NGO cannot competently deliver a service, the Government should step in, while arranging for a new public tender.

It should be incumbent upon the Government to launch a full, independent and public inquiry, as to why the first provider failed to deliver. The Government should be required, within a fixed time frame, to respond to any findings and recommendations coming from the inquiry. The independent report and Government response should be tabled in Parliament, in a similar fashion to any other committee report.

37. Would consolidation across NGOs improve management and governance standards?

No, given my experience at the Centre, I do not necessarily believe that size leads to improved operational abilities. In preference to consolidation, I refer you to my previous answer.

Yours faithfully,

A handwritten signature in black ink that reads "Adam Johnston". The signature is written in a cursive style with a horizontal line underneath.

Adam Johnston

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Adam Johnston

35 Woolrych Crescent

Davidson NSW 2085

[REDACTED]

Dear [REDACTED]

It is easy when we are in prosperity to give advice to the afflicted. - **Aeschylus (525-456BC) Greek dramatist, tragic poet***

This inquiry is very timely, particularly as it comes amid growing media and public concern over the probity of charitable fundraising techniques,¹ along with queries over how much of the funds raised (perhaps bullied) from the public actually make it to those in need.² I note that in response, charitable leaders and spokesmen for various not-for-profit bodies are racing to distance themselves

* Taken from *Daily Quotes for Wed 04 Apr 2012*, <http://www.just-quotes.com/quotes.shtml> as at 4 April 2012.

¹ See for example, Jonathan Marshall, *Special investigation: Charities use the hard sell*, The Sunday Telegraph, February 19, 2012 12:00AM, <http://www.dailytelegraph.com.au/news/special-investigation-charities-use-the-hard-sell/story-e6freuy9-1226274694765>; Jonathan Marshall, *Charities outsourcing fundraising to Legacy Marketing unaware of 'highly offensive' tactics*, The Sunday Telegraph, February 19, 2012 12:00AM, <http://www.dailytelegraph.com.au/news/charities-outsourcing-fundraising-to-legacy-marketing-unaware-of-highly-offensive-tactics/story-e6freuy9-1226274706619>; Staff Writer, *Oxfam's 'death squad'*, The Sunday Telegraph, March 04, 2012 12:05AM, <http://www.dailytelegraph.com.au/news/oxfams-death-squad/story-e6freuy9-1226288305850>; Jonathan Marshall, *St Vincent's Hospital in Melbourne used confidential medical files to get donors*, The Sunday Telegraph, March 04, 2012, 12:00AM, <http://www.dailytelegraph.com.au/news/st-vincents-hospital-in-melbourne-used-confidential-medical-files-to-get-donors/story-e6freuy9-1226288220475>; Jonathan Marshall, *Top 10 Aussies a rich target for charities*, The Sunday Telegraph, March 04, 2012 12:13AM, <http://www.dailytelegraph.com.au/news/top-10-aussies-a-rich-target-for-charities/story-e6freuy9-1226288311751>; Jonathan Marshall, *The tricks charities try to cash in on the vulnerable, elderly and dying*, The Sunday Telegraph, March 04, 2012 12:00AM, <http://www.dailytelegraph.com.au/news/the-tricks-they-try-to-cash-in-on-the-dying/story-e6freuy9-1226288206819>; Jonathan Marshall, *How to get a bequest, according to the experts*, The Sunday Telegraph, March 04, 2012 12:00AM, <http://www.dailytelegraph.com.au/news/how-to-get-a-bequest/story-e6freuy9-1226288214579> all articles accessed as at 11 March 2012

² See for example, Richard Noone, *Charities forced to show records on new MySchool like website*, The Daily Telegraph, October 24, 2011 12:00AM, <http://www.dailytelegraph.com.au/news/charities-forced-to-show-records-on-new-myschool-like-website/story-e6freuy9-1226174511400> as at 25 October 2011; *Charities under scrutiny*, News Limited Newspapers, October 24, 2011 12.00am, The Mercury, http://www.themercury.com.au/article/2011/10/24/271211_todays-news.html as at 11 March 2012

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from fundraising companies like *Legacy Marketing*,³ while making soothing noises about wanting to restore trust⁴ with a public now openly questioning the decency, integrity and sincerity of many in the charitable sector.⁵ Yet, it is into the hands of the same charitable/non-government organisations that the State Government appears to want to place more and more of the responsibility for the care of those suffering housing stress, as well as those who are frail, disabled or elderly. Long may the public continue to ask questions about the conduct and integrity of charities; at the same time, we should ask what the proper role of Government actually is?

In this age of fiscal austerity it sometimes appears that policymakers believe that governments *should not* have any role in direct service delivery. This is a concern on many levels, as I outlined in my submission to the Commonwealth Government's review of corporate governance in the not-for-profit sector, which is included as Appendix 1 to this submission. In summary, the Appendix makes the following points:

- The not-for-profit sector has changed substantially in the last 30 years, moving from small community organisations to large corporate businesses, whose focus is primarily corporate events and fundraising. In my personal experience, and in that of some researchers I cite, the leadership of such organisations can be far removed from those they are allegedly working to support, and at times, managers have little insight into the true needs or aspirations of service recipients;⁶
- Even where non-government agencies/charities have been established, which allegedly provide the elderly, disabled or other potentially vulnerable service recipients with "freedom of choice," these bodies are often heavily subsidised by government. They are therefore highly constrained in what they can offer and on what terms, so the exercise of "choice" can be a highly generic exercise, much like buying no name brands from the supermarket. While the principal example used in the Appendix 1 comes from the Commonwealth sphere of employment services,⁷ the experience of "the Clayton's choice"⁸ can be had in any number of other areas.

³ See Jonathan Marshall, Disgraced fundraising firm Legacy Marketing shuts its doors after dirty tactics revealed, *The Sunday Telegraph*, March 11, 2012 12:00AM, <http://www.dailytelegraph.com.au/news/disgraced-fundraising-firm-legacy-shuts-its-doors-after-dirty-tactics-revealed/story-e6freuy9-1226295987998> as at 11 March 2012. Sadly, the article claims that the proprietor of *Legacy* David MacDonald "will continue to work for major charities." It is to be wondered how much has been learned by charities, if anything?

⁴ See Tim Costello, Charities must work hard to restore the sacred trust, *The Sunday Telegraph*, March 11, 2012 12:00AM, <http://www.dailytelegraph.com.au/news/opinion/charities-must-work-hard-to-restore-the-sacred-trust/story-e6frezz0-1226295844477> as at 11 March 2012.

⁵ Refer to the *Letters page* of *The Sunday Telegraph*, Sydney, March 11, 2012, and also refer to the comments under the article Jonathan Marshall, *Expert Simon Quinn calls for urgent change in fundraising tactics*, *The Sunday Telegraph*, March 10, 2012 11:22PM, <http://www.dailytelegraph.com.au/news/expert-calls-for-urgent-change/story-e6freuy9-1226295986219> as at 11 March 2012.

⁶ See Appendix 1, pp. 4-5 of 14 [Adobe numbering]

⁷ See *ibid*, pp. 6-7 of 14. In particular, note the comment on the top of page 7 that: "To me, much of the work conducted by not-for-profits in the disability employment sector is done with one eye to the next round of government grants and/or subsidies. This underscores...earlier cited comments of (commentator Vern) Hughes, about many in the not-for-profit sector morphing into little more than a silo of government".

⁸ See *Claytons* <http://en.wikipedia.org/wiki/Claytons> as at 14 March 2012

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On a State level, I have used my rather adverse experience of entry onto the Attendant Care Program (ACP) as an example of how an initiative, allegedly designed to give people with disabilities and their families freedom of choice in care (as well as securing care arrangements to allow people to age in place) operated as a mechanism where headstrong caseworkers/managers attempted to impose unnecessary, unwelcome and most notably unrequested changes to my daily life and that of my mother. It is my observation that commentators and policymakers, be they politicians, bureaucrats or others, have great difficulty critiquing the charitable sector – as anything other than selfless people doing wonderful things for the poor and underprivileged. This is a naïve construction, which while true to a certain extent, is far from the full story.

Matteo Tonello has written in the *Harvard Law School Forum on Corporate Governance and Financial Regulation* that the chief executive officers of corporations who donate funds to charities can benefit from what is known as a "halo effect". That is, by appearing to act as generous agents of their shareholders, employees and other stakeholders, senior management receives a further benefit of high esteem from their colleagues, as well as more general public acclaim for their apparent generosity to those less fortunate. I contend that a similar "halo effect" occurs in relation to charitable workers and the management of not-for-profit organisations.

As a result, scrutiny is minimal (for fear of being seen as harsh and ungrateful) allowing many practices to go unchallenged. [REDACTED]

[REDACTED]

9 [REDACTED]

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- Many not-for-profit enterprises are so dependent on government funds/subsidies that their entire operation would cease without it. The most telling example in my experience is the structure and operation of employment services for people with a disability. Based on an analysis of a discussion paper from the then Fair Work Commission (the Commission), I concluded that there was no aspect of the Supported Wage Scheme (SWS) or the Special Business Enterprises which made use of the SWS scheme, that were not entirely dependent on a government subsidy for every aspect of their operation to remain viable. I included my submission to the Commission in a recent contribution to a Senate inquiry into the administration and purchasing of disability employment services in Australia.

My comments to the Senate called for complete competitive tendering for employment services, noting the Commission's earlier report.¹⁰ The relevance to this inquiry is twofold; I do not see the proposed reforms as adding to many real improvements in service or choice for vulnerable consumers. Rather, I see a growing malaise of not-for-profit organisations rent-seeking from the same taxpayers they have already sought donations from. As someone who is in part dependent on the sector, it troubles me that the community may form the view that not-for-profits are double-dipping; accepting people's generosity via donations with one hand, while also attracting public funds (which taxpayers were legally bound to give to government) with the other hand. Ultimately, this was one of many reasons I resigned from the board of a major NSW charity.¹¹ In particular, please note these comments from Appendix 1:

(As) someone with a disability who is reliant on community goodwill the last thing I want to do is be complicit in asking people to donate to "charity" when in truth we are talking about hybrids which are part government business enterprise, part marketing firm, and part commercial entity hoping for an operating surplus.¹²

- Finally, the State Government should not leave the elderly, disabled and homeless in the hands of organisations, many of whom cannot claim to have a representative membership base capable of truly holding management to account. [REDACTED]

¹⁰ Submission: The administration and purchasing of Disability Employment Services in Australia, <https://senate.aph.gov.au/submissions/comitees/viewdocument.aspx?id=a6fa4e6a-eb31-49de-bb0f-c9f11849c86c> as at 15 March 2012. In particular, I said at page 56 of 68:

I (am) highly critical of employment agencies and the general "employment bureaucracy" which is visited upon the unemployed. It is often complex, slow, inefficient and counterproductive – indeed, media reports show that it can also be corrupted. These institutions, often funded by large amounts of Government money are just as much part of the disability employment/wages "problem", as is (the Commission's) decision to maintain the SWS. Therefore, we see that public money subsidies employment agencies placement activities. This is then often followed by the subsidisation of wages, also courtesy of the taxpayer. And this outcome is called "employment", despite the fact that vast amounts of taxpayers' money is being poured in at both ends of the system?

¹¹ I was a Board Member of the Cerebral Palsy Alliance (formerly the Spastic Centre of NSW) between 2009-2011. The organisation's homepage is <http://www.cerebralpalsy.org.au/home> as at 15 March 2012. Also see the *Annual Report*, p.19 at http://www.cerebralpalsy.org.au/_data/assets/pdf_file/0015/1068/Annual-Report-2010.pdf as at 31 March 2012.

¹² Appendix 1, p.5 of 14 [Adobe numbering]

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[REDACTED]

[REDACTED] For families who built many charities first as voluntary concerns to care for needy loved ones, it is confronting to now:

find themselves referred to, in the annual reports of the bodies they created, as “stakeholders” in the welfare of their sons and daughters. They appear alongside key stakeholders such (as) local governments, suppliers and corporate partners. Many shake their heads in disbelief at the entity they unknowingly created. “We gave birth to a monster,” some say.¹³

Recommendation 1: That the Committee should closely examine the probity of the not-for-profit sector. The Committee should further note that over the past 20 or 30 years, it has transformed radically, to the point where many charities are indistinguishable from for-profit businesses. The managers and directors of these businesses are often remote and largely unaccountable to vulnerable service recipients, who may not be members of the organisations they rely on for service. With devolution and out-sourcing, the Government shows a similar inclination for remoteness from some of its own citizens, leaving them further disadvantaged and vulnerable.

What or who is (or is not) a citizen?

Another aspect of devolution and outsourcing the Committee should consider is; what does the proposal say about the stake which certain groups hold in wider society and public policy? In this respect, it is noteworthy to reflect on the words of Sir Robert Menzies, founder of the Liberal Party of Australia and our longest serving Prime Minister. Often derided by leftist critics, even today,¹⁴ Menzies’ political philosophy and policies were much more complex and nuanced than some will concede. Equally, despite what some might choose to believe, he did see a definite role for the State in social policy. For example, presenting the 1999 lecture for the *Sir Robert Menzies Lecture Trust* Petro Georgiou MP argued the Menzies had a strong commitment to both liberalism and social justice. Menzies own words from a radio broadcast in 1942, gives form to these commitments, where he said:

The country has great and imperative obligations to the weak, the sick, the unfortunate. It must give to them all the sustenance and support it can. We look forward to social and unemployment insurances, to improved health services, to a wiser control of our economy to avert if possible all booms and slumps which tend to convert labour into a commodity, to a better distribution of wealth, to a keener sense of social justice and social responsibility. We not only look forward to these things; we

¹³ Ibid, p. 7 of 14, quoting Vern Hughes, *Non-profits lose sight of volunteer heritage*, February, 4, 2011. Opinion <http://www.smh.com.au/opinion/society-and-culture/nonprofits-lose-sight-of-volunteer-heritage-20110203-1afbi.html> as at 28 December 2011

¹⁴ See Gerard Henderson, *History - Why Menzies Still Matters*, Quadrant On-line, December 2008, <http://www.quadrant.org.au/magazine/issue/2008/12/why-menzies-still-matters> as at 17 March 2012. In particular, refer to the commentary under the heading “The Left’s Attack on Menzies—Living and Dead”

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*shall demand and obtain them. **To every good citizen the State owes not only a chance in life but a self-respecting life.***¹⁵ (my emphasis)

One element of this position which should sound a caution to current plans for outsourcing is a much less repeated caveat, which shows the nature of these obligations and, where the responsibility lies for their delivery. Georgiou cites further comments from Menzies, where Australia's allegedly conservative Prime Minister said:

The purpose of all measures of social security is not only to provide citizens with some reasonable protection against misfortune but also to reconcile that provision with their proud independence and dignity as democratic citizens. The time has gone when social justice should even appear to take the form of social charity.¹⁶

However, by outsourcing service delivery to *allegedly* benevolent organisations, it is arguable that public policy is taking a significant step backwards to a pre-Menzies liberalism; suddenly, social security provision is not clearly in the public realm, and recipients may well struggle to hold private organisations to account for poor service. As a result, social security may become little more reliable than the social charity Menzies sought to avoid.

The 'insidious trend'

My submission to the Senate regarding disability employment services,¹⁷ as well as my submission to the Disney Review into the Job Seeker Compliance Review,¹⁸ both aimed to show gaping holes in the logic behind publicly subsidised, private benevolence bodies operating public welfare/support systems. Principally, while I as a job seeker was legally obliged to make applications, attend interviews and the like, I was not a party to any contract between my employment agent, the government or any potential employer. When these parties decided a recruitment process was to be discontinued, "defunded" or otherwise cancelled, I had no means of redress against any of them. This was partly because the agreements they entered were conveniently legally unenforceable memoranda of understanding (MOU).

You quickly learn as an unemployed person (who happens to have a disability) where you sit in the employment 'pecking order' when you complain to the Commonwealth Department of Employment, and they respond:

The MOUs are designed to articulate the available services required by each employer to assist them hire people with disability. Legal contracts are not used because it would be unlikely that employers would risk facing penalty in the case that they had to defer or stop a recruitment process.

¹⁵ Taken from Petro Georgiou MP (quoting Menzies), *Menzies, Liberalism And Social Justice*, Sir Robert Menzies Lecture Trust, 1999 Lecture, Thursday 18 November, 1999, Monash University, Caulfield Campus, Melbourne, p.3 of 10 [Adobe numbering] <http://www.menzieslecture.org/1999.html> as at 13 March 2012

¹⁶ Ibid, quoting Menzies

¹⁷ See generally, footnote 10, above

¹⁸ See generally, footnote 9, above

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It is important that employers are not discouraged from seeking to employ people with disability by requiring them to be penalized if their fluctuating business concerns cause them to cease a planned recruitment process.¹⁹

Heaven forbid that someone with a disability or their family should conclude that an undertaking from a service provider is a guarantee, or even 'a non-core promise'!²⁰ Yet, I have found that the disability services sector is replete with inequitable arrangements, where parties are brought together²¹ but duties of reciprocity and privity of contract are absent.

