



DISCUSSION PAPER - REVIEW OF HUMAN TISSUE LAWS

Discussion Paper 90, November 2025

Dear Sir,

This is a submission written from a purely personal perspective. All of what is said below should be attributed to me alone.

Introduction

There is an important opportunity for reform with this Discussion Paper. However, what I find dreadfully annoying about this, and many other public inquiries, is the timidity. As someone with disability who is now middle-aged, you begin to wonder what medical advances might have come had policymakers been more ambitious. A clear example is paragraph 15.34, where you express various doubts about an opt-out organ donation model. While none of the points made are wrong, the over-reliance on the precautionary principle has one clear drawback. This is that it allows politicians at all levels of government to avoid making difficult policy choices on complex issues. They can rather simply employ the cliqued response: the experts have advised us...! This then excuses limited or negligible reform.

Again, there would have been a time when I was far more cautious. It is a luxury you can afford while health and time are on your side. But as I've observed elsewhere, medical and clinical technology increasingly exists (or is not far off) to cure many diseases.¹ Personally, this idea keeps me going, as does the belief that family carers deserve much better than what they are receiving. My mother (and my late father) devoted their lives to my care and education. It would have been rewarding to think I could have played a small role in delivering parents and children of this as well as succeeding generations, a world where no one had to experience chronic illness and disability; alas this is not what is happening.²

Contested meaning

This means that I increasingly take a differing view of what principles like freedom, dignity, and autonomy should encompass. Autonomy should also consider pathways to prevent and cure disease and disability. Freedom and dignity, at least in part, should be based on the autonomy coming from good health. Good health would mean less reliance on both the formal paid 'care workforce' while giving more relief to those providing family or informal care. Because of my

¹ See e.g. Megan English, Adam Johnston: Dreaming big, Macquarie Matters, Dec. 7th 2020, <https://www.mq.edu.au/macquariematters/adam-johnston-leaving-a-legacy-for-medical-intervention/> as at 22/12/2025

² Points I unapologetically keep pressing for; see e.g. Amanda Sheppeard, Public health and disability pundit pays tribute to his mum, Health Services Daily, 25th January 2025, [Public health and disability pundit pays tribute to his mum | Health Services Daily](#) as at 23/12/2025

continued concerns about my safety (and that of many others) in the care sector,³ my plea is for the ALRC to ask deeper questions about human life and human tissue.

Recommendation 1: That values like autonomy, equity and freedom must include prevention and cure of disease, facilitating freedom from disability and chronic illness, for this and future generations

For example, it is a little too easy for the writers of international declarations to proclaim the equal value of every human being. The other side of that question is: can every one of us realise the potential in our lives to the extent that we wish? With my mild to moderate disability, while one may be confined to a wheelchair, opportunities to lead a full and busy life (supported by my mother)⁴ are never lacking.

However, for those with severe incapacities, who are non-verbal and completely dependent on paid staff for every element of their care and daily living, what is their perception of life? Does the 'equal value proposition' still hold true? I honestly do not know but these questions worry me, every time I see such completely dependent people at various NGO treatment/therapy centres. If it were me, a madness would consume me, over my complete inability to control anything or anyone around me, nor where I was taken, nor what was done to or (allegedly) for me. Where is the rush to reanimate these people, so they enjoy at least some dominion over their own lives, free of such overwhelming dependence on others? It continues to surprise me that an 'equity of experience' requirement is not part of the 'equal value' proposition. It could be that asking such questions begins to expose inclusion, reasonable adjustments, positive discrimination and other elements of the current social model of disability/chronic illness, may not be delivering as much as thought.

Recommendation 2: That policy prioritize prevention and cure so that the equal value proposition expands to include a concept of the equal experience of life itself

Tissue, in all its forms, holds the cells, DNA and other biological keys to life, as well as markers for inherited and other illnesses which blight the human condition and have done so for centuries. As such, your Discussion Paper, while noting a series of prior ALRC Reports, might also look towards examples such as the Patent Amendment (Human Genes and Biological Materials) Bill 2010. While the Bill was ultimately unsuccessful, it prompted much debate on how patents could limit access to genes, cells and tissues with vital research and therapeutic potential. Former Senator Bill Heffernan and others attempted to combine to rebalance the Patent Act so that it better reflected judicial opinion and public aims. This would have been to

³ See e.g. my submission to the Productivity Commission Care Economy inquiry at <https://engage.pc.gov.au/document/1218> as at 24/12/2025

⁴ For a small insight in the work my mother has done every day of every week of my 52 years of life, see her submission to the Productivity Commission's Disability Care inquiry at [Submission 110 - Sally Johnson - Disability Care and Support - Public inquiry](#) as at 27/12/2025. Note well though, how difficult service systems and providers were to deal with over a decade ago, and how nothing much has changed today.

prohibit the patentability of naturally occurring products but not innovative processes of growth or creation.⁵

Exploitation reconsidered

When addressing the Tissue Acts, the failed 2010 Bill should also be reconsidered. This is because, from my perspective, there is a glaring inconsistency between Proposal 40 and what clearly happens in the so-called Care Economy today. In the latter case, there is clearly multiple financial exchanges for profit. These come from many vulnerable aged and disabled people (as well as children) having our care and support needs turned into transactions.⁶ Acknowledging that I am a somewhat reluctant NDIS participant, my complaint is that not only have support services been commodified⁷ but also the recipients of 'care' themselves.

I have an allegedly individually tailored NDIS plan with my name on it. However, government holds all the funds, and it (or its delegates) approve all key service and funding outlays. While I nominally sign service contracts, the consideration (and legally binding element) passes between government and NGO providers. My role as a participant is at best a third-party beneficiary and at worst the defective/disabled product purchased in a transaction.⁸ This has never felt like an exercise in individual choice, control or human rights.⁹ Rather, as it has been said of social media; if you sign up, pay nothing and are handing over personal data, consider whether you have become the product? People, including me, who are marooned by physical dependence in the 'care economy' have arguably become its products. If there is a human right

⁵ See paragraphs 1.35 to 1.38 in Dissenting Report by Senator The Hon Bill Heffernan, Senator Rachel Siewert and Senator Nick Xenophon, Senate Legal and Constitutional Affairs Committee, https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Completed_inquiries/2010-13/patentamendment/report/d01 as at 26/12/2025. My submission to the inquiry opened with a survey of relevant English history and policy, considered the modern-day conduct of a few key corporations, then considered possible reforms and is available at <https://www.aph.gov.au/DocumentStore.ashx?id=66cb520a-6be4-4927-ad0a-5510204770ec> as at 17/01/2026. Laws, norms, custom and regulation change over time, as does society. This is not a relativist comment about whether change is good or bad, or about specific times in history or contemporary times. Rather, given that change is constant we need to appreciate the history, economic and other social pressures within which it occurs.

⁶ See e.g., Peltier, Bruce, and Lola Giusti. "Commerce and care: The irreconcilable tension between selling and caring." *McGeorge L. Rev.* 39 (2008): 785. [Commerce and Care: The Irreconcilable Tension between Selling and Caring](#) as at 26/12/2025. While this is a somewhat dated US article, a contemporary discussion comes from Macdonald, Fiona. "Australia's care systems have been transformed by neoliberal policies that have created so-called quasi-public or managed markets." *Captured: How neoliberalism transformed the Australian state* (2024): 175. [Captured: How neoliberalism transformed the Australian state - Google Books](#) as at 26/12/2025

⁷ See argument in Fiona Macdonald, *Marketising social care*, *Arena Magazine* (Fitzroy, Vic), No. 149, Aug 2017: 22-25, [Marketising social care | Arena Magazine \(Fitzroy, Vic\)](#) as at 27/12/2025

⁸ I made this point to the ACCC during its inquiry into Digital Marketing at [Adam Johnston submission \(27 July 2021\).pdf](#) as at 27/12/2025. There seemed to be far more effective choice over whether I buy a book from Amazon.com as opposed to whether I "purchase" services from the NDIS. The latter comes from the omnipresent need to mitigate the impact of my disability on me and my family.

⁹ See e.g., Johnston, A. D. (2018). *The NDIS: The Mark of Pre-War or Post-War Public Policy Making?*. *Humanity*. Retrieved from <https://novaajs.newcastle.edu.au/hass/index.php/humanity/article/view/63> as at 27/12/2025

to be expressed in this legal malaise, it should be a right to be cured, and thus freed from dependence, disability and commodification.

Similarly, when the ALRC expresses concern in Chapter 11 about exploitation and human trade or trafficking, I think there are some blind spots and inconsistencies in the argument. As suggested above, there are many areas of public social policy, where people (and their dependencies or vulnerabilities) have already been commodified and are effectively traded.¹⁰ I began to realise this amid my own experience of Welfare to Work policies, initiated by the Keating Government and expanded by the Howard Government, along with its successors. From an ardent supporter to harsh critic, I watched the march into every make work scheme imaginable of many incompetent charities, who insisted on my handing over of vast amounts of personal data.¹¹ None sourced permanent employment for me, most sourced no work at all, while all showered me in “training courses” and other paperwork.¹²

Many agencies from the ATO, to Centrelink, NGOs, and the NDIS continue to insist on ever more personal data. In this light, it seems almost trivial to express a peculiar or particular concern about human tissue. The Commission itself acknowledges at paragraphs 11.48 – 11.50 that despite pre-existing recommendations to prohibit organ tourism and trade, the Commonwealth has yet to act. The status quo, however, leaves many people under the auspicious of Australian welfare. By contrast, a regulated fee-based donation model for organs and tissue may provide many people a measure of freedom from economic and social dependence on the welfare state. In other words, altruism is a wonderful thing, but only if you can afford it.

Personally, I’m happy to give test tubes of saliva, blood and the odd melanoma sample (once it is removed) to medical science for clinical research, without any thought of recompense. I have a loving family to support me and have never been down to my last dollar. Spend any time answering telephone inquiries at Ombudsman offices (as I have done) and you soon hear from those in desperate need. However, as noted in footnote 11¹³ when it comes to a similarly complex organisations like Centrelink, it can take many months (as in my case) to have pensions and other payments reviewed and restored.

Nowadays, social services have become compliance exercises by government, where even the reviews of same can struggle to find real evidence of compliance engendering engagement or employment of any value.¹⁴ Public bodies, like Centrelink, the NDIS and the ATO can also fail to

¹⁰ See generally, my submission to the Joint Standing Committee on Foreign Affairs, Defence and Trade, Inquiry into establishing a Modern Slavery Act in Australia - Submission 15, pp. 18-27 of 212 [Adobe numbering]
<https://www.accc.gov.au/system/files/Adam%20Johnston%20submission%20%2827%20July%202021%29.pdf> as at 28/12/2025

¹¹ See generally Adam Johnston, Submission: The administration and purchasing of Disability Employment Services in Australia (and related appendices and submissions) 25th September 2011, <https://www.aph.gov.au/DocumentStore.ashx?id=a6fa4e6a-eb31-49de-bb0f-c9f11849c86c> as at 28/12/2025

¹² This kept me occupied and no doubt kept many NGOs KPIs ticking over. But it did little else. For a discussion of this, see generally Adam Johnston, Disability Advocacy Framework, https://engage.dss.gov.au/wp-content/uploads/2023/05/Submission-ID-S0009-Received-27-June-2022-Email-Only_Redacted.pdf, pp.4-6 [Adobe numbering] as a 1/01/2026. I have not used disability employment services for many years and, have been far more successful in employment as a result.

¹³ See footnote eleven, above, pp. 16-18 of 68 [Adobe numbering]

¹⁴ See generally Julian Disney, Anna Buduls and Peter Grant, Independent Review of the Job Seeker Compliance Framework: A Report to the Parliament of Australia, Printed September 2010,

appreciate what poverty, need and human vulnerability is, leading to a cruel and crude trade in and on human misery, rather than social security. Royal Commissions like the Robodebt inquiry have said as much. This is the context in which I seek to have the ALRC reconsider its prohibition on human organ and tissue trafficking. The fact is that many vulnerable people and their needs are trafficked every day by governments and NGOs in childcare, aged care, disability

Recommendation 3: That organ and tissue donors be fully and properly reimbursed for what they provide

services and the like. Some call it innovative, person-centred social policy. I view much of it as a distasteful and unethical trade in human dependence and suffering. Regardless, I have little choice but to deal with NGOs, in my condition.¹⁵ As such, payment for organ and tissue donation may not be as odious as first thought, when compared to some of the excesses of modern welfare, government compliance regimes and the State's NGO accomplices.

An opportunity to fix real problems and make lasting change

The way ahead is to ask several key questions. The first is to inquire as to the positions of Intellectual Property (IP) Australia, the ACCC and the Scientific Research Future Fund (SRFF). Paragraph 1.16 and Table 2 set out the current administrative framework, but the three bodies I list above are not there. Why? They should sit on a coordinating authority with all the other bodies mentioned in the table, at the table.