I cite as further evidence of unreasonable program structure and rigidity, an urgent request made to the ACP last year. My manual wheelchair suddenly collapsed under me, and we rushed to the nearest sales and service centre in Dee Why to obtain a replacement. The chair is a piece of equipment relied on daily, so I can move around my house; without it, I would be bedridden. As the chair collapsed on a Friday, the replacement had to be found by Saturday. Given Saturday trading hours, it was necessary to move quickly before the shops closed; we also knew of several thousand dollars in equipment funding held on our behalf (and allegedly for my benefit) by ACP. However, the ACP initially declined to reimburse me for the cost of the chair, claiming we required pre-purchase approval.²² It was only after my Homecare Service Manager made a retrospective application and, I argued that ACP guidelines could not be taken as a legally binding document that the ACP agreed to refund me for the purchase of the wheelchair.²³ I emphasise that this was what one had to do to obtain money which was supposed aimed solely at providing equipment for my care and support.

¹⁹ *Submission: The administration and purchasing of Disability Employment Services*, op. cit., pp. 56-57 of 68 [Adobe numbering], quoting a letter from ██████████ to Adam Johnston, dated 24 November 2006

²⁰ See <http://www.urbandictionary.com/define.php?term=non-core+promise> as at 18 March 2012

²¹ Sometimes by force of law, as is the case with the Job Seeker Compliance Regime

²² I note that the offices of the Department of Ageing, Disability and Homecare are not open on the weekend, and while it would be unreasonable to expect them to be so, there was no way they were going to be able to approve the wheelchair in the time required. Further, there can often be a strong element of condescension from case officers, be they in the government or not-for-profit sector; i.e. every single item or issue needs to be intensively assessed and documented by a 'qualified expert', seemingly because clients and their families are blank canvases, incapable of understanding or acting on their own needs without professional guidance. My mother and I have never allowed such a stereotypical view to take hold about us. However, you may find there a few care providers who would say that in our case it's not the dog you should be wary of, but the owners. And in many ways, that's a good thing.

The service providers we have now know they are retained because they continue to deliver what we want; and, in relation to Homecare we were prepared to seek an out-of-guidelines ruling to retain its services. But none of this was settled easily, and no amount of devolution or outsourcing will free the elderly or disabled from the coterie of alleged social welfare experts, be they social workers, physiotherapists, occupational therapists or others, who continue to be the gatekeepers of assessment for funding and services. See my comments to the Productivity Commission's Inquiry into Disability Care and Support, in my third and final submission, here provided as Appendix 3. In particular, note ██████████ comments, with I cite of page 6 of 10 of the document. [Adobe numbering] Although, given that I hold a Masters in Law and my mother is a Scientist/Laboratory Manager, we could not possibly claim to know everything, unlike those obnoxious types who hold certificates in social work (and thus know it all)!

²³ See Appendix 2. In particular, note the email exchanges between me and ██████████ between 15th and 16th August 2011, pp. 5-7 of 8 [Adobe numbering]

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Again, ACP only yielded when I showed a propensity to argue, combined with a history demonstrating my willingness to put matters before the Minister. Most are not as willing as me to advocate on their own behalf, nor have the advantage of my legal training or knowledge of government. Many people fear that complaining will result in the loss of a service, however poor or inappropriate it may be. Thus, many will be subject to “the guidelines,” which the former Attorney General of Victoria the Hon. Rob Hulls MP warned, had serious implications for due process in Australia. He told the Centennial Sitting of the High Court that:

In our defence of the rule of the law, we must also be alert to, and alarmed by, attempts to bypass judicial scrutiny, whether it be via privative clauses or **the more insidious trend towards unenforceable guidelines.** In my view, any suggestion that an Executive’s “non-binding guidelines” be accepted as authoritative is dangerous terrain. Yet it is increasingly the case that we are asked to accept the legitimacy of such guidelines, whether it be in Industrial Relations, decisions concerning grants of Legal Aid, or more poignantly in the immigration area.²⁴ (my emphasis)

In my view, Mr Hulls is right. The “insidious trend” has spread like a cancer throughout public administration, and by extension, infected not-for-profits who accept public grants (with guidelines attached). This was why, when NSW Premier the Hon. Barry O’Farrell MP issued a discussion paper on *Recall Elections in NSW*, my response was to recommend in part that:

(Given) the growing amount of Government goods and services being delivered by the private sector, it is in my view vital to bring government contractors and private sector providers of goods and services funded by the State, within the remit of the recall procedures. As someone with a disability, government funded employment, equipment and other care providers who fail to deliver on promises (even when I sign contracts of service) have truly tested my patience at times. To find further that one cannot legally enforce fulfilment of agreements because they are based on unenforceable memoranda of understanding (to which I as a client am not a party to) is the ultimate insult and frustration...Ministers, Department CEO’s and Director Generals, the Executive Officers of NGO’s, their staff, judicial and other officers; indeed anyone who finds themselves responsible for running a publicly funded agency or program, whether it is identified in the State Budget for financial assistance, or support comes as a grant or via some departmental instrument, agreement, or authorisation, all should know the potential power of a Recall Petition.²⁵

In short, I am very concerned the devolution and outsourcing will reduce the elderly, disabled and other vulnerable members of the community to little more than helpless serfs of not-for-profit vassals; where the principal concern of the later will be keeping the government and, corporate philanthropists (read: principal Lords of the Manor), on-side.

²⁴ The Hon. Rob Hulls, *Ceremonial - Special Sitting at Melbourne - Centenary of High Court of Australia* [2003] HCATrans 406 (6 October 2003), available at <http://www.austlii.edu.au/cgi-bin/disp.pl/au/other/HCATrans/2003/406.html> as at 29 March 2012

²⁵ My submission to the Panel of Constitutional Experts, pp. 3-4, http://www.dpc.nsw.gov.au/_data/assets/pdf_file/0008/131120/06_Johnston.pdf as at 3 January 2012. Also see Appendix 1, p.7 of 14 [Adobe numbering]

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A slave to benevolence?

William Wilberforce played a critical role in ending the United Kingdom's involvement in the cross-Atlantic slave trade,²⁶ while Lord Mansfield declared in the case of *Somerset* in 1772 that England's law would not recognise the claim of an owner over a slave. His Honour said, in answer to the claim that slavery was comparable to villeinage, that:

Villeinage, where it did exist in this country, differed in many particulars from...slavery...At any rate, villeinage has ceased in England and it cannot be revived. Every man who comes into England is entitled to the protection of English law, whatever oppression he may hereto have suffered and whatever may be the colour of his skin. The air of England is too pure for any slave to breathe. Let the black go free.²⁷

The reason for drawing on this history is to bring into focus a key question; how does devolution do anything more than change the agency upon which a disabled or elderly person is dependent? Furthermore, once you have included the subsidies/grants from government (and accompanying guidelines) the not-for profit sector looks like little more than an "echo of government administration"²⁸ rather than an innovative, customer-centred alternative service provider. And while some will dismiss the analogy to slavery as too strongly put, I think not; the shackles applied by both are the "guidelines" handed down by government, so any flexibility or choice will be constrained by these insidious acts of administrative fiat.²⁹ A government provider will stick resolutely to their guidelines because the document represents to them the most convenient way to structure their interactions with the public. The private or not-for-profit agent will do the same, because conformity guarantees ongoing government funding; and it is this funding which they need more than anything else, to subsidise their otherwise uneconomic ventures.³⁰

In all this, client/end user tastes and preferences are not determinative. This is why, in my first submission to the Care Inquiry I rejected the idea of a national disability body, in preference to my highly personalised (and with minimal regulation) *Minder-style* model. In particular, I said:

²⁶ See generally, William Wilberforce http://en.wikipedia.org/wiki/William_Wilberforce as at 29 March 2012

²⁷ Cited in Lord (Alfred) Denning, *The Due Process of Law*, Butterworths, 1980, p.159

²⁸ Or as Vern Hughes puts it: *Many organisations that began life as voluntary associations have become corporatized instruments of government service delivery and, no longer want, or even need volunteers...Most (have) found it easier to seek and obtain public contracts for their operations and tailor their mission to the delivery of those contracts, than to rely on private fund-raising or commercial income generation. In the process, their programs and operations (have come) to reflect the silo structure of government, and their internal cultures (now mirror) the government's risk-averse culture.* (Hughes, op. cit., and as cited in Appendix 1, p.4 of 14)

²⁹ I discussed my growing concerns over the encroachment of government and guidelines into the most minor aspects of our lives and behaviour, in a submission to Father Frank Brennan's Human Rights Consultation several years ago – see *Key Consultation Questions* by Adam Johnston (submission) 10 April 2009, pp. 1 -2 [http://www.health.gov.au/internet/main/publishing.nsf/Content/eHealth2-010/\\$FILE/010_Adam%20Johnston%20pt2_31-12-09.doc](http://www.health.gov.au/internet/main/publishing.nsf/Content/eHealth2-010/$FILE/010_Adam%20Johnston%20pt2_31-12-09.doc) as at 22 May 2010. This related to the conduct of a Commonwealth Rehabilitation Service caseworker who, by virtue of her guidelines, almost vetoed my university enrolment plans, a day before I was to enrol. However, in my experience (and in the name of their guidelines) service administrators, be they in the public or not-for-profit sector, will make these unilateral decisions with a blink of their eye.

³⁰ Refer, for example, to footnote 10, above.

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It is sad (that is, the rigid structure and regulation around service delivery), because I did have hopes for the ACP providing a *Minder* style relationship – a ‘Terry’ to my disabled/incapacitated ‘Arthur Daley’, though I would claim far better scruples than Arthur ever had. What was produced was the same as any government-run program...This is one of the greatest ironies of modern government. It will go to great lengths to adopt the language of the markets, turn citizens into ‘clients’ and tell you how much ‘choice’ you are receiving. Funny then, how this market is shackled by the same sort of government red tape that Sir Humphrey Appleby would be proud of. Furthermore, it would appear that the suite of ‘choices’ a ‘client’ is invited to make conveniently suits the administrative arrangements of the service provider.³¹

I was therefore dismayed when the Productivity Commission persisted with the proposal for a National Disability Authority in its *Discussion Paper*. One suggested that this would quickly become, for people with disabilities, the sad contemporary equivalent of the High Court of Chancery in Charles Dickens’ *Bleak House*; that is, a large maelstrom of bureaucratic misery for those trying to access services.³² Add devolution and outsourcing to this, and there is scope for great confusion. How do we ensure that individuals and their families have clear mechanisms to complain about, and report the wrong conduct of, service providers? In Appendix 1, I propose that the “charitable veil” be pierced so that government (as a key revenue source) continue to be clearly held vicariously liable.³³ Failure to do this will say much about the value of some people’s citizenship, with reference to their access to means of redress. Remember Menzies’ words; it is the State (and not the not-for-profit sector) that is supposed to provide protection against misfortune, in a manner consistent with the dignity and independence of the democratic citizen.³⁴

³¹ Refer to my response to the Productivity Commission’s *Issues Paper*, pages 3-4

[http://www.pc.gov.au/ data/assets/rtf file/0006/99510/sub0055.rtf](http://www.pc.gov.au/data/assets/rtf_file/0006/99510/sub0055.rtf) as at 31 March 2012

³² See my *Second Submission to the Productivity Commission’s Inquiry into Disability Care and Support*, pp. 9-11 of 19 [Adobe numbering] [http://www.pc.gov.au/ data/assets/pdf file/0016/100726/sub0186.pdf](http://www.pc.gov.au/data/assets/pdf_file/0016/100726/sub0186.pdf) as at 31 March 2012. Ultimately, my third and final submission challenged the constitutionality of the National Disability Insurance Scheme [NDIS] (see Appendix 3, page 10 of 10 [Adobe numbering]). People with disabilities often experience a series of co-morbidities (perhaps better described as “multi-morbidities”), many of which require a suite of medication. The Productivity Commission has suggested that to receive funding under the NDIS, people would have to enter an arrangement with the National Disability Insurance Authority (NDIA) about “agreed therapies”. Many therapy arrangements, would by necessity, have components relating to medication. Yet, for the NDIA to mandate certain medications as conditions precedent to funding, may well violate Section 51 (xxiiA) of the *Australian Constitution*. This provides that:

The Parliament shall, subject to this Constitution, have power to make laws for the peace, order, and good government of the Commonwealth with respect to: ...
(xxiiiA) the provision of maternity allowances, widows’ pensions, child endowment, unemployment, pharmaceutical, sickness and hospital benefits, medical and dental services (but not so as to authorize any form of civil conscription), benefits to students and family allowances; (my emphasis)

In my view, it is unfortunate that the prohibition is not written much more widely; even so, it could potentially be brought to bear against some of the more punitive aspects of welfare policy.

³³ See Appendix 1, p.8 of 14 [Adobe numbering]

³⁴ Refer to footnote 16, above.

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If we think of all three indicia (dignity, independence and democracy), then requiring people to live under the spectre of guidelines which are *technically* unenforceable but practically immutable, while also having failed to come under any Parliamentary scrutiny,³⁵ should be (and be seen as) immediately unacceptable. Yet, if past practise is any indication, guidelines and MoUs will likely lay at the heart of devolution and outsourcing. Thus, our political leaders, on all sides of politics, will be able to politely excuse themselves from addressing the detail of the difficulties faced by those who are living with housing stress, disabilities and other frailties of age. However, just as the Right Hon. Pierre Trudeau³⁶ sought to bring the *British North America Act* (the Canadian Constitution) 'home to Canada'³⁷ it is long overdue to *Patriation* agency guidelines back home to Parliament, as regulations. From here, our citizenship cannot be ignored or 'devolved away' by any Minister or Government.

If parliamentarians still decline to follow the legitimate and (most importantly) justiciable route of approving regulations, then they should leave us free to set up our own *Minder-style* arrangements, liberated from the yoke of the not-for-profit/charitable sector and the bureaucracy's guidelines. Perhaps Aeschylus (quoted at the beginning of this submission) had some more Nostradamus-like insights which he thought better of mentioning?

Secondly, the importance of such a change in approach (that is: bringing guidelines back to Parliament) signifies one vital point: there is one Government in NSW. My own experience is that larger charities in particular, can feel and function more like miniature, self-contained governments; in this I concur with earlier cited comments of Hughes about charities becoming mere 'silos of government',³⁸ but go further to suggest some become Monaco-like, containing many "regal" egocentrics, absent the casinos and Grand Prix.³⁹ Meanwhile, many of the case workers in the same

³⁵ By contrast, Regulations are required to be tabled in Parliament, can be objected to and, referred to a parliamentary committee for inquiry. Guidelines are not subject, even to this limited oversight, but arguably should be similarly scrutinised, given Mr Hulls' earlier cited comments.

³⁶ Prime Minister of Canada; see http://en.wikipedia.org/wiki/Pierre_Trudeau as at 3 April 2012

³⁷ See the discussion of *Patriation* at <http://en.wikipedia.org/wiki/Patriation> as at 3 April 2012

³⁸ Refer to footnote 28, above.

³⁹ Of course, when it suits them, major charities will want to morph into something more akin to the Holy See. They will profess to the public, corporate donors, government and others, their heartfelt concern over the unmet needs of many disadvantaged groups, the selfless work they are doing to address these unmet needs and, how they urgently need more donations. They speak far less about the taxes and charges from which they are excused, or how much of their budget is devoted to organising and running fundraising events; see, for example Richard Noone, *Charities forced to show records on new MySchool like website*, The Daily Telegraph, October 24, 2011 12:00AM, <http://www.dailytelegraph.com.au/news/charities-forced-to-show-records-on-new-myschool-like-website/story-e6freuy9-1226174511400> as at 25 October 2011. And one fortunate aspect of the international financial crisis is that churches (who also often run not-for-profit/charitable organisations) are coming under pressure to pay taxes – see *Church 'must pay tax'*, Sydney Morning Herald, (Italy), December 13, 2011, Read more: <http://www.smh.com.au/world/church-must-pay-tax-20111212-1orcc.html#ixzz1hy0VdxGY> as at 30 December 2011; see also Nick Squires, *Italian Catholic Church under pressure to start paying property tax*, 2:29PM GMT 11 Dec 2011, The Telegraph, <http://www.telegraph.co.uk/news/worldnews/europe/italy/8949226/Italian-Catholic-Church-under-pressure-to-start-paying-property-tax.html> as at 30 December 2011. The Vatican has avoided these responsibilities, largely on its claim to be an independent, sovereign State. But, as Juliette Hughes writes in her review of Geoffrey Robertson's book *The Case of the Pope*, the claim is dubious, if not fallacious and, was entered into with a less than honourable party. She explains:

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charitable organisations will conduct themselves in the lecturing manner observed by Aeschylus, but have neither the wit nor wisdom to ever perceive the chaos and pain they bring to other people's lives; note my earlier discussed dealings with *Community Care Northern Beaches*. It was this experience after all, which made me design the *Minder-model* of care, as an alternative to the Productivity Commission's NDIA.

Thirdly, the only clear "winners" out of devolution and out-sourcing will be the charities; particularly the large ones, who will have the time, resources and government consultants/lobbyists on staff to position themselves advantageously for any change. These are not the organisations I want to see prosper in the future, because as explained in Appendix 1 they often lack true benevolence or charitable intent, this having been replaced by corporate plans and fundraising targets.⁴⁰ The Government should ask a body like the Independent Pricing and Regulatory Tribunal (IPART) to undertake a study of the charitable sector, investigating its pricing and cost structure, as well as whether either consumers, donors or government are getting value for money (or indeed, customer service) from current providers. As a consequence of my own concerns over the policies of devolution and outsourcing, I have written to the [REDACTED], asking him to consider auditing Government funding of the not-for-profit sector.⁴¹

Recommendation 2: That the Committee note the words of Sir Robert Gordon Menzies, to the effect that measures of social security are not matters of charity. On this basis, the Committee should consider devolution and out-sourcing, as inconsistent with long held positions on public welfare policy.

Recommendation 2(a) That the Committee expresses its concern to the Government over the use of non-justiciable guidelines and MoUs, both within and between government agencies, and between government and not-for-profit/charitable service providers.

Recommendation 2 (b) That the Committee should express further concern that MoUs often leave end users of services as non-contracting parties. Thus, they have few, if any, rights of redress if service delivery is poor.

Recommendation 2(c) That, as a consequence of 2(a) and 2(b), the Committee recommends that:

- i. All guidelines and MoUs be "Patriationed" back to Parliament as Regulations (subordinate legislation) and;**
- ii. Any not-for-profit/charitable organisation that continues to accept grants from the State, be subject to a Recall Petition, whereby their staff and officers could potentially**

(The) Vatican's own claim to statehood at the UN rests on the shady and altogether embarrassing Lateran Treaty.

Popes after Italian unification were simply squatters in Vatican City until Mussolini did a deal with Pius XI in 1929.

*Now that Robertson has demonstrated the problematic situation of the pope as a head of state, the rest of the world may well wonder why any Catholics stay in the church — or at any rate, why they don't start suing the soutanes off the cardinals and take it back. (Juliette Hughes, *The case of the Pope*, Sydney Morning Herald, Entertainment – Books: Reviews, October 9, 2010, <http://www.smh.com.au/entertainment/books/the-case-of-the-pope-20101007-169bj.html#ixzz1rJzuv4yV> as at 7 April 2012)*

⁴⁰ See Appendix 1, pp. 12-14 [Adobe numbering]. In my view, charities work best as small, local, unincorporated bodies (e.g.: a cooperative) dealing with a local concern. See [REDACTED] comments regarding the Cod Hole and Ribbon Reef Operators Association, as one example.

⁴¹ See generally, "Request to Audit the Performance of State services provided via allocations to the Non-Government charitable sector" (Appendix 4)

be required to answer to a sitting of Parliament about their conduct and stewardship of public funds.

Recommendation 3: That the Committee request IPART (or some such similar body like the NSW Audit Office) to undertake research as to the not-for-profit sector's true cost and pricing structure, as well as considering whether it truly provides efficient and effective service to consumers.

"Oh Grandma, what big teeth you have?"

Just like Little Red Riding Hood, when most people hold a view about something, it takes a remarkable amount of contradictory evidence before they will even *consider* changing their mind; much harder still is to *actually change* their mind and their actions. As I acknowledge in Appendix 1, when it comes to charities, most people think of selfless workers doing underpaid (if paid at all) and undervalued work, for the most vulnerable in our community. While I don't deny some truth to this picture, which is often supported by marketing campaigns from charities themselves, the reality is much more nuanced.⁴²

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

⁴² See Appendix 1, pp. 1-2 [Adobe numbering]

⁴³ Go to <http://www.yes-minister.com/ypmseas1a.htm> as at 6 April 2012

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[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

SUBMISSION: THE DEVOLUTION AND OUTSOURCING OF HOUSING, DISABILITY AND HOME CARE SERVICES TO THE NON-GOVERNMENT SECTOR

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

SUBMISSION: THE DEVOLUTION AND OUTSOURCING OF HOUSING, DISABILITY AND HOME CARE SERVICES TO THE NON-GOVERNMENT SECTOR

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

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[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

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[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

The wider public policy questions

In light of all of the above, the principal public policy question should be: Why would the Government even think of devolving or outsourcing services to the not-for-profit sector? Government Ministers and the advisers will no doubt be proceeding on the basis of a misty-eyed

[REDACTED]

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adherence to the 'benign, benevolent charity' mirage. I trust this submission does something to challenge long held assumptions, because (to continue the Oklahoma analogy) the '(charitable) corn is as high as (an) elephant's eye;' however, this should not obscure several 'elephants' per sae. These 'policy elephants' are:

- **We have been here before:** During a prior inquiry into the services delivered or funded by the Department of Ageing, Disability and Homecare (ADAHC),⁶⁰ I observed:

As a client, I have been around Homecare long enough to see the organisation amalgamate offices, devolve them again, declare staff should compile their own rosters, then declare coordinators will prepare service rosters; add to this a plan to have staff only work in fixed geographical areas and, a plan that only staff of a particular grade will work with particular high needs clients.

All of these ideas have their merits and look good on paper (and it may well be the same piece of paper from when the same idea was implemented, and then discontinued, several years previously).⁶¹

In many respects, devolution is nothing new and, neither is Homecare's use of private nursing agencies when it has staff shortages. The concern now though, is the Government's apparent wish to hand over care services in toto to the non-government sector.

Quite apart from questioning whether many in the sector have the resources to cope with such a change, it is worth asking whether this would result in less rather than more choice for service recipients. I can foresee an outcome where large organisations, like the [REDACTED] [REDACTED] would become part of oligopolistic, anti-competitive market, noted for poor service. The Government should explain to the Committee what economic modelling it has undertaken in preparing its plans for devolution and outsourcing, what assumptions underpin any such modelling, and what measures it would take to avoid an oligopolistic outcome.

The Committee would also be well advised to have IPART and the Australian Competition and Commission (ACCC) examine the Government's response, to ensure it withstood market scrutiny. As stated earlier,⁶² my observation is that there does not appear to be much in the charitable sector now which is not heavily subsidised by multiple levels of government. Therefore, whether a devolved and outsourced care system would ever really represent "a market," as this concept is generally understood, is highly debatable. Along with subsidised

⁶⁰ See Social Issues Committee, *Services provided or funded by the Department of Ageing, Disability and Home Care (Inquiry)* <http://www.parliament.nsw.gov.au/Prod/parlment/committee.nsf/0/012F70C073C28F78CA25774D0011708A> as at 10 April 2012.

⁶¹ My submission, p.3 of 5 [Adobe numbering] available from: [http://www.parliament.nsw.gov.au/Prod/parlment/committee.nsf/0/f710d4fd79c7da25ca257796007cc9c4/\\$FILE/Submission%200104.pdf](http://www.parliament.nsw.gov.au/Prod/parlment/committee.nsf/0/f710d4fd79c7da25ca257796007cc9c4/$FILE/Submission%200104.pdf) as at 10 April 2012.

⁶² Refer to footnote 10, above.

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providers, many care “buyers” are pensioners whose fixed income gives them little or no market power.

In short, I believe that any claim that devolution and outsourcing represents ‘choice’ for service users is a shaky proposition at best. And as exemplified by Homecare’s own repeated internal restructuring machinations, the policy rationale may have swung round again in say five years’ time, to centralisation. In many respects government policy is like fashion; wait long enough and “everything’s that’s old will be new again”.

- **Charity may not equate with benevolence or compassion:** With my discussion of Vern Hughes’ noteworthy article critiquing the non-for-profit sector, my submission to the Commonwealth Government’s review of governance in the charitable sector⁶³ and, the retelling of my experience as a former director of the Spastic Centre/Cerebral Palsy Alliance, I trust the Committee (and the Government) will have pause for thought. The Government needs to reflect on just how much of the lives and needs of vulnerable people it is prepared to put in the hands of the not-for-profit sector; further, it needs to specify what rights of redress will be available to service recipients, if they are dissatisfied with the service they receive.
- **The policy’s ‘lack of vision’:** This policy, just like the NDIS,⁶⁴ assumes disability and dependence will remain a permanent part of the human condition. Such a position shows a distinct lack of policy vision, given the continuing advances in stem cell and related regenerative/restorative technologies. As I say in my Pre-Budget Submission to the Commonwealth Treasury, one wants to be cured. In particular, I said:

(The) question will and should be increasingly asked by people with disabilities and their families: why should we settle for care if we can have cure? An initial public investment would be speedily returned as those who were on welfare truly became well. It may well also encourage gifted Australian scientists like ██████████ to return home and continue their work.⁶⁵

This is a future worth fighting for, and it makes devolution, outsourcing and the NDIS look like mundane policy follies by comparison. I know where I want resources to be focused.

Recommendation 4: That the Committee take as an example, the various devolution and centralisation processes conducted by ADAHC over my years. The Committee should question the true value of these reforms when, only a few years after implementation, they are undone. The Committee should consider the likelihood that there will be a similar outcome in relation to current proposals for devolution and outsourcing.

Recommendation 5: That the Committee call on the Government to table all economic modelling behind its devolution and outsourcing proposals (including the assumptions behind the modelling).

Recommendation 5 (a) That the Committee asks the IPART and the ACCC to scrutinise the Government’s modelling and, advise on its robustness.

⁶³ See generally, Appendix 1

⁶⁴ Refer to footnote 32, above.

⁶⁵ Appendix 7, p.3 of 4 [Adobe numbering]

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Recommendation 6: That the Committee ask the Government to explain how it will ensure that outsourced services are not delivered to vulnerable consumers (who have little or no market power) by an oligopolistic marketplace.

Recommendation 7: That the Committee ask the Government to explain what measures it will take to ensure that devolved, outsourced services are delivered by sustainable organisations that can demonstrate their probity, and have robust governance.

Recommendation 8: That the Committee consider the potential opportunity cost of reorganising service delivery (again), as opposed to increasing investment in life changing research and development, such as stem cell therapies.

I trust these remarks will assist the Committee in its deliberations and, am happy to meet with Members if they have further questions.

Yours faithfully,



Adam Johnston⁶⁶

12 April 2012

⁶⁶ All views expressed in this submission are my own and, in no way should they be taken as representing a group or organisations. Any errors and omissions are also mine alone.

STATEMENT IN RESPONSE

16 March 2011

To understand why I am facing allegations of “conspiracy” you need to understand a prior appointment to the Enable NSW Advisory Panel. It is an advisory panel with no Executive powers – the Director General of Health drew up a shortlist for the Minister and I was asked to keep my short listing confidential. I did so until the offer was made, and then made discourses to a number of organisations. CPA stands alone in expressing any concerns. In a prior meeting with two of those present tonight, my acceptance and maintaining of a confidence at Enable’s request were alleged demonstrations of “my loyalties”. It is absurd to describe any role I hold and have declared as being a matter of allegiance. We all hold various personal and professional interests outside this room and I reject the notion that I should have declined to be considered because the President of the CPA needed to be consulted first. No-one else questioned my Enable offer or my handling of it; nor did they suggest that there was any impropriety in my acceptance.

This is the context in which we come to the principal email tonight. In conversations stretching back to the “Corporate Plan” planning day of a year ago, ██████████ sought my advice on disability and hospitalisation. I learned subsequently that Northern Sydney Health was preparing a disability plan and provided ██████████ with the name of the relevant officer, indicating that I stood ready to assist if needed.

My involvement was mentioned at the last Services Committee meeting. I was immediately concerned given the reaction of the President whose comments referred yet again to the separation between directors and

management, to which I responded that where a director has the ability to assist in the progress of an issue, they should do so. About 48 hours later the “Communications with the Board” email was received. The timing appeared very significant, as were the highlighted words from [REDACTED]

Even if we accept (as has been insisted to me) that no action was taken, or will be taken against [REDACTED] and that the CWB email was not directed at that), it has two implications. The first is that all information coming to directors or emanating from them travels exclusively via the President or the CEO. If you are content to rely on that advice alone, in a strict formal structure, then that is your choice. My personal preference is to look to multiple sources of advice, and that has been encouraged and promoted everywhere else I have been.

This organisation is unique from any other I’ve ever been involved with, be it paid, voluntary, large or small. The first point is the emphasis on process, hierarchy and protocol. While other bodies have formal decision making lines, there are informal networks where people can act as sounding boards and managers are encouraged to have “open door policies” whenever possible.

Here, there is an immediate need to advise others (usually the President) of any interaction. I discovered this first when I received a client complaint and alerted management, only to find it was referred to the President. The complainant was not pleased and told me in no uncertain terms. Immediate escalation of matters is not best complaint handling practise anywhere.

I also join organisations to do things, or at the very least to facilitate and support others to develop projects. Yet, I have been reminded more than once that the director's role is "strategy". In my view, this should never prevent our involvement in management problems. People should be free to approach us without needing specific approval for communication. The concerns I expressed to [REDACTED] were primarily meant for him, expressing my genuine concerns over what I believed to be happening, as a result of the discussion of our collaboration. These conclusions were based on my observation of the organisation's strict enforcement of the management/director distinction and insistence that information only come through certain channels

Signed:

A handwritten signature in cursive script that reads "Adam Johnston". The signature is written in black ink and is positioned above a horizontal line.

Adam Johnston

From: Adam Johnston [mailto:adamdj1@optusnet.com.au]
Sent: Wednesday, 17 November 2010 2:58 PM
To: [REDACTED]
Subject: FW: ENAC Appointment Letters & Meeting Papers

Dear [REDACTED]

Please be advised that I have been appointed to the Advisory Committee of Enable NSW (see email below) Please enter this on the Interests Register.

Regards

Adam Johnston
35 Woolrych Crescent
Davidson NSW 2085
Phone: (02) 9402 0539
Fax: (02) 9402 0540
Mobile: 0408 471 089
Email: adamdj1@optusnet.com.au

Libertas inaestimabilis res est - Liberty is a thing beyond all price.
(Corpus Iuris Civilis: Digesta) (Latin-English Phrase)

From: enac [mailto:enac@hss.health.nsw.gov.au]
Sent: Wednesday, 17 November 2010 2:46 PM
To: [REDACTED]
[REDACTED]
adamdj1@optusnet.com.au; [REDACTED]
Subject: ENAC Appointment Letters & Meeting Papers

Dear all,

Please be advised of the following:

- ENAC appointment letters have been signed and mailed to you from the Department of Health. Kindly note that the letters advise applicants to contact Bronwyn to accept offer of membership by 17 November. Since you won't receive the letter until after today, please disregard this and contact [REDACTED] as soon as possible once you have received the letter.

- Meeting papers for the upcoming November 25th meeting will be posted to you today from Enable.

Kind regards,

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Excellence in the delivery of support services to NSW Health

This message is intended for the addressee named and may contain confidential information.

If you are not the intended recipient, please delete it and notify the sender.

Views expressed in this message are those of the individual sender, and are not necessarily

the views of NSW Health or any of its entities.

From: [REDACTED]
Sent: Friday, 25 February 2011 9:16 AM
To: Adam Johnston
Subject: RE: Area Health

Adam,

You have no need to apologise. To my knowledge the emails from [REDACTED] have nothing to do with our conversations and workings on the health issues. In fact I have been letting [REDACTED] that you have been giving me some good advice and contacts to help me work my way through the "Health Maze".

The intent of [REDACTED] email to us and our respective service managers is only a reminder that if our staff would like a presentation by a Board member that we need to run it past him. The reason for this is that we acknowledge that as Board members you already contribute a great deal of your time and expertise to support the organisation. He, quite correctly wants to make sure that if there are requests from the services that they are a valuable use of Board members time.

Alternately I think [REDACTED] email is to provide clarity and encouragement to the Board that they can approach her with any issues.

[REDACTED] very supportive of the executive and our service managers and we all know that we have a Board that is engaged and approachable.

I can reassure you that there was no post Service Committee meeting "fall out" in any way.

Thanks for you your concern

[REDACTED]

P.S. I have sent an email to [REDACTED] seeking the opportunity to meet with her.
Thanks for the introduction

From: Adam Johnston [mailto:adamdj1@optusnet.com.au]
Sent: Thursday, 24 February 2011 10:06 PM
To: [REDACTED]
Subject: RE: Area Health

Dear [REDACTED]

I am most relieved to have heard you, and can only express my sincere apologies and sympathies for what must have occurred after the Services meeting. Given the attached email

from the President, following the Senior Staff email from the CEO, it dismays me that so little faith is apparently placed in senior staff or board members by our respective "leaders" with regard to our ability to manage the director/management relationship with good judgment. Therefore, it is but for me to apologise again for what you must have faced at the management meeting and, my complete failure to anticipate the response.

Your continuation with the health initiative is very much appreciated, particularly for the stoicism this must now require. As stated, I remain ready and willing to assist, should such assistance be needed. And, while working part time is an advantage, be assured that I can manage my diary. As for you, can I urge you to proceed with extreme care. You have already clearly taken a risk, with my encouragement. Yet, I am virtually powerless to support or protect you, but am clearly responsible. Please be careful.

Kind regards
Adam

From: [REDACTED] [mailto:CCampbell@cerebralpalsy.org.au]
Sent: Thursday, 24 February 2011 1:57 PM
To: Adam Johnston
Subject: RE: Area Health

Adam,

To tell the truth I hadn't made contact with [REDACTED] as yet, as I thought That I would wait until after I had completed my 2 week rural tour.

I will be contacting her over the next couple of days to make a time.

Thanks

[REDACTED]

From: Adam Johnston [mailto:adamdj1@optusnet.com.au]
Sent: Wednesday, 23 February 2011 10:20 AM
To: [REDACTED]
Subject: Area Health

Hi [REDACTED]

Given your comments last night re health being a hard nut to crack, were you able to set up a meeting with [REDACTED] Is anything further needed by you, from me? I'll be seeing [REDACTED] (hopefully) and the GM later today (see attached)

I'll await your advice before saying anything to anyone.