Equally, Section 118 is the full faith and credit provision of our Constitution,¹⁶ so there is the capacity for State laws to be upheld by the Commonwealth Parliament with Sir Zelman Cowan suggesting that it is an 'orphaned clause' little explored and underutilised by jurists in Australia

<https://www.dewr.gov.au/download/5426/impacts-new-job-seeker-compliance-framework-report-independent-review/36809/impacts-new-job-seeker-compliance-framework-report-independent-review/pdf> as at 30/12/2025. Years later, little seems to have changed, given the findings of the Hon. Catherine Holmes AC SC, The Royal Commission into the Robodebt Scheme, Publication date: 7 July 2023, <https://robodebt.royalcommission.gov.au/publications/report> as at 30/12/2025

¹⁵ See e.g. my submission in Response To: Review of Australian Charities and Not-For-Profits Commission (ACNC) Legislation at [Adam-Johnston-310865.pdf](#) as at 30/12/2025. At page 4 of 7 in the submission, I draw parallels between the words of Sir Robert Menzies and Oscar Wilde. Both come from very different personal and political perspectives, but one suspects neither would be pleased with contemporary developments. Mr. Menzies clearly saw a directly role for government in cushioning the ebb and flow of economic activity on a population. Mr. Wilde was clearly sceptical of charity, seeing it more as a site of social failure rather than as a solution. As I have aged, there has been more common points between these views.

As a voter, my government/s should see me as a citizen and resident first. The accountability and governance should be in the formal institutions of State and it should never leave that point, although it clearly has; see my submission to the Productivity Commission's Philanthropy Inquiry at https://assets.pc.gov.au/data/assets/pdf_file/0009/376380/sub305-philanthropy.pdf as at 05/01/2025. The fact that much formal authority and day-to-day governance has been divested to third parties, should be a concern to all Australians.

¹⁶ See Commonwealth of Australia Constitution Act - Sect 118 [COMMONWEALTH OF AUSTRALIA CONSTITUTION ACT - SECT 118 Recognition of laws & c. of States](#). as at 1/01/2026.

and only used a little further in the US, even though both are federations.¹⁷ Nonetheless, Memoranda of Understanding, interoperability provisions and reciprocity between jurisdictions¹⁸ would seem preferable to imposing a single national model. National models, such as the NDIS, are often so much a creature of compromise that they end up suiting no one.¹⁹

Recommendation 4: That a national organ and tissue authority is not desirable, and the benefits claimed can be achieved by more modest measures

Recommendation 5: That all human cells, organs, and excrement of any kind be regarded as tissue

Tissue

The only point where uniformity would seem undeniably useful is on the matter of tissue. It is difficult to see how anything of human origin cannot be regarded as tissue. It is also not clear why some things clearly of human origin are excluded from the definition of tissue in some State enactments.²⁰ Equally, the European Union's broad definition of substance of human origin (under Regulation 2024/1938) is useful but for the fact it excludes organs.²¹

NSW Health provides a somewhat useful definition of tissue²² but all jurisdictions struggle for the all-encompassing definition. All tissue is cellular; all organs are cellular. While urine is

¹⁷ See generally Zelman Cowan, Full Faith and Credit: The Australian Experience, Res Judicatae, [imageREAL Capture](#) as at 02/01/2026; also see B. O'Brien, The Role of Full Faith and Credit in Federal Jurisdiction, Vol. 7., [imageREAL Capture](#), as at 03/01/2026

¹⁸ I did something similar, calling for reciprocity between the States and Territories before the House of Representatives Standing Committee on Family Community Affairs, 1997 report *Concessions: Who Benefits*, Chapter 6, p.72 [18 of 21, Adobe numbering] https://www.aph.gov.au/parliamentary_business/committees/house_of_representatives_committees?url=fca/concard/chap06.pdf

Chapter 7, p. 88 [12 of 14, Adobe numbering] https://www.aph.gov.au/parliamentary_business/committees/house_of_representatives_committees?url=fca/concard/chap07.pdf as at 03/01/2026

¹⁹ See footnote three, above. Also note Amanda Sheppard, 'Heartbreaking': disability stalwart forced to cut services, *Health Services Daily*, 08 April 2025, ['Heartbreaking': disability stalwart forced to cut services | Health Services Daily](#) as at 03/01/2026. Further note Heike Fabig, NDIS: rights-based paradigm shift or same old charity?, *Ramp Up*, 11 Apr 2013, [NDIS: rights-based paradigm shift or same old charity? – Opinion – ABC Ramp Up \(Australian Broadcasting Corporation\)](#) as at 03/01/2026. Centralizing services based on social, economic, or other theories can have unintended consequences. My conclusion is that textbooks are the best place for social and economic theories and that is where they should stay.

²⁰ See Discussion Paper, paragraphs 4.4 – 4.6

²¹ See *ibid.*, paragraph 4.9, Table 4

²² Human tissue

Human tissue is described as an organ or part of a human body or any substance extracted from a human body. The Human Tissue Act 1983 sets out the law for the use of human tissue in NSW. Taken from <https://www.health.nsw.gov.au/humantissue/Pages/default.aspx> as at 5/01/2026, though the Act still notes some exclusions. Consulting my Sixth and Centenary Edition of Black's Law Dictionary also yielded no discussion of 'organ' or 'tissue'.

mainly water,²³ it also contains cells,²⁴ as does human breast milk.²⁵ Therefore, there is cause to consider all human tissues, organs and excrement as forms of “cells.”²⁶ Thus, while giving full faith and credit to State laws, they should be read down to a point of consistency regarding the definition of tissue and, if this is not possible, section 109 of the Australian Constitution applies, where Commonwealth law supersedes inconsistent State law.²⁷

It is all tissue, now let's save lives!

IP Australia has any number of categories and classes that describe the function and value of different trademarks and brand names. We could have different classes of tissue but all under the umbrella of “tissue”. In my view, this would bring simplicity and the required amount of consistency. Simplicity is also a foil to religious and clerical interpretations. I have fought for years against religious leaders tempering the advance of research,²⁸ but they continue to be deferred to far too readily, in terms of public funding (e.g. of church schools), favourable tax treatment and ready access to policymakers.

It is time for this to end. It is also time for the ALRC to look closely at the enlightened dissenting judgment of Justice Stanley Mosk²⁹ in the case of *Moore v. Regents of the University of California* (1990). The case concerned a patient, Mr. Moore, who discovered post treatment for leukemia that his doctor had retained his diseased spleen, removed during surgery. Cells derived from the spleen had been cultured, patented and the ‘Mo’ cell line was then of significant value. Mr. Moore sued, claiming a share of the patent’s value and that his doctor had failed to tell him that his spleen would be retained. The majority claimed that giving Mr. Moore such a right would

²³ See e.g.: Cleveland Clinic, Urine, last reviewed on 13/01/2025, <https://my.clevelandclinic.org/health/body/urine>, as at 6/01/2026.

²⁴ See e.g. MedlinePlus, Epithelial Cells in Urine, Last updated November 12, 2024, U.S. Department of Health and Human Services: National Institutes of Health, <https://medlineplus.gov/lab-tests/epithelial-cells-in-urine/> as at 6/01/2026

²⁵ See e.g. Witkowska-Zimny, Malgorzata, and Ewa Kaminska-El-Hassan. “Cells of human breast milk.” *Cellular & molecular biology letters* vol. 22 11. 13 Jul. 2017, doi:10.1186/s11658-017-0042-4, <https://pmc.ncbi.nlm.nih.gov/articles/PMC5508878/> as at 6/01/2026

²⁶ All tissue or tissue-like being of human origin, as well.

²⁷ The section states:

109. Inconsistency of laws

When a law of a State is inconsistent with a law of the Commonwealth, the latter shall prevail, and the former shall, to the extent of the inconsistency, be invalid.

Taken from the Australian Constitution, Chapter V: The States,

https://www.aph.gov.au/About_Parliament/Senate/Practice_and_Procedure/Constitution/chapter5#chapter-05_109 as at 6/01/2026

²⁸ See e.g. Adam Johnston, Submission: Somatic Cell Nuclear Transfer (SCNT) and Related Research Amendment Bill 2006, Senate Community Affairs Committee, [https://www.aph.gov.au/~media/wopapub/senate/committee/clac_ctte/completed_inquiries/2004_07/leg_response_lockhart_review/submissions/sub53_pdf.ashx](https://www.aph.gov.au/~/media/wopapub/senate/committee/clac_ctte/completed_inquiries/2004_07/leg_response_lockhart_review/submissions/sub53_pdf.ashx) as at 07/01/2026. Also see Legislation Review: Issues Paper Legislation Review Committee Reports, Prohibition of Human Cloning Act 2002 and Research Involving Human Embryos Act 2002, December 2005, © Commonwealth of Australia 2005, p.75 [103 of 284, Adobe numbering], p.140 [168], 156 [184], where I explored similar issues; <https://www.nhmrc.gov.au/sites/default/files/documents/attachments/legislation-review-reports-lockhart.pdf> as at 7/01/2026

²⁹ See California Supreme Court Historical Society, History: Stanley Mosk, <https://www.cschs.org/history/california-supreme-court-justices/stanley-mosk/> as at 8/01/2026

inhibit scientific research.³⁰ However, Justice Mosk took on all elements of the majority decision and found much of it wanting.³¹ In particular, I note that Mosk J said:

[To] the extent that cell cultures and cell lines may still be “freely exchanged,” e.g., for purely research purposes, it does not follow that the researcher who obtains such material must necessarily remain ignorant of any limitations on its use: by means of appropriate recordkeeping, the researcher can be assured that the source of the material has consented to his proposed use of it, and hence that such use is not a conversion. To achieve this end the originator of the tissue sample first determines the extent of the source's informed consent to its use - e.g., for research only, or for public but academic use, or for specific or general commercial purposes; he then enters this information in the record of the tissue sample, and the record accompanies the sample into the hands of any researcher who thereafter undertakes to work with it. “Record keeping would not be overly burdensome because researchers generally keep accurate records of tissue sources for other reasons: to trace anomalies to the medical history of the patient, to maintain title for other researchers and for themselves, and to insure reproducibility of the experiment.” (Toward the Right of Commerciality, *supra*, 34 UCLA L.Rev. at p. 241.) As the Court of Appeal correctly observed, any claim to the contrary “is dubious in light of the meticulous care and planning necessary in serious modern medical research.”³²

Notable as well to me is Mosk J’s willingness to highlight error in the jurisprudence of the majority.

As the majority acknowledge, the law of conversion is a creature of the common law. “The inherent capacity of the common law for growth and change is its most significant feature. Its development has been determined by the social needs of the community which it serves. It is constantly expanding and developing in keeping with advancing civilization and the new conditions and progress of society, and adapting itself to the gradual change of trade, commerce, arts, inventions, and the needs of the country!...[Thus in] our contemporary complex industrialized society, advances in science and technology create fungible goods which may harm consumers and which cannot be traced to any specific producer. The response of the courts can be either to adhere rigidly to prior doctrine, denying recovery to those injured by such products, or to fashion remedies to meet these changing needs.”³³

³⁰ See e.g. Nott, Rohini, “Moore v. Regents of the University of California (1990)”. Embryo Project Encyclopedia (2020-11-18). ISSN: 1940-5030 <https://hdl.handle.net/10776/13188> Copyright Arizona Board of Regents Licensed as [Creative Commons Attribution-NonCommercial-Share Alike 3.0 Unported \(CC BY-NC-SA 3.0\)](https://creativecommons.org/licenses/by-nc-sa/3.0/) Last modified Monday, September 11, 2023 - 10:58, <https://embryo.asu.edu/pages/moore-v-regents-university-california-1990> as at 8/01/2026

³¹ See the discussion by Debra Mortimer, Proprietary Rights in Body Parts: The Relevance of Moore's Case in Australia, *Monash University Law Review* [Vol 19, No 2 '93], pp. 229-230 [14-15 of 39 Adobe numbering] <https://www.austlii.edu.au/au/journals/MonashULawRw/1993/10.pdf> as at 08/01/2026

³² Mosk J [in dissent] *Moore v. Regents of University of California*, 51 Cal.3d 120, Supreme Court of California, July 9, 1990 P.30 [30 of 40, Adobe numbering] https://web.archive.org/web/20180510144641/http://www.eejlaw.com/materials/Moore_v_Regents_T08.pdf as at 09/01/2026

³³ *Ibid.*, p.22-23 [22-23 of 40]

Mosk J laments the majority's doctrinal approach,³⁴ but I would counsel Arabian J that that which he feared (the fungible human article) is a reality. Relying on everything stated above, my view is that we need Mosk J's reasoning to deal with the fungible human article or FHA. The ALRC should realise that this is not just a result of failing patent or tissue laws but missteps in wider social, economic and political policy.