Regards

Adam Johnston
35 Woolrych Crescent
Davidson NSW 2085
Phone: (02) 9402 0539
Fax: (02) 9402 0540
Mobile: 0408 471 089
Email: adamdj1@optusnet.com.au

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Before opening or using attachments, you should check them for viruses and defects. I do not accept liability in connection with computer virus, data corruption, delay, interruption, unauthorised access or unauthorised amendment.

From: [redacted] [mailto:[redacted]]
Sent: Tuesday, 1 March 2011 10:53 AM
To: adamdj1@optusnet.com.au; [redacted]
Subject: FW: Room Booking - Thursday 3/3/11

FYI

Cheers

[redacted]

[redacted]
[redacted]
[redacted]
[redacted]
[redacted]
[redacted]

From: [redacted]
Sent: Tuesday, 1 March 2011 10:52 AM
To: [redacted]
Subject: RE: Room Booking - Thursday 3/3/11

Hi there [redacted]

Thanks for this. As the Boardroom will be in use, yes, we will use [redacted] office at 9.30am, if that's okay.

Thanks for the offer of 'anything else', but just some water and glasses would be good. (We are a party of 3 people.) We can always help ourselves to some tea or coffee, should we want it.

Thanks [redacted]

Cheers

[redacted]

[redacted]
[redacted]
[redacted]
[redacted]
[redacted]
[redacted]

From: [REDACTED]
Sent: Tuesday, 1 March 2011 10:43 AM
To: [REDACTED]
Cc: R [REDACTED]
Subject: Room Booking - Thursday 3/3/11

Hi [REDACTED]

I hope you are well.

[REDACTED] mentioned that you would like a room here for a meeting on Thursday morning. We will be holding a Senior Management meeting that morning in the Boardroom and so [REDACTED] office will be free from 9:30am – 2:00pm. You are welcome to take his office.

Please let me know if there is anything else that you will require on the morning.

Cheers,

[REDACTED]

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

From: [REDACTED]
Sent: Tuesday, 1 March 2011 4:04 PM
To: adamdj1@optusnet.com.au
Cc: [REDACTED]
Subject: Meeting - Thursday 3 March - 9.30am - [REDACTED]

Hi Adam

As requested by you earlier today, the main points for discussion on Thursday morning are:

1. E-mail from you to General Manager, Services, [REDACTED]
2. Earlier matters:
 - a. change of name of the organisation
 - b. Enable
3. Board of Directors/Chairman/CEO/Senior Management relationships

I look forward to meeting with you.

Cheers

[REDACTED]

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

From: [REDACTED]
Sent: Monday, 28 February 2011 12:11 PM
To: adamdj1@optusnet.com.au
Cc: [REDACTED]
Subject: FW: Meeting Request

Hi there again Adam

I was wondering whether or not you had received the e-mail below sent to you on Saturday afternoon. Sometimes e-mails "slip through the cracks" so to speak!

I look forward to hearing from you at your earliest convenience.

Cheers

[REDACTED]

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

From: [REDACTED]
Sent: Saturday, 26 February 2011 4:19 PM
To: 'Adam Johnston'
Cc: [REDACTED]
Subject: Meeting Request

Hello Adam

Thanks for your attendance this morning. I know just how precious weekends are and therefore, how very generous everyone was with their time today.

My e-mail is to request that we meet to discuss a number of matters that have come to my attention recently and about which I believe we need to have a conversation. [REDACTED] is likewise aware of this need and will attend the meeting also. I think that one hour should be sufficient for our meeting.

For your convenience, we can meet in the Boardroom at Terrey Hills (as this will be closer for you than any other venue). To that end I proffer the following dates and times in an effort to accord with your commitments and with [REDACTED] and mine.

Monday (next - 28th February) 5.00pm – 6.00pm

OR

Tuesday (1st March) 9.00am – 10.00am
or
9.30am – 10.30am
or
3.00pm – 4.00pm

OR

Wednesday (2nd March) 1.00pm – 2.00pm

OR

Thursday (3rd March) 9.30am – 10.30am
or
10.00am – 11.00am

OR

Friday (4th March) 9.30am – 10.30am
or
4.00pm – 5.00pm

Perhaps you could let me know which of these dates and times suits you best.

I look forward to hearing from you.

Cheers

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

From: [REDACTED]

Sent: Wednesday, 23 February 2011 4:17 PM

To: adamdj1@optusnet.com.au; [REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Subject: FW: Communication with the Board

Dear Colleagues

Please see [REDACTED] e-mail below to his Senior Staff in respect of Board communication and involvement with matters/events etc. within our organisation.

It is important that [REDACTED] is across these matters but more importantly, that it is [REDACTED] as the CEO (and therefore the conduit from the Board to the staff and vice versa) who should be given charge of invitations, requests and communications. I know you will agree that this is simple, good management and appropriate protocol.

In the same way, it is important that whenever directors are issued invitations or requests or asked to take on speaking roles in their capacity as a director of Cerebral Palsy Alliance, both inside and outside the organisation, that as Chairman, I am aware of it or have it run it past me in the first instance. This too is just good practice.

This is all about one of our guiding principles about having the right people in the right places at the right times and respecting the roles and responsibilities of CEO, Chairman, Director and Senior Staff and how those roles intersect and interrelate.

Thanks for your understanding and assistance in this matter.

Cheers

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

From: [REDACTED]
Sent: Wednesday, 23 February 2011 3:19 PM
To: _Senior Staff
Cc: [REDACTED]
Subject: Communication with the Board

Hi Everyone

At the Senior Staff Meeting today we heard about the growing number of wonderful activities and events happening all around the organisation. Many of these activities involve staff, clients and Board members.

To avoid the potential for confusion and overload, could I ask that **any communications or requests for involvement** with the members of our Board come to me in the first instance.

We are fortunate indeed that our Board members are so engaged and energetic; I am ever conscious that they are also volunteers and make enormous personal contributions of their time and expertise. I therefore feel the need to keep a handle on the demands that we collectively make on their generosity.

Thanks for your assistance with this.

Regards

[REDACTED]

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]



Yours sincerely,

We look forward to hearing from you with final approval for this project. Please contact me if there are any additional queries regarding this project.

Telephone script
• We have amended the telephone script as per Research Committee instructions. Please find attached the amended script for your review.

Assent form for children
• The contact details for Australian researchers has been amended and footnote added as per Ethics Committee recommendations. Please see amended form for your review.

Permission to take part in research study version #4
• We have attached the amended Permission to Take Part in Research Study form. All changes specified by the Research and Ethics Committee have been made, including details relevant for Australian participants, contact details of Australian researchers and ethics committee, and relevant footers.

• Please find attached copies of the tools mentioned in the application.





Mr Adam Johnston
35 Woolrych Crescent
DAVIDSON NSW 2085

adamdj1@optusnet.com.au

Dear Mr Johnston

Thank you for your correspondence of 3 February 2020 directed to the Treasurer concerning the favourable tax treatment of churches and charities. The Treasurer has asked me to respond to you.

Charities operate on a not-for-profit basis and provide a valuable public benefit to the Australian community, helping vulnerable and disadvantaged people in our society. The government provides tax concessions, such as deductible gift recipient status, to charities in order to encourage philanthropy and donations to these organisations. Charities also benefit from other tax exemptions to allow them to allocate more funding to their charitable purpose.

These tax concessions are provided to charities with a range of charitable purposes, including advancing religion. The advancement of religion has been accepted as a charitable purpose throughout the history of charity law. As such, religious organisations have access to the tax concessions provided to charities.

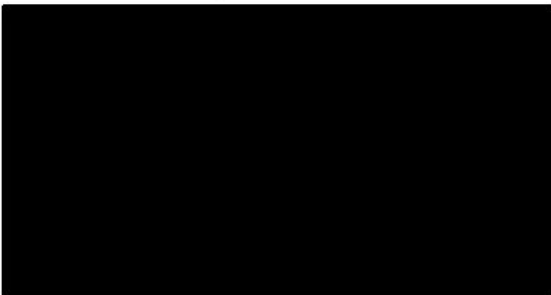
Comparable international jurisdictions, including the United Kingdom, Canada, the United States and New Zealand provide similar tax concessions to charities, including religious organisations.

Access to tax concessions generally requires an entity to have Australian Business Number registration, registration by the Australian Charities and Not-for-profits Commission (ACNC) and, in most circumstances, Australian Taxation Office (ATO) endorsement. Ongoing registration and endorsement are subject to a number of requirements and conditions to ensure tax concessions are only available to genuine Australian charities and other Australian community organisations.

The government remains committed to appropriate regulation of the charity sector, ensuring charity funds are utilised as intended.

Once again, thank you for taking the time to write.

Yours sincerely





[REDACTED]

Attorney-General
Minister for Industrial Relations
Leader of the House

[REDACTED]

[REDACTED]

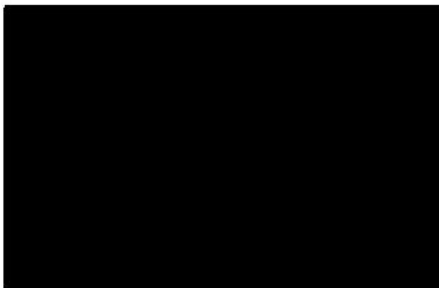
Dear [REDACTED]

Thank you for your letter of 24 December 2019, on behalf of Mr Adam Johnston of Davidson, regarding the second exposure draft of the Religious Discrimination Bill.

I confirm that my department received Mr Johnston's submission to the second exposure draft consultation process on 11 December 2019. I will be considering all substantive submissions when preparing the Bill for introduction to Parliament.

I appreciate that Mr Johnston has some concerns about the operation of the Religious Discrimination Bill. The first consultation process on the religious freedom legislative package demonstrated that while the Australian community is generally supportive of the proposition that discrimination based on a person's religion is not acceptable and should be prohibited, there is a wide range of views on the legislation. This is to be expected with any topical issue before the Parliament. This diversity of opinion informed the Government's decision to undertake a second round of consultations. As the Prime Minister, the Hon Scott Morrison MP, stated when we released the second exposure drafts in December 2019, it is important that the Government takes its time to get this legislation right.

I note Mr Johnston has raised concerns that extend beyond the remit of my portfolio and the Religious Discrimination Bill. Matters such as registration of charities and decisions about eligibility for charity tax concessions would be issues for the Treasury portfolio. As such, Mr Johnston may wish to contact the responsible Minister, the Treasurer, at the following address:



Thank you for bringing Mr Johnston's concerns to my attention. I trust this information is of assistance.

Yours sincerely

A large black rectangular redaction box covers the signature and the beginning of the next line of text.



Our ref: MIN17/1307

Mr Adam Johnston
Via email: adamdj1@optusnet.com.au

Dear Mr Johnston

I refer to your correspondence to the [REDACTED] Minister for Innovation and Better Regulation, regarding your request for a Commission of Inquiry into all charities in NSW. The Minister has asked me to respond to you.

At this time, there is a lack of evidence necessary to support a wide-ranging and costly Commission of Inquiry.

There are approximately 5,600 charities in NSW. Their operations are regulated through the *Charitable Fundraising Act 1991* (the Act). In addition to this, some charities may also be regulated by the Australian Charities and Not-for-profit Commission (ACNC).

NSW Fair Trading carries out inspections and compliance operations based on complaint data and marketplace intelligence. Despite the size of the charitable fundraising industry, Fair Trading receives relatively few complaints concerning financial mismanagement by charities.

Section 24 of the Act requires that a charity must have its accounts audited annually by a person qualified to audit accounts for the purpose of the *Corporations Act 2001*. This requirement has been modified by clause 12 of the Charitable Fundraising Regulation 2015, which provides an exemption for charities that do not receive more than \$250,000 per year. However, the Minister may direct a charity to have its accounts audited in accordance with Section 24.

Charitable tax concessions are applied by the Australian Taxation Office to charities which are regulated by the ACNC under Commonwealth legislation. The NSW Government does not have jurisdiction or control over a charity's charitable tax concession status.

If you have evidence of financial mismanagement by a specific charity, please contact [REDACTED] or at [REDACTED]

Yours sincerely

[REDACTED]

Adam Johnston

From: Adam Johnston <adamdj1@optusnet.com.au>
Sent: Friday, 18 April 2014 8:30 PM
To: 'contact@childabuseroyalcommission.gov.au'
Cc: 'register.interest@childabuseroyalcommission.gov.au'
Subject: Submission - The Care of People with Disabilities
Attachments: Papers.zip; Responses.zip

[REDACTED]

Dear [REDACTED]

I am writing to you, not as someone who claims to have been abused, but rather as a person confined to a wheelchair by cerebral palsy. One has sat on the Board of a major charity (the Cerebral Palsy Alliance - CPA) and has previously worked for the NSW Ombudsman in the areas of Child Protection and Community Services. I further note that future issues papers you will release include:

- Reportable conduct schemes for employees
- Obligations to report to police and to child welfare authorities allegations of child sexual abuse
- Aspects of civil claims procedures relevant to the victims of child sexual abuse
- Compensation and redress schemes

[REDACTED]

Treasury Consultation – Definition of a Charity

<http://www.treasury.gov.au/~media/Treasury/Consultations%20and%20Reviews/Consultations/2013/A%20statutory%20definition%20of%20charity/Submissions/PDF/Johnston%20Adam.ashx>

Treasury – Review of Not-for-Profit Governance Arrangements

<http://www.treasury.gov.au/~media/Treasury/Consultations%20and%20Reviews/Consultations/2011/Review%20of%20not-for-profit%20governance%20arrangements/Submissions/PDF/Johnston%20Adam.ashx>

ALRC - Review of Equal Recognition Before the Law and Legal Capacity for People With Disability

http://www.alrc.gov.au/sites/default/files/subs/12. a_johnston.pdf

In my own experience working for the NSW Ombudsman (and also being a current lay member of the NSW Nursing and Midwifery Disciplinary Panels) one quickly learns that there is a relationship between small transgressions and later potential bigger ones. Given the evidence your Commission has already heard concerning evidence about the

YMCA, the Salvation Army, the churches and some government agencies, it troubles me greatly that State and Federal Governments are so intent on outsourcing services for children, the elderly and disabled to many of the very same NGO sector organisations appearing before your Commission. I have raised these issues [REDACTED] with the ICAC, State and Federal Parliamentary Committees, as well as regulators including the Charities Commission, ASIC and the ATO. The ATO never replied, ASIC chose not to investigate, matters relating to the CPA pre-dated the Charities Commissions legislation, ICAC acknowledged my submission and produced a position paper (http://www.icac.nsw.gov.au/component/docman/doc_download/4044-funding-ngo-delivery-of-human-services-in-nsw-a-period-of-transition), while the NSW Legislative Assembly Community Services Committee declined to publish my submission. See the ZIP file "Responses," attached.

It would not surprise me, to see another Royal Commission similar to your own in about 10 years' time. It is my fear that such an inquiry will concentrate on the financial, psychological, physical and sexual abuse and neglect of disabled people (both children and adults) in the care of NGOs, as part of the National Disability Insurance Scheme (NDIS). My experience of the rationale of NGO management was that corporate image and organisational survival were principal motivators, while the interests of clients were much further down this list, particularly if they had an adverse impact on the organisation. [REDACTED]

From here, I make two observations. The first is that while the parliaments of Australia can legislate for all the mandatory reporting schemes imaginable, Governments need to fund them (and/or have service delivery bodies put money into an independent, blind trust). This funding needs to come with a level of certainty (i.e.: triennial funding, such as that enjoyed by the ABC), so that forensic and strategic investigations, as well as prompt complaint handling can be undertaken. These are labour intensive activities, yet with each succeeding budget process, efficiency dividends come by retrenching staff, the area with the greatest overheads. To address this, the Ombudsman and like bodies hire a number of staff (including me, on a number of occasions) on temporary contracts. This allowed release and re-hiring with relative ease, while also meeting budget constraints. What this meant though was a loss of corporate knowledge and organisational continuity.

Similar observations can be made about the NGO sector, with a few additional comments. These are that you can have reporting schemes and you can even make them mandatory; organisations and individuals have to want to make them work though. Oversight bodies can never assess or audit everything, as there will never be the resources for that. Even with "Open Disclosure" policies in the public sector and, reforms to civil liability laws in NSW allowing people to apologise without this being admissible, I still sense that such openness goes against the grain in "don't be a dobber" Australia. Organisational reputation will be a powerful disincentive for making admissions (or reports) even in situations where this would be best practise and/or mandatory. Equally, for individual staff, the question of risk is important. While there are risks in not reporting things, there are also risks to career, reputation and income/employment if you are perceived to be "making a fuss". If you also have a mortgage to pay and a family to feed, this will justifiably influence you. Furthermore, children's services, disability and elderly care are not industries known for pay, conditions or social standing. Many of the funding and employment uncertainties which exist in the public sector also exist within NGOs; this is partly due to many NGOs becoming dependent on public grants for much of their recurrent funding. This also means there will be regular staff turnover.