Therefore, in rejecting the majority position in the Moore case, I believe Arabian J mischaracterised Mosk J's dissent if he thought it was just a question of tort. Mortimer gives a compelling account of nuances in Mosk's ruling. Further, to the matters of profit, loss and what one might call the proper delineation between science and economics, Mosk J observed:

I would agree that "scientific use" at least includes routine postoperative examination of excised tissue conducted by a pathologist for diagnostic or prognostic reasons (e.g., to verify preoperative diagnosis or to assist in determining postoperative treatment). I might further agree that "scientific use" could be extended to include purely scientific study of the tissue by a disinterested researcher for the purpose of advancing medical knowledge - provided of course that the patient gave timely and informed consent to that use. It would stretch the English language beyond recognition, however, to say that commercial exploitation of the kind and degree alleged here is also a usual and ordinary meaning of the phrase "scientific use."

The majority dismiss this difficulty by asserting that I read the statute to define "scientific use" as "not-for-profit scientific use," and by finding "no reason to believe that the Legislature intended to make such a distinction." (Citation removed) The objection misses my point. I do not stress the concept of profit, but the concept of science: the distinction I draw is not between nonprofit scientific use and scientific use that happens to lead to a marketable by-product; it is between a truly scientific use and the blatant commercial exploitation of Moore's tissue that the present complaint alleges. Under those allegations, [defendant doctors] were not only scientists, they were also full-fledged entrepreneurs: the complaint repeatedly declares that they appropriated Moore's tissue in order "to further defendants' independent research and commercial activities and promote their economic, financial and competitive interests."...To exclude such traditionally commercial activities from the phrase "scientific use," as I do here, does not give it a restrictive definition; rather, it gives the phrase its usual and ordinary meaning, as settled law requires.³⁵

Mosk J's position would seem the most reasonable. He does not rule out science for profit but is concerned to ensure the fully informed consent of patients. Patient's rights were championed by Mr Moore himself after his experience, according to Rohini Nott.³⁶

³⁴ To be fair to the majority opinion, in a concurring opinion, Arabian J states in part:

I share Justice Mosk's sense of outrage [at the conduct of Moore's doctors], but I cannot follow its path. His eloquent paean to the human spirit illuminates the problem, but not the solution. Does it uplift or degrade the "unique human persona" to treat human tissue as a fungible article of commerce? Would it advance or impede the human condition, spiritually or scientifically, by delivering the majestic force of the law behind plaintiff's claim? I do not know the answers to these troubling questions, nor am I willing - like Justice Mosk - to treat them simply as issues of "tort" law, susceptible of judicial resolution.

Ibid., Arabian J concurring with the majority, p. 19 [19 of 40]

³⁵ Ibid., Mosk J in dissent, pp. 24-25 [24-25 of 40]

³⁶ See footnote thirty, above.

FHA – better than the alternative

FHA became a clear issue in my mind with the Commission's Essentially Yours inquiry. However, even before then, the application of genes to both individual and public health was driven home by an ABC Four Corners presentation. The potential lack of access if genes were patented and the potential impact on both researchers and their patients were immense.³⁷ Meanwhile, the likely profits were immense too. This prompted me into action both publicly,³⁸ academically,³⁹ and at relevant scientific conferences.⁴⁰

Given what we now know about the body, genes, and tissue the ALRC, government and other agencies are not doing enough. Firstly, as my opening suggested, we are on the verge of real scientific and medical change.⁴¹ Yet, what do our leaders present us with? Lifelong charity and lifelong dependence. The clearest example of this is Rule 7.5 of Participant Supports under the NDIS. The Scheme will not fund anything aimed at the improvement of function, nor lacking a consensus of professional opinion as to efficacy.⁴² These rules prevent the deployment of many cutting-edge technologies,⁴³ and literally condemns generations of people to lifelong

³⁷ See Mark Summerfield, Gene Patents to Feature on Australian "Four Corners" TV Program, 06 September 2010, 9:44 AM, <https://blog.patentology.com.au/2010/09/gene-patents-to-feature-on-australian.html> as at 09/01/2026

³⁸ See Adam Johnston, Reserving the right to protect our genetic code, The Punch, 19 Nov 2010 16:47, <https://webarchive.nla.gov.au/awa/20101119054718/http://www.thepunch.com.au/articles/reserving-the-right-to-protect-our-genetic-code/?from=puff&pos=5&referrer=home> as at 09/01/2026. Also see Adam Johnston, Who owns you?, On-line Opinion, 18 October 2010, <https://www.onlineopinion.com.au/view.asp?article=11109> as at 09/01/2026

³⁹ See Adam Johnston, Question: How does the Common Law look at (a) the body and (b) property as it might relate to the body or body parts, cells or cellular information?, Master of Laws by Research, Supervisors: Paul Martin and John Page, University of New England, Armidale NSW, Library Collection, <https://rune.une.edu.au/entities/publication/153c2c88-7371-401a-872e-e7905d76f59c> as at 09/01/2026

⁴⁰ See 18th NSW Stem Cell Network Workshop: Expanding the use of cord blood, Darlington Centre City Rd, Sydney. Tuesday, May 21st, 2013, Posters including one summarizing my LLM project in footnote thirty-nine, above, p.15 [15 of 26] <https://d3n8a8pro7vhmx.cloudfront.net/stemcellnetwork/pages/41/attachments/original/1576462793/18thWorkBook.pdf?1576462793> as at 09/01/2026; see also Stem Cells Australia, Stem Cells in the Hunter Valley, November 2015, https://research-management.mq.edu.au/ws/portalfiles/portal/178305790/News_summary_Stem_Cells_in_the_Hunter_Valley.pdf#:~:text=There%20was%20also%20a%20very%20inspiring%20talk,engagement%20and%20lack%20of%20engagement%20from%20the; also see Danielle Goldberg, The Business of Stem Cells in Australia, November 12, 2015, LinkedIn, https://research-management.mq.edu.au/ws/portalfiles/portal/178305790/News_summary_Stem_Cells_in_the_Hunter_Valley.pdf#:~:text=There%20was%20also%20a%20very%20inspiring%20talk,engagement%20and%20lack%20of%20engagement%20from%20the as at 10/1/2026. Slide show included with this submission.

⁴¹ See e.g. Stem Cell Australia, Associate Professor Michael O'Connor and Dr Rachel Shparberg, Western Sydney University, You Tube, 6 years ago, [Associate Professor Michael O'Connor and Dr Rachel Shparberg](#) as at 10/01/2026. Dr Shparberg is now Chair of the NSW Stem Cell Network [Meet the Team - NSW Stem Cell Network](#) as at 11/01/2026

⁴² See my attached critique of Rule 7.5 in my presentation 'What Would Grandma Say?' to the Public Involvement in Health Service Research – International Symposium, Thursday February 21st, 2019, The University of Sydney, Faculty of Health Sciences, pp. 19-20 [42-43 of 70, Adobe numbering] and slideshow: Staying Disabled under the NDIS, p.[66 of 70]

⁴³ See e.g. Johnston, A. (2017). From citizen to charity case: has contracted welfare breached the Sovereign's duty to Her Subjects?. Poster session presented at Neuroscience & Society, Sydney, New South Wales, Australia. <https://researchers.mq.edu.au/en/publications/from-citizen-to-charity-case-has-contracted-welfare-breached-the--5/> as at 11/01/2025. Paper attached, including several examples

impairment, disability and dependence. They are based purely on the NDIS legislated view of safety, setting the bar impossibly high. This is not good enough! This is because they are also setting the bar far too low, when considering what an ordinary and reasonable life may encompass.⁴⁴ Recalling my Recommendation 2, above (equal value, equal experience), the Human Tissue Act should state in the statute (and accompanying State and Territory laws) that all take precedence over the NDIS Act, including Rule 7.5.

All the Human Tissue or Anatomy Acts should also clearly have a stated aim of preventing and curing human disease, particularly where the disease is inherited, chronic, degenerative or otherwise disabling. Here is the opportunity to grow replacement organs that will not be rejected by a recipient's body, turn off genes whose expression will disable, disfigure, or incapacitate. Why would anybody reject these life-changing opportunities for cultural, or another of the proliferating forms of 'safety' that advocates and academics have argued for over recent years. Equally, what value does the social model of disability (or any other status) really have if it opposes a medical intervention will preserve both life and improve function?⁴⁵

Recommendation 6: That the ALRC accept a notion of the Fungible Human Article (FHA) with a bundle of property rights under law, which can be changed over time but are not voided (refer to Mortimer's article and Mosk J's ruling)

Recommendation 7: That Commonwealth, State and Territory Tissue Acts override the NDIS Act and allow NDIS participants to use funding for function improving trials, research and other developments

of the NDIS seeming to abandon highly needy people, or those with degenerative conditions, as not worth the trouble to support.

⁴⁴ See e.g. The Mindful Word, Creating a Better Society: The importance of empowering people with disabilities, Contributor: Community Building: December 11, 2014, [The Importance of Empowering People With Disabilities](#) as at 14/01/2026; Contra: Change My View, I believe severely mentally disabled people are nothing but a burden and a waste of everyone's time. CMV., 12y ago, Reddit, https://www.reddit.com/r/changemyview/comments/1tl2sz/i_believe_severely_mentally_disabled_people_are/ as at 14/01/2026. While these views are most contradictory and will likely offend many, I put them here to demonstrate the range of opinions that exist.

I further highlight data from the Australian Bureau of Health and Welfare which notes that people with disability are more likely to be lonely, have difficulty with transport and getting out of their home less often than they would like to, and are less satisfied with their level of community participation. This varies across the demographics as well as urban and regional localities. Interestingly, there is generally high satisfaction with the NDIS, which is not my experience nor what I hear anecdotally; see AIHW, People with disability in Australia, Web report, Last updated: 23 Apr 2024, Topic: Disability [People with disability in Australia. Social inclusion and community support - Australian Institute of Health and Welfare](#) as at 14/1/2026.

⁴⁵ See e.g. World first trial for kids with Duchenne Muscular Dystrophy, 19 July 2023, NSW Health Press Statement, https://www.health.nsw.gov.au/news/Pages/20230719_00.aspx as at 14/01/2026. From the age of 14 onwards, until the end of school, I attended multiple funerals for school friends dying of muscular dystrophy. This explains my lack of patience with the social model of disability. Advocating for policies of inclusion and trying to convince everybody that disability is 'normal' often sounds as credible as The Flat Earth Society, even to me who lives with disability.

In this light see also Kate Aubusson, Baby Mackenzie's parents endure online attacks ahead of genetic trial, Sydney Morning Herald, October 7, 2018 — 12.01am, <https://www.smh.com.au/healthcare/baby-mackenzie-s-parents-endure-online-attacks-ahead-of-genetic-trial-20181006-p50851.html> as at 15/01/2025; see also Kate Aubusson, Couples to be tested for 500 genes linked to childhood disorders

Furthermore, it needs to be considered whether change is only possible when risk is present. The ALRC seems to have gone ‘nil by mouth’ when it comes to a risk appetite. Funny then, that as a patient awaiting multiple orthopaedic surgeries, the nil by mouth process only made me hungrier. When I was a child, it was hungry for food and water; now as an adult it is for policy reform. As stated, we now have (or are close to having) the technology to deliver cellular and genetic antidotes to wicked diseases and disabilities. Why are we delaying; we moved especially quickly to deal with Covid-19, while the likes of the late Princess Diana made us care about AIDS by demonstrating true compassion, in a crisis, for people who were suffering and dying. Carrie Bickmore, Glenn McGrath, Neale Daniher, the late Olivia Newton-John and Christopher Reeve have all launched vital campaigns (as have others) to support people with life threatening and/or life shortening conditions. An important part of most, if not all these organisations, is working towards a cure.

For example, the Reeve Foundation motto is ‘Today’s Care, Tomorrow’s Cure.’⁴⁶

Conclusion

My main question is, when is tomorrow coming? Governments can do something when they give project grants. However, more significant change requires both law and policy to prioritise cure explicitly. Requiring researchers to undertake some due diligence as suggested by Mosk J, as well as moving to an opt-out tissue donation system, is essential if change is truly sought. For all the calls to ‘inclusion’ and ‘diversity’⁴⁷ by a Royal Commission, it is hard to read (without tears of anguish and anger) the concept of cure being denounced as ableist and discriminatory in the same official document. This should be reconsidered by the ALRC and the wisdom (or not) of the Disability Royal Commission challenged.