In conclusion, my fear is that with the outsourcing of many social services to the NGOs in contemporary Australia, we are set to repeat the horror stories your Commission is hearing about church institutions of the 20th century. Given the more recent issues experienced by the YMCA and Salvation Army, it appears little has been learnt. And yet, public policy is hurtling towards an NDIS which will be reliant on NGOs and a public purse that cannot afford it. As [REDACTED]

"...Well this is the bottom line: we didn't know what those fifth year numbers were in Opposition and of course in relation to the National Disability Insurance Scheme, there's been a report out recently – an independent report – which likened the National Disability Insurance Scheme to a plane that had taken off and is still being built in the air which indicates that potentially, if we don't get on top of the proper management of the National Disability Insurance Scheme, not only would it not be sustainable, but it could end up as big a farce as the pink batts programme or the \$900 test programme..." (<http://jbh.ministers.treasury.gov.au/transcript/019-2014/>)

I agree with ██████████ – his words underline and emphasise my fears. As someone with a disability who has the ability to communicate in his own right (rather than being subject to an NGO advocate) my obligation is to speak not only for myself, but for those who cannot and/or those who feel critiquing the NGO sector in a true light themselves will lead to retribution. I urge the Commission to question the fitness of many churches, charities and NGOs to deliver services to anyone in need, now or in the future. This will save many from unnecessary neglect, suffering and abuse under the NDIS.

Should you require anything further, please contact me.

Yours faithfully,



Adam Johnston

35 Woolbrych Crescent

Davidson NSW 2085

Phone: 9402-0539

Mobile: 0408 471 089

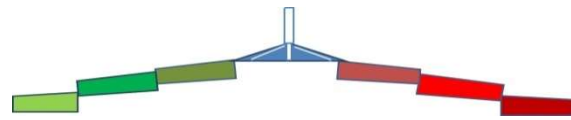
Email: adamdj1@optusnet.com.au

You can see my paper on the Social Science Research Network (SSRN) at:

<http://ssrn.com/abstract=1855924>

Libertas inaeestimabilis res est - Liberty is a thing beyond all price. (Corpus Iuris Civilis: Digesta) (Latin-English Phrase)

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ABN: 62 275 253 029

REGISTERED TRADE MARK No: 1592249

ADJ Consultancy Services

To: The Royal Commission into Institutional Responses to Child Sexual Abuse
From: Adam Johnston, Proprietor, ADJ Consultancy Services
Date: 24th June 2016
Re: Submission With Reference to the Public Notice Placed in the Sydney Morning Herald of Friday 17th June 2016 – Public Hearing into Disability Service Providers

Dear Commissioners,

With reference to the scope of this hearing, this submission addresses reference points 7, 8, and 9. In doing so, I make three clear declarations; firstly, as someone confined to wheelchair by cerebral palsy, one has been deemed eligible for the National Disability Insurance Scheme (NDIS); secondly, I am a solicitor with a background as a former Complaints Officer with the NSW Ombudsman. My employment involved assessing reportable conduct notifications received under Part 3A (Child Protection) of the Act, introduced as part of the recommendations stemming from the Wood Royal Commission into Police Corruption in NSW.¹ As such, while what appears below has been influenced by this experience, my submission represents my views and conclusions alone. Thirdly, I am a former Board Director of the Cerebral Palsy Alliance (CPA - formerly known as the Spastic Centre of NSW). My 19 month tenure as a Director fundamentally changed my opinion of disability service providers.²

Reference Point 7

My prior email to the Commission raises a number of points in relation to current systems. The issue which should be underlined here is one of pragmatic reality. All manner of reporting regimes can be introduced and even still (presuming adequate funding) people have to be prepared to use them. Making something mandatory is only one element; many factors will effect whether agency staff or clients will report abuse of any type, even if they are subject to it.

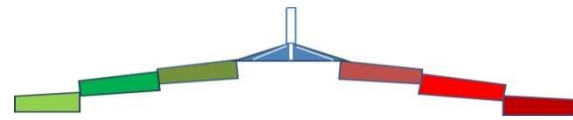
Fear of embarrassment, fear of losing their job, fear of being wrong, fear of not being believed; indeed a long list of things beginning with fear could be itemised. In my experience, fear of *not fulfilling* a statutory or regulatory requirement would be lucky to make it to the Top 10 of most people's lists. This is not to imply any intentional disregard of law, but rather to emphasise far more immediate concerns, like impact on family and community, as well as loss of identity and standing in a local community and/or within an institution which has been the focus of someone's life or career.

¹ My employment was extended when I secured a contract with the Community Services Division, a division established when the NSW Community Services Commission was amalgamated with the NSW Ombudsman

² The Commission would be aware of this in part, given that I sent you an email entitled *Submission - The Care of People with Disabilities* (Sent: Friday, 18 April 2014 8:30 PM – To:

contact@childabuseroyalcommission.gov.au – Cc: register.interest@childabuseroyalcommission.gov.au with attachments). The attachments comprised a submission I made to the NSW Legislative Assembly's Committee on Community Services - Report 2/55 – November 2013 - Outsourcing Community Service Delivery.

[REDACTED]



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While not claiming any formal knowledge of psychology or the like, my observation of human nature on the phones of the NSW Ombudsman were that many people found themselves in a vexed position about making allegations and/or reports of abuse, be they sexual or other forms of abuse. Some people would ring saying they thought the Ombudsman should know something, “but don’t put my name to it”. I would explain that it made further inquiry or investigation by the Ombudsman difficult, by us not having contact details, but some people would insist, so I would take an anonymous complaint.

Equally, assurances that Ombudsman Act provided protection against reprisal for those raising bona fide concerns with the office³ rarely changed a caller’s demeanour. In their defence, only callers could assess the pressures they were under and, the personal, professional and legal risks they were prepared to take in response. While the Act imposed specific duties on the management and staff of agencies responsible for the care of children, as an Ombudsman officer, I never knew all the motives behind a caller, anonymous or otherwise. Judgement was not mine to impose; rather one advised and assisted the public in their dealings with the Ombudsman and relevant child welfare agencies, while recording, analysing and reporting information to my superiors in line with office procedure.

While only being able to speak of my experience in NSW, we do have reporting and investigative regimes which provide protection. This of course, comes with the caveat that those with reporting obligations meet them, while also making complaint processes readily accessible, so that staff, families, carers and youngsters themselves not only feel confident enough to use them, but are advised that such processes are available and will be responsive.

Reference Point 8

Given the above, I am confident that large State Government agencies such as the NSW Department of Education have robust reporting regimes; admittedly this comes from interactions as a former Ombudsman official.

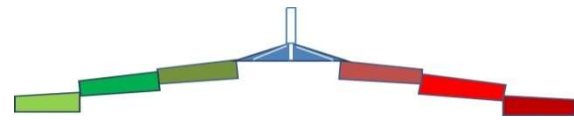
However, my submission to the Commonwealth Department of Human Services on the NDIS Safety and Quality Framework draws together many concerns I have about the provision of care services by non-government organisations (NGOs).⁴ These concerns come from a range of personal experiences; the first was facing increasingly poor service as the recipient of allegedly specialist disability employment services from NGOs whose contracts of service I could not enforce, as they were merely memoranda of understanding between the State and charitable entities. This leaves a person with disability like me, governed by a document which is not legally binding and, to which I as the end user/recipient am not a party.⁵ If you want to create a culture which provides space for

³ See *Ombudsman Act 1974 (NSW)*, s. 37 (4) – (7)

http://www.austlii.edu.au/au/legis/nsw/consol_act/oa1974114/s37.html as at 19 June 2016

⁴ See generally, my submission regarding the NDIS Quality Framework at <https://engage.dss.gov.au/wp-content/uploads/2015/05/Submission1.docx> as at 19 June 2016

⁵ See generally, my submission to the Senate Education, Employment and Workplace Relations Committees inquiry into *The administration and purchasing of Disability Employment Services in Australia* at <http://www.aph.gov.au/DocumentStore.ashx?id=a6fa4e6a-eb31-49de-bb0f-c9f11849c86c> (2011) and my submission to the most recent Standing Committees on Education and Employment *Social Security Legislation Amendment (Strengthening the Job Seeker Compliance Framework) Bill 2014*



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abuse and neglect of any sort, then take a vulnerable person and, make them the object of a contract over whose terms and performance they have no control.

In response, it seems reasonable to treat NGOs as organs of State, subjecting their books to examination by the State or Commonwealth Auditor (depending on the jurisdiction advancing funds), as well as making NGOs who receive public funds directly accountable to Parliamentary Committees and Estimates hearings, as if they were public agencies. The NSW Auditor cannot currently audit the books of NGOs in receipt of public funds. Although having recommended that the *Public Finance and Audit Act 1983 (NSW)* be amended⁶ and the NSW Public Accounts Committee having supported the recommendation,⁷ the State Government has yet to act.⁸

The Commission could well form the view that governments, in general, show a systemic and repeated level of disinterest in the care and wellbeing of citizens with disabilities, verging on officially sanctioned neglect by authorities. The number of repeated scandals has brought me to this conclusion; whether it is a matter of sexual assault,⁹ underpayment of disabled workers,¹⁰ or even whether the same workers will get the money a court said they were entitled to,¹¹ official acknowledgement of need (much less citizenship¹²) appears begrudging at best. When people with

<http://www.aph.gov.au/DocumentStore.ashx?id=b0e07f8c-3f2b-43f0-b6de-3e7f0ceaf38e&subId=301892> as at 20 June 2016

⁶ See my submission to the NSW Public Accounts Committee inquiry into the *Effectiveness and Efficiency of the Audit Office of NSW* (2013) at

<https://www.parliament.nsw.gov.au/committees/DBAssets/InquirySubmission/Summary/48395/Submission%20No%207.pdf> as at 21 June 2016

⁷ The Committee's Final Report (Report 11/55 – September 2013) is available at

<https://www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/5507/Efficiency%20and%20effectiveness%20of%20the%20Audit%20Office%20o.pdf> as at 21 June 2016. Amending the Finance and Audit Act is cited as Recommendation 5 on pages vi (Chair's Foreword) and viii (List of recommendations). The amendment itself is discussed in Chapter 5, from pages 35-43

⁸ The Baird Government is yet to enact the Recommendation, so I continue to campaign it wherever possible; such as during public consultations for a Disability Inclusion Bill, which received this submission from me:

http://www.adhc.nsw.gov.au/_data/assets/pdf_file/0010/296254/Adam_Johnston.pdf as at 21 June 2016

⁹ See e.g.: *Federal govt won't probe disability abuse*, 25 Nov 2014 - 6:22pm, SBS

<http://www.sbs.com.au/news/article/2014/11/25/federal-govt-wont-probe-disability-abuse> as at 21 June 2016

¹⁰ See e.g.: *Disabled workers underpaid while working in government enterprises may be eligible for one-off payment*, *The World Today*, By Samantha Donovan, Updated 15 Jan 2014, 5:41pm, ABC News Online

<http://www.abc.net.au/news/2014-01-15/disabled-workers-may-be-compensated-for-underpayment/5201638> as at 21 June 2016

¹¹ See e.g.: Dan Harrison, *We'll give you half: Senate's deal for underpaid intellectually disabled workers*, Sydney Morning Herald, 15 June 2015, <http://www.smh.com.au/federal-politics/political-news/well-give-you-half-senates-deal-for-underpaid-intellectually-disabled-workers-20150615-ghoa2f.html#ixzz4CBX06Rca> as at 21 June 2016

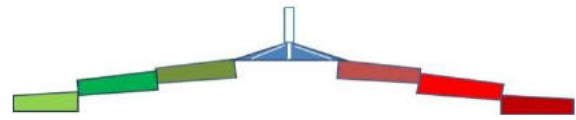
¹² See my submission to the Australian Law Reform Commission's inquiry, *Review of Equal Recognition Before the Law and Legal Capacity for People With Disability*, available at

https://www.alrc.gov.au/sites/default/files/subs/12_a_johnston.pdf as at 23 June 2016. In particular, note pages 8 and 9. I query whether many people with disabilities cast ballots in elections and, whether policy makers, with their deterministic and paternalistic insistence that those with disability settle for charitable care providers, appreciate the full implications of such a policy. In my opinion, the disturbing revelations of abuse

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This quote underlines the three pillars of inaction, indifference and minimisation in the NGO sector.



I always had my doubts about how freely any such decisions could have been made, by clients or their families alike. These people are absolutely reliant on service providers, which mean most people will fear retribution if they complain and “rock the boat”. Such doubts have been underlined, yet again, by recent media reports of unexplained injuries and even a death, in disability group homes.¹⁷

Yet, despite Ombudsman reports and a Senate Report, referred to in the ABC broadcast, little has changed. Given that Australia is going to an election and the Government is in “Caretaker mode” I doubt there will ever be a response to the Senate Report; the new Parliament will have enough of its own business to attend to and, one Parliament cannot bind its successors. In any event, even if there is a response, trying to commit a Government to positive action can be extraordinarily difficult; my attempt to empower the NSW Auditor to examine the accounts of NGOs being a case in point.

Ultimately, I do not believe people with disabilities will ever receive care or protection in the NGO sector. Furthermore, the continued extension of grants and tax free status to churches and charities only perpetuates a service delivery model of dependence, abuse and neglect. Without these dispensations, government would be forced to step in and directly deliver what are truly (and should always have been seen as) public obligations owed to full citizens and subjects of the Crown.¹⁸ This is an argument I have made to the House of Representatives Committee on Economics during its recent inquiry into tax deductibility, as I sought to abolish deductions and exemptions.¹⁹

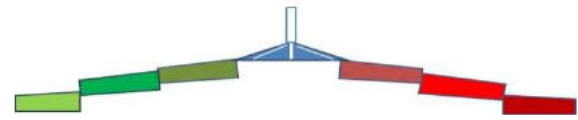
If we must maintain an NGO presence in the care of people with disabilities, then it has to be under a completely different regime. The organisations must be subject to far more public scrutiny, financial and otherwise. I have previously considered how this might be done, as part of an inquiry

¹⁶ Ibid

¹⁷ See Cuts, bruises, death: ABC TV 7:30 with Leigh Sales: *Stories from group homes*, by the National Reporting Team's [Alison Branley](#) and [Norman Hermant](#), Updated Wed 22 Jun 2016, 11:30pm, <http://www.abc.net.au/news/2016-06-22/cuts-bruises-death-stories-from-group-homes/7520456>; also see *Families raise concerns about 'culture of cover-ups' in disability group homes*, [7.30](#), by the National Reporting Team's [Alison Branley](#) and [Norman Hermant](#), Wed 22 Jun 2016, 3:14pm, as at 23 June 2016

¹⁸ I am preparing to study this issue for a PhD Thesis

¹⁹ See my submission to the House of Representatives Committee on Economics at <http://www.aph.gov.au/DocumentStore.ashx?id=00874c93-07f4-4b37-9403-c50fef481832&subId=407687> as at 23 June 2016. Regrettably, the calling of the Federal Election has caused this inquiry to lapse; see http://www.aph.gov.au/Parliamentary_Business/Committees/House/Economics/Tax_deductibility as at 24 June 2016



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into Recall Elections in NSW.²⁰ However, this proposal did not get far, so I bring it to you, for your consideration. Something needs to be done to bring NGOs and their operations out of the shadows and into public view; it is these long shadows which allow abuse and neglect to prosper.

Reference Point 9

I am desperate for policies which go beyond care and, blithely accept that disability and impairment will be part of the human condition for time immemorial. In a generation, cellular and genetic science should have put an end to most (if not all) chronic illnesses and disabilities. This is the world I want to prepare for, even if it does not arrive in time for me. But, we must fund medical science, as argued in my 2015 Pre-Budget submission.²¹ Furthermore, there are increasingly alternatives to hiring human carers to care for disabled people. Within the Pre-Budget bundle is an Appendix 3. This is a submission to the *McClure Review of Welfare* and discusses in part, the possibility of using increasingly sophisticated robotics in care. Alongside it is a fourth appendix outlining my attempts to acquire a robotic walking suit or exo-skeleton and bring it to Australia; while this was unsuccessful, compare it to the treatment that my mother received from an officer of [REDACTED].

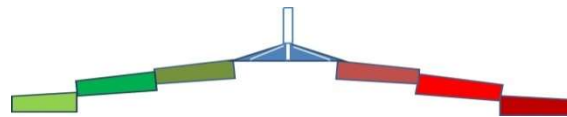
[REDACTED] This is why I also attach an unabridged copy of my first submission to the Productivity Commission's *Disability Care Inquiry*. This made clear my opposition to the proposal for an NDIS, based on these personal experiences, which while not meeting the definition of sexual abuse, was highly abusive to my mother and I. When people get away with that sort of behaviour, this gives implicit licence for behaviours to escalate. Further, unlike me and my mother, many people with disabilities and their families will be unable or unwilling to fight and complain. They will fear retribution and a loss of all services, no matter how bad these support services are currently. The service providers, rarely censured for their conduct, will likely be emboldened and more vulnerable people will suffer even greater abuses and injustices.

Is this living? Is this the life any rational person wants to lead? Of course not! With the template of horrors your Commission has revealed, I can only look into the future and see the past as the best predictor of what is to come. This gives urgency to my calls to fund medical science and, to stop public funding of NGOs. The governments of Australia must step in and directly fulfil their public responsibilities to citizens – regardless of whether we have disabilities or not. We should never be “farmed out” or sold-off like cattle or slaves to third parties. And, as explained in Appendix 5 of the Budget bundle, outsourcing services to NGOs feels very much like a form of indentured servitude to

²⁰ See my submission to the *Panel of Constitutional Experts – Recall Elections in NSW* at http://www.dpc.nsw.gov.au/_data/assets/pdf_file/0008/131120/06_Johnston.pdf as at 24 June 2016. The submission called for recall provisions to be extended to all arms of government, including all NGOs funded by the State. Regrettably, the Panel (see pages 150-154) were divided as to the usefulness of Recall polls and possible negative impacts on the current system of government. Ultimately, while a limited petition pertaining to the Legislative Assembly was suggested, though with only 21 submission received, I am not surprised that little action has been taken; see

http://www.dpc.nsw.gov.au/_data/assets/pdf_file/0013/134221/Panel_of_Constitutional_Experts_-_Review_into_Recall_Elections.pdf as at 24 June 2016

²¹ See generally, the compressed file “Pre-Budget 2015 submission,” (ZIP file) attached



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me.²² To receive any disability support services at all however, I must soon pick from a grab bag of NGOs, most of whom I've seen before, as has your Commission for that matter. No-one has ever asked me whether I want this, nor why it is the stuff of nightmares.

All I can say is bring on the robotic carers (as they won't abuse us), bring on medical research (as it will cure us) and stop the NGOs (as they will do what they always have done to us). I do not believe there is any "system" that can truly be devised to guarantee the protection of vulnerable, disabled people, so long as they are reliant on other human beings; some of whom will have malicious intent.

Yours faithfully,

Adam Johnston

²² See *ibid*, Appendix 5, pp. 9-13 of 21. This document also outlines my experience as a CPA Board Director. While the Parliamentary Committee declined to publish my submission, I stand by every word, in private or in public

**Supplementary
Submission
No 251a**

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Name: Mr Adam Johnston

Date Received: 7 August 2018

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7 August 2018

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LEGISLATIVE COUNCIL

**PORTFOLIO COMMITTEE NO. 2 – HEALTH AND
COMMUNITY SERVICES**

**Inquiry into the implementation of the National
Disability Insurance Scheme and the provision of
disability services in New South Wales**

Supplementary Submission

Dear [REDACTED]

(j) policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales

I wrote to you previously in a submission dated 21 July 2018.

Since then, I've been confronted with even more even more evidence of the NSW State Government's departure from direct disability service delivery and oversight. This came when I complained to the State and Commonwealth Ombudsman's offices about a provider charging me for a service which I did not receive. As the instance of charging occurred in December last year, I discovered this in an account received by mail February this year, whereupon I raised it with both my plan manager and the service provider.

As July was closing and neither agency has been able to provide a straight answer as to whether the charge will ever be repaid, I sent the question off to both Ombudsman offices; the State Ombudsman given that the provider used to be the Department of Ageing, Disability and Homecare (ADHC – now Australian Unity) and the Commonwealth Ombudsman because plan management is now part of the ballooning 'third sector' bureaucracy created by the *National Disability Insurance Act 2013 (Cth)*, all of which continues to be uncritically subsidized by State and Commonwealth alike.

Both Ombudsman offices referred me off to the newly established NDIS Safety and Quality Commission.¹ While agreeing to the referral, I described the change as ‘regrettable’; both because yet another Commonwealth bureaucracy is created, while resolution of complaints and problems with NDIS providers is that much further away from end users (participants) as a result.

Advantages of State-based management

There were always good reasons at on policy, practical and pragmatic grounds to keep service delivery functions at a State or local level. Under ADHC I knew who was responsible in my locality for service delivery. It was also relatively easy to escalate matters. Some years ago, when my wheelchair broke in pieces (due to age), we moved quickly to replace it that weekend, knowing I would be bedridden otherwise.

When the then NSW Attendant Care Scheme declined our equipment funding request based on a lack of prior approval for a relatively simple shop floor manual wheelchair, a quick Ministerial email had the Attendant Care office rethinking its guidelines. My local Homecare manager was then asked to submit an approval form. This was all sorted out in a week or two; a timeline unimaginable at the National Disability Insurance Agency (NDIA). The earlier cited example of a charge levied for services not delivered in December last year still standing unresolved today optimizes the delay and dysfunction of the NDIS as a Scheme and the NDIA as an entity. You will note that in complaint emails to both Ombudsman offices I say:

As an NDIS participant, I am sick and tired of chasing providers to simply have them do their job. Things worked much better under the old system, when budgets were a matter for the Department of Ageing and Homecare.²

I meant these remarks when I wrote them, I mean them now and, I mean the Committee to see them clearly. And they do not relate to one incident; rather there have been a series of stuff-ups, bungles, and delays happening regularly, ever since I entered the NDIS. Quite seriously, if the NSW Government offered to put ADAC back together tomorrow, I would happily transfer.

Great expectations not realized

Defenders of the NDIS would say that it is a new expanded system which gives ‘choice and control’. My prior submission addressed the fiction of choice and control; therefore, the only real question to ask is how many ‘second chances’ should I give an overwhelmed and overstretched ‘new system’? The NDIS has tested my patience and endurance, as well as that of my family, particularly my mother. She remains my principal carer into her 70s and, we see no sign of this ever changing.

For a system that made promises akin to a new era of ‘milk and honey’ the NDIS has in truth been a savage dash to grimly hold on to what you had with ADHC, hoping that a half-witted planner with a social work degree and a grade point average just above absolute zero, does not delete critical supports from your planning document. By writing many letters to MPs, Ombudsman offices and the NDIA itself, I have pretty much managed to hold onto my ADHC-style services.

¹ See Appendix 1.1 and Appendix 1.2

² Ibid

These personal care supports are vital for me and Mum to continue to be able to live together in the family home. But why should it involve so much of what can only be described as “administrative trench warfare?” I have been a Homecare client since 1987, yet with the NDIS everything had to reassessed and, with that, there was the worry of losing resources and ADHC staff (State employees) which both I and my mother relied upon. We also felt more willing to trust them, as they had been background-checked by the State and came with the State’s imprimatur. While no system is perfect, no provider in the NDIA can claim the position of ADHC; even though most ADHC care staff transferred to Australian Unity (the company that took over ADHC).

The Commission

Now we have an NDIS Safety and Quality Commission. But has no-one in the State or Federal Parliaments or bureaucracy seen what this has done? As someone with a disability, a large part of my life and access to goods and services has now been partitioned off to the church and charitable sector, while oversight of same has been equally partitioned off to an NDIS specialist quangos, like the Commission. What an incestuous little club that will likely turn into; to the advantage of everyone except the participants at the end of the line, one suspects!

For a Scheme that claimed it wanted to integrate people with disability into the community, I’ve never felt more disturbed and uncertain in my life, nor worried so much about the future for me and my mother. I’ve also never been further away from services which are truly publicly run (and publicly accountable) with the option to make a complaint to a public Department or Ombudsman that any other NSW resident can access on similar terms. The NSW Government must bear a measure of responsibility for this; you ripped ADHC out from under me and many others. This came after a formal meeting with and plea to then NSW Disabilities Minister the Hon. Andrew Constance MP, not to proceed with the NDIS.³ However, even in 2011, the NDIS ass (you could hardly call it a horse) appeared to ‘have bolted’. It is disturbing and depressing how most of my predictions about the NDIS have come to fruition.

A better way

As I’ve said previously, there must be better ways to truly improve the lives of people with disability, beyond placing them in the care of charity and, leaving them to contend with the effects of their disability for the rest of their natural lives. Indeed, the NDIS Agency itself would seem to have a limited appreciation of the value of technology for enhancing people’s lives and/or technology acting to compensate individuals for the deficits caused by disability. Two examples are prominent: Victorian Legal Aid launched proceedings in the Administrative Appeals Tribunal for NDIS participant Jessica King. Agency assessors initially decided that Jessica’s physiotherapy and gym membership were not reasonably necessary in the management of her cerebral palsy. However, the absence of these services exacerbated her condition, making it more painful and rendering her unable to walk, with or without crutches. The Tribunal found that these services were reasonable and necessary and should have been funded, but as Jessica’s mother Gail told *The Age*:

³ See Briefing for Minister, 18 October 2011, attached

This whole process has set her right back and that's what I'm angriest about..(the Agency) have robbed her of months of treatment. And we're supposed to (be) grateful for this scheme.⁴

But in an even more pointed example of the Agency's inability to understand the value of current technology, much less what might be possible in the future, there is the case of Sydney mother and former academic Kirsten Harley. With advancing motoneuron disease she applied for communication technology to address the time when her disease robbed Dr Harley of speech. The Agency rejected this application. Dr Harley told the ABC that:

My impression of what [the NDIS assessors] was saying is that the disease is likely to progress rapidly and therefore it's not worth spending the money...The whole point of the NDIS is to promote independence and to promote a place in society for people with significant disability.⁵

In response, the Agency cited its high case load, of 100,000 participants last year, claiming many of these people had no support previously.⁶ This demonstrates the real power of NDIA planners over participants and families, even in the allegedly new model of disability service and support system which claims to be centred on participant need and aimed at improving their participation in the community.

Quite clearly, communication technology was essential to Dr Harley. While unaware of the ultimate outcome in the case, an argument could be mounted on the grounds of early intervention. Early intervention is usually considered aggressive treatment of a disability for a young child, to improve their ultimate life outcomes.⁷ While Section 25 of the NDIS Act does mention young children with developmental delay as one of the groups meeting the criteria, this is not the only criteria and nor is it written as a pre-determined to early intervention supports. Indeed, this section gives the Agency CEO (or delegate) a wide discretion aimed at alleviating and mitigating disability, as well as aiming to maintain current abilities.⁸ A Note under the section also gives guidance that people with degenerative conditions may qualify for the NDIS based on early intervention considerations.

⁴ Miki Perkins, Woman with disabilities scores landmark win over NDIS, June 18 2017, <http://www.theage.com.au/victoria/woman-with-disabilities-scores-landmark-win-over-ndis-20170615-gwrz7c> as at 22 June 2017

⁵ Dan Conifer, "Terminally ill mother fears NDIS 'writing off' people with neurological conditions," Updated 15 Apr 2017, 3:11pm, Sat 15 April 2017, 3:11pm, <http://www.abc.net.au/news/2017-04-15/terminally-ill-mother-fears-ndis-writes-off-people/8445228> as at 22 April 2017

⁶ Ibid

⁷ See e.g.: "Support for your child: What is the Early Childhood Early Intervention (ECEI) approach?", <https://www.ndis.gov.au/ecei> as at 6 June 2018

⁸ See NDIS Act, above n 2, s.25(1)(c)(i) with states that a person will meet the early intervention requirements if:

the CEO is satisfied that provision of early intervention supports for the person is likely to benefit the person by:

- (i) mitigating or alleviating the impact of the person's impairment upon the functional capacity of the person to undertake communication, social interaction, learning, mobility, self-care or self-management; or
- (ii) preventing the deterioration of such functional capacity;

There has been some criticism that after the 2017 budget, the Agency began using annual support reviews to significantly cut back services to various NDIS participants. In particular, *The Australian* newspaper reported that:

The early years of the \$22 billion program's rollout saw wild variability in the value and type of support being granted to participants, forcing (Agency) executives to come up with a way to claw back funding that has "an impact on sustainability". In the process, people with disabilities and their families have been shocked by sudden reversals of fortune.⁹

A lack of ambition

Despite the vagaries of government policy and especially consistency in funding, there is arguably a blind spot in many advocates' view of disability. In my opinion, this has a detrimental effect on the application of technology and the potential for so called "blue sky thinking" about technological applications in the future. This blind spot affects advocates and academics in the disability sector in numerous ways. Firstly, many derive their identity and some their income from the belief that people with disabilities should be included in wider society as they are. To invoke the words of the Disability Discrimination Act, wider society is called upon to make "reasonable adjustments"¹⁰ to facilitate this inclusion. While this position is consistent with many contemporary ideas about disability, it leaves completely unconsidered the possibility of changing an individual's experience through the application of technology to that individual's impairments.

There are plenty of examples where such interventions, while currently at the cutting edge of science. With the correct policy settings and fiscal incentives, these could and should become commonplace. Considering the development of medical technology like stem cells,¹¹ exoskeletons¹² and brain implants,¹³ and the opening of centres for genetics and cellular technology,¹⁴ the public expectation of what amounts to reasonable adjustments and thus what is necessary for economic or

⁹ Rick Morton, "Families' NDIS support slashed in crackdown" *The Australian*, 12:00AM May 16, 2017, <https://www.theaustralian.com.au/national-affairs/health/families-ndis-support-slashed-in-crackdown/news-story/67342b4a10cd2c325d2c1a01f0911288> as at 6 June 2018

¹⁰ Disability Discrimination Act 1992 (Cth), No. 135, 1992, s.5-6; s.30-31, <https://www.legislation.gov.au/Details/C2016C00934> as at 4 June 2018

¹¹ See e.g. New Scientist, "The potential to live indefinitely and cure disease could lie with the placenta," *Stem Cell Medicine* 29 May 2018, <http://view.e.newscientist.com/?qs=e746b9940ff39c130ae617dcfc6e8157d8f9a7f1a5457687eb1f263bcdcedc cff844c3e409e294529dfcf62b0751ab0b2eea560efe07170ac67fdd7f8355c19684d65df31ec8db03fbbb5750816 b330a33baed14619fde79> as at 4 June 2018

¹² See e.g.: Eamonn Tiernan, "ReWalk exoskeleton allows paraplegic Paul Jenkins to walk again," *Sydney Morning Herald*, February 13 2017 <http://www.smh.com.au/technology/sci-tech/rewalk-exoskeleton-allows-paraplegic-paul-jenkins-to-walk-again-20170117-gtt5ar.html> as at 4 June 2018

¹³ See e.g. Bridie: Smith, "Human trials for Australian-made bionic spine to start next year," *Sydney Morning Herald*, February 9, 2016, <http://www.smh.com.au/technology/sci-tech/human-trials-for-australianmade-bionic-spine-to-start-next-year-20160202-gmjgdj#ixzz3zik2ip00> as at 4 June 2018

¹⁴ See e.g.: Marcus Strom, "Hope for the paralysed: UTS to establish Centre for Neuroscience and Regenerative Medicine," *Sydney Morning Herald*, September 16 2016, <http://www.smh.com.au/technology/sci-tech/hope-for-the-paralysed-uts-to-establish-centre-for-neuroscience-and-regenerative-medicine-20160915-grgudc.html> as at 4 June 2018

social participation in the community, under section 24 of the NDIS Act,¹⁵ will change. However, as currently understood, the NDIS assumes disability and then assesses the need for equipment and support services based on reasonable necessity. However, it also makes clear under subsection 24(1)(e) that eligibility requires that the disability be presumed to be permanent. And as both Ms. King's and Dr. Harley's suggest, the Agency seems to have a limited view of the innovation and technology which would reduce and, in some cases potentially eliminate, the negative consequences of disability.

Furthermore, as reports continue to emerge about shortfalls in care staff needed to make NDIS supports a reality,¹⁶ the issue of labour force constraints in this area are widely recognised.¹⁷ While the NDIA devotes part of its Annual Report to 'assistive technology'¹⁸ this mainly seems to concern bedroom and bathroom mechanical aides, along with smart phone applications.

While these might be useful and potentially necessary, we are missing a real opportunity to use mechanisation and robotics in care.¹⁹ Such technological investment could relieve many of the heaviest and most complex aspects of care, while giving assurance to carers (those whose role ■■■■■ earlier downplayed) that the ones they love would be less likely to be abused, neglected, or defrauded. Mechanisation could also free some of us who are heavily dependent on our carers from a degree of our dependency; but I note that those who have obtained exoskeletons and similar technologies have had to base themselves overseas to do it.²⁰ Ultimately, from the point of view of

¹⁵ See National Disability Insurance Scheme Act 2013, No. 20, 2013, s.24(d) <https://www.legislation.gov.au/Details/C2016C00934> as at 3 June 3, 2018

¹⁶ See e.g.: Dan Conifer, "NDIS: Report warns workforce understaffed in major cities, raises concerns over readiness," 25 February 2017, 6:57am, <http://www.abc.net.au/news/2017-02-25/ndis-report-warns-major-cities-not-prepared-for-implementation/8303276> as at 26 October 2017.

¹⁷ See e.g.: Marilyn Harrington and Dr Rhonda Jolly, "The crisis in the caring workforce," Briefing Book, Commonwealth Parliamentary Library, https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/Briefing_Book44p/CaringWorkforce as at 26 October 2017

¹⁸ See National Disability Insurance Agency, Towards an ordinary life: NDIS Annual Report 2015-16, Commonwealth of Australia 7., 34-35

¹⁹ See e.g.: Robert Sparrow and Linda Sparrow, "In the hands of machines? The future of aged care." Minds and Machines 16: 141-161, May 2006, http://profiles.arts.monash.edu.au/rob-sparrow/download/InTheHandsOfMachines_ForWeb.pdf; see also, Heather Kelly, "Robots: The future of elder care?" CNN, July 19th, 2013, 03:42 PM ET, <http://whatsnext.blogs.cnn.com/2013/07/19/robots-the-future-of-elder-care/>; Maureen Dowd, "Silicon Valley Sharknado," The Opinion Pages | Op-Ed Columnist, New York Times, July 8, 2014, http://www.nytimes.com/2014/07/09/opinion/maureen-dowd-silicon-valley-sharknado.html?_r=0 as at 19 July 2014. From Ms Dowd's article I note, in particular:

Vinod Khosla, the Sun Microsystems co-founder, has predicted that algorithms and machines will replace 80 percent of doctors in years to come, making medicine more data driven and less like "witchcraft."