I can’t be silent if another generation is going to be subjected to the pain, suffering, poverty and indignities of chronic illness and disability. If some people choose to find their purpose and identity in a lifelong medical condition, then they are welcome to do so. For those of us seeking

before conception, Sydney Morning Herald, October 3, 2018 — 12.00am, <https://www.smh.com.au/healthcare/genes-disorders-carrier-screening-mackenzie-babies-20180928-p506m1.html> as at 15/01/2025 and also see Maani Truu, ‘It’s magic’: Families, advocates celebrate lifesaving drug announcement, Sydney Morning Herald, May 6, 2018 — 9.38pm, <https://www.smh.com.au/politics/federal/it-s-magic-families-advocates-celebrate-lifesaving-drug-announcement-20180506-p4zdoa.html> as at 15/01/2026; further see Kate Aubusson and Louise Kennerley, Aviana turns one, defying terminal spinal muscular atrophy diagnosis, Sydney Morning Herald, September 2, 2017 — 5.16pm, <https://www.smh.com.au/healthcare/aviana-turns-one-defying-terminal-spinal-muscular-atrophy-diagnosis-20170901-gy8ye6.html> as at 15/01/2026.

If we want to see more life-changing therapeutic interventions, it must be realized that this comes not from ‘magic’ but multiple clinical trials, and people who are prepared to enter them, rather than being pilloried for doing so, like the parents of Baby Mackenzie. Multiple initial animal trials are needed, then hopefully this leads to human trials, where the research is ultimately translated into treatments for patients. However, this is a process of many years with no guarantees of success.

⁴⁶ See Reeve Foundation homepage, <https://www.christopherreeve.org/> as at 15/01/2026.

⁴⁷ See Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Final Report, Executive Summary, Our vision for an inclusive Australia and Recommendations, Commonwealth of Australia, 2023 <https://disability.royalcommission.gov.au/system/files/2023-11/Final%20report%20-%20Executive%20Summary%2C%20Our%20vision%20for%20an%20inclusive%20Australia%20and%20Recommendations.pdf> as at 16/01/2026.

more out of life, please don't hinder our access to the frontiers of medical science and tissue experimentation. I will never forget my late grandmother's amazement at how a specialist surgeon could take a bone graft from my hip in 1987, secure it to my spinal fusion, and as she put it, "tell it to grow". Her wonderment was only matched by my discomfort. Regardless of how much analgesia I was prescribed, the sharp hip pain stayed for weeks, long after other complaints had eased. But for grandma, the bone graft was proof I had been born in 'the right age.'⁴⁸

There is now even greater cause to reflect on grandma's wonderment, for we will spend (according to the last Federal Budget papers) on the NDIS "\$52.3 billion in 2025-26 and up to \$63.4 billion by 2028-29."⁴⁹ When you juxtapose this with reports of significant underspending in the SRFF,⁵⁰ you do wonder 'what are our national priorities and where the hell are they going!' Furthermore, this criticism of the SRFF is not new or limited,⁵¹ which makes one question government commitment to research and development at all. Preventing and curing disease and disability would bring the NDIS spend down. However, this means finding politicians prepared to think beyond a three- or four-year election cycle, and stare down the lobbyists infesting all our parliaments and serving the status quo. Will I live to see grandma's 'right age?'

Finally, what's the ethical, moral or religious problem with the use of tissue? From my own Judeo-Christian tradition, the contention seems overblown. Jesus Christ extended hands of friendship, compassion and love to those people shunned by society.⁵² He also cured many people who were sick and impaired.⁵³ It seems the argument over why we can't do both will never end, nor will the opposition (in some quarters) to cellular/tissue research and restoration.⁵⁴ However, can we cast this to one side? I do not fear religious criticism or even damnation, and neither should you.

⁴⁸ See Adam Johnston, What Would Grandma Say?, On-line Opinion, posted on Friday 15th May 2020, <https://onlineopinion.com.au/view.asp?article=20903> as at 17/01/2026

⁴⁹ Evan Young, The NDIS's wider reputation is at an all-time low. How did we get here?, the Specialist Reporting Team, ABC News, Topic: Budget analysis, Thu 27 Mar, 2025, <https://www.abc.net.au/news/2025-03-27/budget-2025-shows-ndis-has-a-pr-problem/105095724> as at 17/01/2026

⁵⁰ See Natassia Chrysanthos, 'We're losing careers': Leading cardiologist warns Australian medical research is in crisis, January 17, 2026 — 6.00am, Sydney Morning Herald, <https://www.smh.com.au/politics/federal/we-re-losing-careers-leading-cardiologist-warns-australian-medical-research-is-in-crisis-20260116-p5nuju.html> as at 17/01/2026.

⁵¹ See Goggle Search: smh smrff underspend - https://www.google.com/search?q=smh+srff+underspend&rlz=1C1CHWL_en&oq=smh+srff+underspend&gs_lcrp=EgZjaHJvbWUyBggAEEUYOTIHCAEQIRigATIHCARiPAjIHCAMQIRiPatIBCTMwNzAwajBqNKgCALACAA&sourceid=chrome&ie=UTF-8 as at 17/01/2026

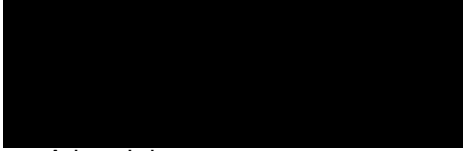
⁵² See Robert Sang, 6 outcasts In Luke's Gospel that Jesus welcomed openly, Drawing on The Word, Published: August 9, 2018, <https://drawingontheword.com/outcasts-in-lukes-gospel/> as at 18/01/2026

⁵³ Jesus Film Project, All the Healings of Jesus, 9/19/2022 (US), 100 Lake Hart Drive, Orlando, FL, 32832, <https://www.jesusfilm.org/blog/all-the-healings/> as at 18/01/2026

⁵⁴ See Google search: churches opposing regenerative and other medicine - [https://www.google.com/search?q=churches+opposing+regenerative+and+other+medicine&sc_esv=d5f090da7ec2ef61&rlz=1C1CHWL_en&ei=BF5saYfhJNTb4-EP--jLsQ4&ved=0ahUKEwiH8-bnsnJSSAxXU7TgGHXv0MuYQ4dUDCBE&uact=5&oq=churches+opposing+regenerative+and+other+medicine&gs_lp=Egxnd3Mtd2l6LXNlcniMWNodXJjaGVzIG9wcG9zaW5nIHJLZ2VuZXJhdG1Z2SBhbmQgb3RoZXIgbWVkaWNpbmUyChAAGLADGNYEGEcyChAAGLADGNYEGEcyChAAGLADGNYEGEcyChAAGLADGNYEGEcyChAAGLADGNYEGEcyChAAGLADGNYEGEcyChAAGLADGNYEGEcyChAAGLADGNYEGEdlgL8HUJ_wBVii_wVwBHgAkAEAmAGwAaAB7AOqAQmWljO4AQPIAQD4AQGYAgagAuYCWgIEECEYCpgDAOIDBRIBMS](https://www.google.com/search?q=churches+opposing+regenerative+and+other+medicine&sc_esv=d5f090da7ec2ef61&rlz=1C1CHWL_en&ei=BF5saYfhJNTb4-EP--jLsQ4&ved=0ahUKEwiH8-bnsnJSSAxXU7TgGHXv0MuYQ4dUDCBE&uact=5&oq=churches+opposing+regenerative+and+other+medicine&gs_lp=Egxnd3Mtd2l6LXNlcniMWNodXJjaGVzIG9wcG9zaW5nIHJLZ2VuZXJhdG1Z2SBhbmQgb3RoZXIgbWVkaWNpbmUyChAAGLADGNYEGEcyChAAGLADGNYEGEcyChAAGLADGNYEGEcyChAAGLADGNYEGEcyChAAGLADGNYEGEcyChAAGLADGNYEGEcyChAAGLADGNYEGEdlgL8HUJ_wBVii_wVwBHgAkAEAmAGwAaAB7AOqAQmWljO4AQPIAQD4AQGYAgagAuYCWgIEECEYCpgDAOIDBRIBMS)