²⁰ See for example, the webpage of Australian paraplegic speaker and campaigner Amanda Boxel, now based in the US and Canada, with her walking machine: <http://www.amandaboxtel.com/index.html> as at 20 July 2014; also see e.g.: ScienceAlert Staff, News – "This exoskeleton has been approved for personal use," Tuesday, 01 July 2014, http://www.sciencealert.com.au/news/20140107-25786.html?utm_source=feedburner&utm_medium=email&utm_campaign=Feed%3A+sciencealert-latestn as at 20 July 2014.

government it is the cost-savings that could result from investment in technology that needs to be considered.

Clinging to disability

Until recently, I was not aware of "ableism" as a serious academic and social concept, despite having spent all my life living with cerebral palsy, as well as having spent the greater part of my adult life in some form of tertiary study. However, it clearly does exist and, when people who I would understand as lacking the benefits of hearing campaign actively against the rollout of Cochlear implants,²¹ it does cause one to pause and reflect on the neurology, psychology, and ideology of those who would prefer to be disabled.

Sparrow explains that some people who were deaf saw Cochlear as "the desire of a majority (hearing) culture to impose its language and values on the Deaf."²² This kind of argument shows the contest between the social concept of disability and the medical construction of disability. The latter view looks at an individual's clinical condition and change it, while the former is internationally accepted and seeks to "accommodate people living with impairment (in the community)".²³ While this might be the internationally accepted standard, some advocates arguably take it further.

The ways in which people with disabilities have been shut out physically, structurally, socially, and economically from many aspects of the Australian community has been well-documented in the commentary; thought the article by Paul Ramcharan is revealing in its title that people with disabilities have apparently moved from the classification of 'deserving poor to customer'.²⁴ This author will return to the question of why *citizen* was not used in place of *customer*?

It is also noteworthy that some commentators argue that the social exclusion of people with disabilities can be seen in how they are "shut out" of popular culture, using what are arguably commercial and neoliberal examples. Helen Meekosha cited the 2006 'Where the Bloody Hell Are You?' Australian tourism campaign. This she said did what many campaigns before had done, in that:

²¹ See generally, Robert Sparrow, "Defending Deaf Culture: The Case of Cochlear Implants," *The Journal of Political Philosophy*: Volume 13, Number 2, 2005, pp. 135–152, <http://profiles.arts.monash.edu.au/wp-content/arts-files/robert-sparrow/Deaf-Culture.pdf> as at 6 June 2018

²² Ibid, 135-6.

²³ People with Disability Australia, "The Social Model of Disability," <http://pwd.org.au/student-section/the-social-model-of-disability.html> as at 6 June 2018

²⁴ See generally, Paul Ramcharan,, "Understanding the NDIS: a history of disability welfare from 'deserving poor' to consumers in control," *The Conversation*, July 6, 2016 6.07am AEST, citing National People with Disabilities and Carer Council, "SHUT OUT: The Experience of People with Disabilities and their Families in Australia: National Disability Strategy Consultation Report," © Commonwealth of Australia [2009], <https://www.dss.gov.au/sites/default/files/documents/05_2012/nds_report.pdf>; <<https://theconversation.com/understanding-the-ndis-a-history-of-disability-welfare-from-deserving-poor-to-consumers-in-control-58069>> as 21 January 2017. Specifically, Ramcharan states:

Resettlement back into the community started around the 1970s in Australia. Community care policies aimed to provide support, education, employment, housing and inclusion services. Forty years after community care started, people with disabilities are living longer. Yet in 2009, [a report based on consultation](#) with people with disabilities found there was still little social inclusion, poor quality disability services and high unemployment.

(In) the images of everyday Australia, the Outback, the beaches, the vineyards and the restaurants, among the dozens of people represented, there is no-one with an identifiable disability. What we do see are images of vital, healthy, “able-bodied” European-descent Australians, with an occasional Aboriginal person as an attraction for the visitors. We see then a nation’s marketing representation of how it believes itself to be; its history, geography, social reality and contemporary divisions are nowhere to be seen.²⁵

But addressing the issue of exclusion goes deeper than making people with disability visible to the broader population. The more crucial questions relate to who constructs the problems facing people with disability, what is their rationale and, do those with disabilities perceive the issues the same way? In relation to the NDIS, Cate Thill argues that not only has the professional and medical establishment overwhelmed people with disabilities, but researchers have not always aided understanding by the hypotheses they have constructed. She cites a re-analysis of a 1967 study of intellectually disabled people which found:

(Participants) in (the original) study challenged the label applied to them and analysed their problems as stemming from oppressive social practices rather than their presumed impairments. Instead of listening to these critiques, (the researcher) interprets them as evidence that participants are in denial about their condition. (This) rejects the authority of participants’ voices and their right to be heard since what they have to say is reduced to a manifestation of their supposed impairment rather than taken seriously as a significant critique of disabling social processes. This practice of appropriating the lived experience of disabled people is deeply problematic insofar as it benefits the careers of researchers while the social circumstances of disabled subjects remain unchanged.²⁶

Thill makes a convincing argument that many people with disabilities, their families, carers and advocates were heavily involved with campaigning for an NDIS. The most obvious example of this was the public ‘Every Australian Counts’ campaign.²⁷ However, highlighting the NDIS assessment process, Thill points out that while the participant prepares a statement of goals and aspirations, these are then subjected to medical and economic tests, which she sees as illegitimate²⁸

²⁵ Helen Meekosha, “What the Hell are You? An Intercategorical Analysis of Race, Ethnicity, Gender and Disability in the Australian Body Politic,” *Scandinavian Journal of Disability Research*, Vol. 8, No. 2-3, 2006, 161, <[http://s3.amazonaws.com/academia.edu.documents/7383443/Meekosha%202006.pdf?AWSAccessKeyId=AKIAIWOWYYGZ2Y53UL3A&Expires=1489440202&Signature=eE%2FE3Un1tZPaA%2FkNVIwi98VA2wA%3D&response-content-disposition=inline%3B%20filename%3DWhat the hell are you An intercategorical.pdf](http://s3.amazonaws.com/academia.edu.documents/7383443/Meekosha%202006.pdf?AWSAccessKeyId=AKIAIWOWYYGZ2Y53UL3A&Expires=1489440202&Signature=eE%2FE3Un1tZPaA%2FkNVIwi98VA2wA%3D&response-content-disposition=inline%3B%20filename%3DWhat%20the%20hell%20are%20you%20An%20intercategorical%20analysis%20of%20race%20ethnicity%20gender%20and%20disability%20in%20the%20australian%20body%20politic.pdf)> as at 14 March 2017

²⁶ Cate Thill, “Listening for policy change: How the voices of disabled people shaped Australia’s National Disability Insurance Scheme,” *Disability and Society* on 17 Dec 2014, University of Notre Dame Australia, ResearchOnline@ND, Arts Papers and Journal Articles School of Arts 2014, citing Ashby, C. (2011). Whose “voice” is it anyway?: Giving voice and qualitative research involving individuals that type to communicate. *Disability Studies Quarterly*, 31(4) and Oliver, M. (1992). Changing the Social Relations of Research Production? *Disability, Handicap & Society*, 7(2), 101-114. doi: 10.1080/02674649266780141 <http://researchonline.nd.edu.au/cgi/viewcontent.cgi?article=1111&context=arts_article> accessed 6 November 2016.

²⁷ See *ibid.*, 3.

²⁸ See *ibid.*, 12-13.

The real conundrum

it is fair to say that I am yet to be convinced by the concept of disabling social processes (even as someone with a lifelong physical disability) and, while I welcome modifications to infrastructure that facilitate my inclusion in various activities, the notion that my condition is not a significant medical issue is something I find laughable. While some of the disability advocates, supporters, carers and others have been prosecuting these arguments however, the potential of people with disabilities to use technology to aggressively intervene in their impairments has been diminished.

This is partly because, as the neoliberal approach to public policy has spread from pure economics and fiscal policy, to all areas of service delivery, there has been a fundamental change in how the government views the people and the Australian people view their various governments. Now, market forces, competition and choice theory readily dominate how policy is made.

Going to the market

In the realm of social services generally and disability services specifically, this can be most clearly seen in the policy shift in NSW. This occurred in consort with the introduction of the NDIS. Prior to the NDIS, the State and Territory governments had primary responsibility for the delivery of disability services. This was usually achieved through a Department of State. In the case of NSW, it was through the Department of Ageing, Disability and Homecare (ADHC). ADHC had been in existence in NSW, in a public form, since 1943.²⁹ However, in 2015, the NSW Government announced that it was transferring the disability support components of ADHC to the company, Australia Unity. The \$100 million received in the transaction, the Government announced in a press release, would be “reinvested into the disability sector to help with transition to the NDIS”.³⁰

This press release is important for several reasons. Firstly, it acknowledged that ADHC provided for 70% of disability and aged care support in NSW.³¹ Secondly, it confirmed that the outsourcing of human services was being followed in other jurisdictions.³²

Thirdly, the State government argued the outsourcing service delivery to the charitable, mutual, or private sectors would give ADHC clients and their families more ‘choice and control.’ Just exactly what is this ‘choice and control’ particularly when considered alongside the standards set in the UN *Convention* and notions of the ‘reasonably necessary’ in the context of Australia? Mr. Wallace’s analysis suggests it might not mean that much when, as of 2013:

²⁹ See Department of Family and Community Services, “Ageing, Disability and Home Care, Home Care Service client handbook,” Department of Family and Community Services March 2014, 4 https://www.adhc.nsw.gov.au/_data/assets/file/0010/257590/3075_ADHC_HC_clientHandbook_May2014.pdf as at 21 October 2017

³⁰ Ibid., “Media Release Archive, \$100m to be reinvested in Disability Services after NDIS milestone”, 28 Aug 2015, [https://www.facs.nsw.gov.au/about_us/media_releases/media_release_archive/\\$100m-to-be-reinvested-in-disability-services-after-ndis-milestone](https://www.facs.nsw.gov.au/about_us/media_releases/media_release_archive/$100m-to-be-reinvested-in-disability-services-after-ndis-milestone) as at 21 October 2015

³¹ See *ibid*

³² See e.g.: Leah MacLennan, “Elderly and disability care services being outsourced to SA private sector,” Wed 8 February 2017, 5:19pm, <http://www.abc.net.au/news/2017-02-08/elderly-and-disability-care-services-outsourced/8252820> as at 21 October 2017

(In Australia) 45 per cent of people with a disability live in or near poverty; more than double the OECD average of 22 per cent. We rank 21st out of 29 OECD countries in employment participation rates for those with a disability. We rank 27th out of 27 in terms of the correlation between disability and poverty.³³

As a client of ADHC, who was generally satisfied with the government service, it was not clear to me how a shift to the NGO sector would result in miraculous improvement. However, as I acknowledged, one is living in the age of market forces, The NDIS came into force within a context of 20 years of neoliberal theory being the dominant policy framework since the Hawke/Keating government.³⁴ In this time, governments at State and Commonwealth level have outsourced or sold off numerous public instrumentalities (and their clientele) to the private sector or charitable institutions. The general argument in favour of this reform has been that the private or charitable sectors are more efficient than government, or more focused and aware of client needs. The retraction of the state in the delivery of services is further justified as empowering clients by allowing them to make decisions about service provision. This is seen as actively positively giving people with disabilities choices regarding the provision of services and thereby ensuring their needs are met.

However, do these theories represent what many people want? Before dismissing them altogether, Sheldon Loman and others argue the people with disabilities require support to learn how to make decisions and what consequences flow from them. While their examples concentrate on senior school students, they say:

One instructional model for increasing student-directed learning, that has been empirically validated, is the Self-Determined Learning Model of Instruction ..The SDLMI is a three-phase model for teaching a self-regulated problem-solving process that allows students to set goals, plan a course of action, evaluate their own performance, and make adjustments to plans or goals as needed ...The instructional process consists of teaching students to pose four questions during each phase of the process that require the student to (a) identify the problem, (b) identify potential solutions, (c) identify barriers to solving the problem, and (d) identify consequences of each solution

The SDLMI instructional model has been shown to help secondary students with disabilities to increase appropriate behavior in classroom and jobsite settings and to achieve transition-related outcomes such as: improved job task performance, improved budgeting and

³³ Craig Wallace, "Disability reform in Australia unfinished business" [online]. *Precedent (Sydney, N.S.W.)*, No. 125, Nov/Dec 2014: 41. <http://search.informit.com.au/simsrad.net.ocs.mq.edu.au/documentSummary;dn=857499153442568;res=IELAPA> as at 21 October 2017

³⁴ See e.g. Mark Beeson, and Ann Firth. "Neoliberalism as a political rationality: Australian public policy since the 1980s." [online]. *Journal of Sociology*, Vol. 34, No. 3, Nov 1998: 215-231. <http://search.informit.com.au/simsrad.net.ocs.mq.edu.au/documentSummary;dn=200005021;res=IELAPA> ISSN: 1440-7833 as at 10 December 2017.

personal hygiene skills, and increased success in making independent transportation arrangements.³⁵

This may seem to be unquestionably beneficial for the individuals concerned and the wider community. The Productivity Commission made similar observations in its NDIS Costs Report, while conceding that there was likely a greater role for support agencies, to help those with little experience of managing their own affairs, to do that.³⁶

Despite arguments for self-management, the very same report acknowledged submissions saying that some participants did not want to self-manage 'because it is perceived to be too complicated and burdensome'.³⁷ Furthermore, the Commission had evidence that in the first year of the NDIS, that about 80 per cent of participants let the NDIS Agency or another plan management agency administer their plans.³⁸ This broadly corresponds with international evidence suggesting that in comparable jurisdictions, where self-management is as low as 11 percent.³⁹

Where rates of self-management did rise, these participants were children, whose allocation was actually being managed by their parents. Even then, the rate rose to only to 17 percent, where "active carers...have the time and skills to manage funds for their children."⁴⁰ Otherwise, there were clear reports of a system overwhelmed and a market that was failing.⁴¹ Despite the many formal representations to the contrary,⁴² the States and the Commonwealth have held belligerently to a market forces model.⁴³

Much has gone wrong with the NDIS; indeed, as a participant, one doesn't hesitate to use the word 'failure'. As the writers cited in footnote 42 variously say, great uncertainty has been created, some

³⁵ Sheldon Loman et. al, "Promoting Self-Determination: A Practice Guide, A National Gateway to Self-Determination." Funded by the US Department of Health and Human Services, Administration on Developmental Disabilities, June 2010, 27, http://ngsd.org/sites/default/files/promoting_self-determination_a_practice_guide.pdf as at 18 November 2017

³⁶ See Productivity Commission, "National Disability Insurance Scheme (NDIS) Costs" Productivity Commission Study Report, October 2017, 375, <<http://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs.pdf>>

³⁷ Ibid., 374

³⁸ See *ibid.*, 380

³⁹ See Luke Bo'sher, "Self-management: is a new world of cash payments on the horizon?," Disability Services Consulting, February 12, 2015, <<http://www.disabilityservicesconsulting.com.au/resources/self-management>> as at 20 November 2017

⁴⁰ See *ibid.*

⁴¹ See e.g. Peter Ryan and Sabra Lane, "Report warns NDIS rollout will be delayed and costs will rise," ABC "AM" broadcast <http://www.abc.net.au/radio/programs/am/report-warns-ndis-rollout-will-be-delayed-and-costs-will-rise/9064750>; see also Victorian Legal Aid, "NDIS 'market failure' leading to vulnerable people being unfairly jailed," Thursday, 9 November 2017, <https://www.legalaid.vic.gov.au/about-us/news/ndis-market-failure-leading-to-vulnerable-people-being-unfairly-jailed> as at 1 January 2018

⁴² See e.g. Lois O'Callaghan, "Market Failure in Rural and Remote Areas," Mallee Track Health & Community Service (MTHCS) http://www.pc.gov.au/data/assets/pdf_file/0007/219067/subpp0222-ndis-costs.pdf; see also Simon Viereck, "Submission to (NDIS) Costs Inquiry," Mental Health Community Coalition ACT, https://www.pc.gov.au/data/assets/word_doc/0006/215772/sub0135-ndis-costs.docx as at 1 January 2018

⁴³ See e.g. Marie Sansom, "NDIS opening up new and competitive market," Government News, August 12, 2014, <https://www.governmentnews.com.au/2014/08/ndis-opening-new-competitive-market/> as at 1 January 2018

programs that worked well have been trashed, some people are withdrawing from services because they just can't cope with all the change and, the notion of a viable market is a nonsense in many places, particularly in rural Australia. Given that both Bo'sher and Loman's work make the point about the considerable preparation and training resources that need to be put into self-management, how much of the funds could actively be deployed to research and technological developments instead? This is particularly when, even if you can train someone to self-manage under the NDIS, there are a range of demarcation lines and restrictions over what will be funded as "disability" and what will not. As the King and Harley cases showed the demarcation is not necessarily reasonable, with an Agency not seemingly geared towards innovation and technological enhancements of people's lives. This sometimes extends to the Agency's view of standard personal care activities. In particular, Bo'sher observes:

NDIS funds to spend on work readiness cannot be used to purchase dental work to fix gum and teeth issues even if this would be the most useful assistance to getting a job. Self-management may be intended to provide more empowerment, but it still does not allow participants full autonomy over how to most effectively and efficiently achieve their goals.⁴⁴

Government must return

When considering disability services and the vulnerable people who access them, this author asks whether neoliberal policy theories result in satisfactory outcomes. In arguing that they are unsatisfactory, this thesis makes the case that the government has real and abiding duties that cannot and should not outsource to other parties.⁴⁵ The argument rests partly on the notion of public citizenship and public accountability for the goods and services rendered to those in our society who are most needy.⁴⁶

it is to be recalled that Paul Ramcharan wrote an article which briefly chartered the changes for people with disabilities, from being seen as poor and deserving to an active market customer. While

⁴⁴ Bo'sher, above n 39.

⁴⁵ For a consideration of this issue from the US perspective see generally, Paul R. Verkuil, "*Outsourcing Sovereignty: Why Privatization of Government Functions Threatens Democracy and What We Can Do about it*," 2007, Cambridge University Press, <http://www.langtoninfo.com/web_content/9780521867047_frontmatter.pdf>; see also from an Australian perspective, Richard Mulgan, "*Transparency and the Performance of Outsourced Government Services*" *Occasional Paper No. 5*, This research paper was commissioned by the Queensland Office of the Information Commissioner and prepared for the Australia and New Zealand School of Government March 2015, <<http://apo.org.au/system/files/53659/apo-nid53659-12231.pdf>>; Contra: Dr David Kemp MP, "*Key Speech: Public Administration in the New Democratic State*," Address to the National Conference of the Institute of Public Administration Australia, Canberra, November 1997, <<http://onlinelibrary.wiley.com.simsrad.net.ocs.mq.edu.au/doi/10.1111/j.1467-8500.1998.tb01378.x/epdf>> as 10 December 2017

⁴⁶ See generally, Helen Dickinson, Catherine Needham and Helen Sullivan, "*Special Issue: Individual Funding for Disability Support: What are the Implications for Accountability?*" *Australian Journal of Public Administration*, vol. 73, no. 4, pp. 417–425 doi:10.1111/1467-8500.12106 <<http://onlinelibrary.wiley.com.simsrad.net.ocs.mq.edu.au/doi/10.1111/1467-8500.12106/epdf>>; from an American perspective compare e.g.: Kimberly N. Brown, "*Outsourcing, Data Insourcing, and the Irrelevant Constitution*," *Georgia Law Review* 49, no. 3 (Spring 2015): 607-692, <http://heinonline.org.simsrad.net.ocs.mq.edu.au/HOL/Page?handle=hein.journals/geolr49&div=20&g_sent=1&casa_token=&collection=journals> as at 11 December 2017

this author disputes elements of the Ramcharan argument, his article is nonetheless useful for historical purposes. Historically, those with disabilities were cared for by their families and, their existence and impairment could be a closely guarded secret. As Western society industrialised, many families had to move to the cities for work. Disabled people could not often keep up with the demands of the new industrialised age, so they came to live in homes and institutions run by various benevolent organisations and religious orders.

The 20th century, impacted by two World Wars and The Great Depression would see greater calls on government to provide greater protection to their populations from these extremes of violence and deprivation. This is exemplified by Sir Robert Menzies, founder of the Liberal Party and Australia's longest serving Prime Minister readily articulated the state's duty to the citizen. As noted in my prior submission (but it seems worth reminding you), in his comments on *Freedom from Want*, during his *Forgotten People* broadcasts, Sir Robert said:

*The country has great and imperative obligations to the weak, the sick, the unfortunate. It must give to them all the sustenance and support it can. We look forward to social and unemployment insurances, to improved health services, to a wiser control of our economy to avert if possible all booms and slumps which tend to convert labour into a commodity, to a better distribution of wealth, to a keener sense of social justice and social responsibility. We not only look forward to these things; we shall demand and obtain them. To every good citizen the State owes not only a chance in life but a self-respecting life.*⁴⁷

Reflecting on Sir Robert's words is essential. They speak to a state with purpose and, definite duties to Her Majesty's subjects (citizens) which is sadly lacking today. Meanwhile, counsel against outsourcing the provision of public goods and services to charity also comes from a well-known man, but from a distinctly different political perspective. Oscar Wilde said:

*But (charity) is not a solution: it is an aggravation of the difficulty. The proper aim is to try and reconstruct society on such a basis that poverty will be impossible. And the altruistic virtues have really prevented the carrying out of this aim. Just as the worst slave-owners were those who were kind to their slaves, and so prevented the horror of the system being (realised) by those who suffered from it, and understood by those who contemplated it...Charity degrades and (demoralises)...Charity creates a multitude of sins.*⁴⁸

In my view, Menzies and Wilde viewed together expose a debate that modern policy makers seem incapable of conducting. It is not just a case of can charity deliver goods or services to people, nor one of simple efficacy, but *should* some public services ever leave the state sphere? Both of the men

⁴⁷ Petro Georgiou, "Menzies, Liberalism And Social Justice," *Sir Robert Menzies Lecture Trust, 1999 Lecture*, 3, quoting as at 13 March 2012, quoting Robert Menzies in a 1942 radio broadcast <http://www.menzieslecture.org/1999.html>; the source is: Robert Menzies, *The Forgotten People: Chapter 5 - Freedom from Want*, 10 July 1942, The Menzies Foundation, Menzies Virtual Museum <http://menziesvirtualmuseum.org.au/transcripts/the-forgotten-people/63-chapter-5-freedom-from-want>) as at 7 June 2018

⁴⁸ Oscar Wilde, *"The Soul of Man Under Socialism."* (1891) <http://abetterworldisprobable.wordpress.com/2012/01/01/oscar-wilde-on-the-problems-of-charity/> as at 26 December 2013

quoted above knew what poverty and armed chaos could do to society. While the philosophies differ, they both see an active role for government in providing for a population's needs.

In the modern day, all people deserve public assurance that their needs will be met. Indeed, if the relevant international covenants have any meaning the State signatory must assume direct and clear responsibility. It is also important to take public notice of the facts about the behaviour of various charitable care agencies exposed by the current McClelland Royal Commission into Institutional Responses to Child Abuse and Neglect.⁴⁹ This inquiry has provided a template showing how easily things can go wrong when churches and charities are entrusted with too much power and discretion, as well as being accorded great deference.⁵⁰

Despite these lessons, this thesis will show that many of the same church and charitable organisations which were found wanting before the McClelland Royal Commission have been given responsibility to provide support and services under the disability insurance scheme and questions have already been raised, with Wallace remarking:

Unless we act now, the next Royal Commission and apology will be about abuse and disability. Sadly, there are indications that what we know from the media exposés might only be the tip of a deep, ugly iceberg. We are overdue for a national inquiry into the abuse and neglect of people with disability.⁵¹

It is hard not to agree with Mr. Wallace on this point, particularly when reports emerged from the Royal Commission itself that demand for NDIS staff were so great, service safety and quality standards for participants risked falling.⁵² Such reports, when combined with the growing efforts to have NDIS participants self-manage their care make me concerned that history is quite literally repeating itself. People with disabilities and their families are being asked to resume the burdens they carried in a bygone era, while this request is cleverly couched in the language of the market and so-called 'freedom of choice.' Personally, one cannot avoid feeling somewhat abandoned by my own state and federal government.

A right to try

Given my concern, technology has become a potentially viable way to argue for a substantial reform to the disability sector. This is on the basis that the NDIS is not a substantial or historic reform and, if anything, it is a disturbing retreat into history. Therefore, the disability sector must find a way to

⁴⁹ See e.g.: Rachel Browne, 'Survivors have waited too long': 4000 institutions named in sex abuse royal commission, Sydney Morning Herald, March 27 2017 <<http://www.smh.com.au/national/survivors-have-waited-too-long-4000-institutions-named-in-sex-abuse-royal-commission-20170326-gv716h.html>> as at 26 June 2017

⁵⁰ There is some case law about undue influence which may be useful here, particularly where the organisation providing support and care services is a religious body; see e.g.: Pauline Ridge, "The Equitable Doctrine of Undue Influence Considered in the Context of Spiritual Influence and Religious Faith: Allcard v Skinner Revisited in Australia" [2003] UNSWLawJl 3; (2003) 26(1) *University of New South Wales Law Journal* 66, <<http://www.austlii.edu.au/au/journals/UNSWLawJl/2003/3.html>> as at 26 June 2017

⁵¹ Wallace above n 33, 44

⁵² See e.g.: Samantha Donovan, "NDIS staffing demand may see drop in disability service standards Royal Commission hears," *ABC "PM" broadcast*, Wednesday, July 20, 2016 18:40:00, <<http://www.abc.net.au/pm/content/2016/s4504131.htm>> as at 20 June 2017

overcome its attachment to "ableism". This comes from an extreme example of identity politics, with seeks legitimacy by denying the normal, fully functional human form. Advocates and academics may applaud this, but I would suggest that it receives a far more mixed review in the wider community. All people have a desire, to some degree, to fit in to a wider community and, not merely to be included. This community by its very nature is able-bodied and, people with disabilities should be able to exercise that aspiration (should they so choose) under the early intervention provisions of the NDIS Act.

Failing the ability to intervene on the cellular and genetic level with consistency and assurance at this stage, mechanical implants and like modifications are a potential alternative. With the development of robotic hands for amputees⁵³ and, the increasing ability of this technology to mimic human behaviour, as well as to appear like human tissue, it is time for the NDIS to acknowledge what reasonable support should look like in the 21st century. Similarly, other people currently confined to wheelchairs may find freedom of movement in exoskeletons. These are currently widely used by industry.⁵⁴ There is currently a lack of standards surrounding the specifications of such equipment and, an international committee is currently working on the issue. This should bring benefits to people with disabilities as well as many others, with Maxwell observing:

(The) attendee makeup of the organizational meeting for the new (international standards) committee reflected the fact that medical uses of exoskeletons represent the largest segment of this emerging industry. (More than half of attendees had a primary interest in medical applications.) Ekso Bionics is one of the more active companies in this segment. "(They) have hundreds of devices being used at customer sites, primarily in North America and Europe, on the medical side,"⁵⁵

This is the future and, with the retreat of government from direct service delivery it is my belief that expediting such research is essential for the safety and welfare of people with disabilities. After all, why should anyone trust any of the church and charitable institutions ever again? As far as I am concerned, Archbishop Fisher's rather limp defence of the church and its finances, which appeared in the Sydney Morning Herald⁵⁶ answers nothing. No amount of good deeds can make up for what has been done, not only by the Church, but by many other allegedly benevolent bodies. I've been both a recipient of services and a member of a charitable board; what has sometimes passed for client service is appalling, while the approach to governance can be far less than robust.⁵⁷

⁵³ See e.g.: Outlook Web Bureau, "Italian Woman Becomes First Person to Receive Bionic Hand That Can Feel Sense Of Touch," 4 January 2018, Last Updated at 5:00 pm, International, <https://www.outlookindia.com/website/story/italian-woman-becomes-first-person-to-receive-bionic-hand-that-can-feel-sense-of/306410> as at 7 June 2018

⁵⁴ See generally, Jack Maxwell, "The promise of exoskeletons," *ASTM Standardization News*, November/December 2017, 16-19, www.astm.org/sn as at 7 June 2018

⁵⁵ *Ibid*, 19

⁵⁶ See Anthony Fisher, "Where will relentless campaign leave the most needy?" *Sydney Morning Herald*, February 12 2018 <http://www.smh.com.au/national/where-will-relentless-campaign-leave-the-most-needy-20180212-p4z00n.html> as at 20 February 2018

⁵⁷ See e.g.: Michael Evans, Patrick Begley, *EXCLUSIVE: NSW Government scraps 'follow the dollar' reform despite Sharobeem, Ella cases* *Sydney Morning Herald*, July 24 2017, <http://www.smh.com.au/nsw/nsw-government-scraps-follow-the-dollar-reform-despite-sharobeem-ella-cases-20170723-gxgzqj.html>; see also

As US President Donald Trump said in his first State of the Union Address with reference to terminally ill Americans and their access to non-approved medications:

To speed access to breakthrough cures and affordable generic drugs, last year the FDA approved more new and generic drugs and medical devices than ever before in our history.

We also believe that patients with terminal conditions should have access to experimental treatments that could potentially save their lives.

People who are terminally ill should not have to go from country to country to seek a cure -- I want to give them a chance right here at home. It is time for the Congress to give these wonderful Americans the "right to try."

One of my greatest priorities is to reduce the price of prescription drugs. In many other countries, these drugs cost far less than what we pay in the United States. That is why I have directed my Administration to make fixing the injustice of high drug prices one of our top priorities. Prices will come down.⁵⁸

A right to try would be a truly historic and revolutionary approach in Australia. It would also give people with disabilities a meaningful freedom of choice; they would have the capacity to entertain the concept of living without disability, or at least with its impact greatly mitigated. While the American example is aimed at the terminally ill, it is always possible that this will expand in future. Equally, the Australian government could use similar principles to accelerate research in a variety of fields, including medicine and technology. Over time, this would relieve individuals of impairments, negating the need to be concerned about their safety while in care.⁵⁹

Nonetheless, there are some questions about reasonable expectations that everyone should have out of life, which people in authority are particularly reluctant to answer. While there is some provision for early intervention services for disabled children and, provision for therapy for potential improvements in some conditions, the NDIS framework does not conceive of cure or substantial improvement. These concepts may be very important to some participants in their conception of what it means to have a worthwhile ordinary life and, they may become increasingly important to a growing number of people as science and technology advances.

This is somewhat reflected in the development of the law on wrongful birth cases (at least the dissenting judgments). For example, in *Harriton v Stephens* (2006) 226 CLR 52 the High Court

Patrick Begley, *EXCLUSIVE: Glen Ella kids' charity 'misappropriated \$20 million', says NSW government*, July 22 2017, <http://www.smh.com.au/nsw/glen-ella-kids-charity-misappropriated-20-million-says-nsw-government-20170721-gxfzp3.html>; see also Michael Evans, Farid Farid, *EXCLUSIVE: Revealed: Sharobeem family sent \$500,000 to relative in Egypt after ICAC grilling*, *Sydney Morning Herald*, July 9 2017, <http://www.smh.com.au/nsw/revealed-sharobeem-family-sent-500000-to-relative-in-egypt-after-icac-grilling-20170621-gwve6n.html> as at 19 February 2018

⁵⁸ Donald Trump, "State of the Union 2018: Read the full transcript," *CNN Politics*, Updated 0912 GMT (1712 HKT) January 31, 2018, <https://edition.cnn.com/2018/01/30/politics/2018-state-of-the-union-transcript/index.html> as at 7 June 2018

⁵⁹ See e.g.: Carmel Laragy, "Four Corners: can the NDIS prevent abuse of people with disability?" *4 Corners*, March 29, 2017 11.13am AEDT, <<https://theconversation.com/four-corners-can-the-ndis-prevent-abuse-of-people-with-disability-75286>> as at 20 June 2017

decided that a child did not have a claim of negligence against their doctor, for the practitioner's failure to correctly diagnose the mother's rubella, leaving the child with significant disabilities when born. The majority refused to consider the concept of life with a disability as against nonexistence, while in a partially dissenting judgment Kirby J observed:

(A)warding damages in a case such as this would provide the plaintiff with a degree of practical empowerment. Such damages would enable such a person to lead a more dignified existence. They would provide him or her with a better opportunity to participate in society than he or she might otherwise enjoy where the burden of care and maintenance falls on the disabled person's family, on charity or on social security.⁶⁰

His Honour's words are notable for the use of the phrase 'a degree of practical empowerment' without clearly defining what that is. Is it an ordinary life, or anything that the justices themselves would be prepared to live out as an ordinary life, not to mention any other person? The final sentence is also revealing in its acknowledgement that care will fall on the family, charity, and the State. With the emergence of the NDIS, the third listed party funds the second, while largely expecting the first to make up the difference, as many have always done.

While this case pre-dates the NDIS, Kirby's J's comments show how little disability policy has changed, particularly as family and charity are still critical elements, even with the NDIS. It is easy to speculate that people with disabilities (and their families) may become increasingly discontent with the charitable dependence norm as they witness the advancement of science and technology. Could a reasonable expectation of an ordinary life come to have with it, as a condition precedent, the absence of permanent disability? We should at least have the right to try.

Supplementary Recommendations

1. That the Committee recommend NSW withdraw its support for the newly established NDIS Safety and Quality Commission;
2. That the Committee recognise that the Commission and other elements of the NDIS are further isolating people with disabilities from the wider community, in partitioning much of our lives off, as the specialist concern of NDIS business units;
3. That the Committee acknowledge that individualized, market-based approaches will not work for a significant number of people and, the State Government should always run some disability support and care services directly;
4. That it should not be presumed by governments (or anyone else) that the church or charitable sector is an acceptable provider of care services;
5. That, even if church, charitable or other NGOs are available and deemed acceptable, no-one should be obliged (or compelled due to the lack of an alternative) to use them.
6. That there should always be a State Government disability support and care service provider, like ADHC;
7. That should the Government not support recommendations like those above, it should grant us the disabled accelerated and enhanced access to cutting edge science and medical

⁶⁰ *Harriton v Stephens* [2006] HCA 15 at 122 (Kirby J.).

interventions. This would give us a “right to try” and free ourselves from disability, as well as freedom from the NDIS.

Yours faithfully,

Adam Johnston