I fear more making it to the afterlife, only to meet with grandma's disapproval. I had the scientists and the technology, but did I tell either of them to grow like the bone graft on my spine? Did tomorrow's cures come? I hope I can give grandma an unreserved 'Yes!' in answer to both questions.

Yours faithfully



Adam Johnston

18/01/2026

**From Citizen to Charity Case: Has
Contracted Welfare Breached the
Sovereign's Duty to Her Subjects?**

Introduction

In the Judaeo-Christian context of Australia's common law, as well as that of many other Western countries, the concept of people altering their neurology or physical body can invoke great passions. This in part relates to the religious notion of each individual being created 'in the image of God' as well as jurisprudential notions of autonomy and bodily integrity. The general understanding also calls on people with disabilities to be stoic and heroic on occasions. Sanctity of life principles also combine with contemporary rights-based framework of what people with disabled can expect from wider society. It is my contention however, that not only with the advance of technology but also with the retreat of some elements of social policy to a bygone era, these assumptions need to be challenged.

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. Moving beyond this question, my argument is that people should be able to make further choices to restore and repair the neurological and physical capacities 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.

The NDIS

You might have expected the National Disability Insurance Scheme (NDIS) which the Commonwealth Government passed into law during 2013, to be an exemplar of a grand new policy vision. From then on, people with significant, lifelong disabilities would be able have a personal budget to access goods and services deemed reasonable and necessary to support them to have an ordinary life in the community. This was initially much heralded as an historic social reform, as the prior State-based system was derided as miserable because according to Anne Manne provincial management meant that:

(a) care package – which makes all the difference to surviving – may depend on something as arbitrary as what side of the street you live on. If you have an accident, make sure you reside on the NSW side of Boundary Road in Tweed Heads, for example. In NSW you can get full support for a disabling motor vehicle injury through that state's no-fault Lifetime Care and Support Scheme; Queensland doesn't have such a system.¹

However, note a critical descriptor in the first sentence: surviving. The language is not improving, healing, or prospering. The psychological, neurological, and legal ramifications are significant and, similar issues appeared in both the former State-based system and the nationwide scheme. This was first realised when the Commonwealth Government decided to call the bureau established to run

¹ Anne Manne. "Two nations: The case for a national disability insurance scheme." *The Monthly* August 2011, <https://www.themonthly.com.au/issue/2011/august/1314794058/anne-manne/two-nations> as at 27th July 2016

the NDIS *DisabilityCare*. This was widely derided as patronising and dismissive of the rights-based focus of the United Nations *Convention on the Rights of Persons with Disabilities*, (the UN Convention) which is cited in the Objects of the NDIS Act and, to which the Parliament claimed to be giving affect.² Disability advocate Craig Wallace argued that the name “puts people with disability to one side - as people to be cared for.”³ Similarly the late Stella Young complained the name was ‘carer-centric’ and did nothing to deal with problems she saw as key issues in the disability community, which she described in terms of what she hated. Beyond *DisabilityCare’s* name, Ms Young hated:

Crappy services. People living with crappy mobility aids that keep them house-bound. People not having access to education, to employment, to their communities. I hate that there have been people living for decades without the support they need to live rich, full lives and participate in the cultural and economic life of Australia.⁴

Such critiques from Mr Wallace and Ms Young can be criticised on many levels. For present purposes, while Ms Young refers to mobility aids, there is no deliberate consideration of technology. Technology in this sense means devices, procedures and interfaces which can improve the mobility, capacity, and productivity of people with disabilities, with the aim of ameliorating disability from their experience. Such objectives will have advantages for the entire community, including the carers that Ms Young all too easily dismissed as too much the focus if the NDIS was called *DisabilityCare*; now the National Disability Insurance Agency (the Agency).

An unfortunate view of technology

Indeed, the 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*:

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.⁵

² See National Disability Insurance Scheme Act 2013, No. 20, 2013, s.3(1)(a), <https://www.legislation.gov.au/Details/C2016C00934> as at 3 June 3, 2018

³ Craig Wallace, “DisabilityCare: What's in a name?” *Ramp Up*, 21 March 2013, <http://www.abc.net.au/rampup/articles/2013/03/21/3720482.htm> as at 3 June 2018

⁴ Stella Young, “DisabilityCare: a bad name but a good direction” *Ramp Up*, 22 March 2013 <http://www.abc.net.au/rampup/articles/2013/03/22/3721427.htm> as at 4 June, 2018

⁵ Miki Perkins, Woman with disabilities scores landmark win over NDIS, June 18 2017, *The Age*, Victoria, <http://www.theage.com.au/victoria/woman-with-disabilities-scores-landmark-win-over-ndis-20170615-gwrz7c> as at 22 June 2017

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.⁶

In response, the Agency cited its high case load, of 100,000 participants last year, claiming many of these people had no support previously.⁷ 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.⁸ 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.⁹ A Note under the section also gives guidance that people with degenerative conditions may qualify for the NDIS based on early intervention considerations.

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

⁶ [Dan Conifer](http://www.abc.net.au/news/2017-04-15/terminally-ill-mother-fears-ndis-writes-off-people/8445228), "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

⁷ Ibid

⁸ 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

⁹ 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;

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.¹⁰

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”¹¹ 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,¹² exoskeletons¹³ and brain implants,¹⁴ and the opening of centres for genetics and cellular technology,¹⁵ the public expectation of what amounts to reasonable adjustments and thus what is necessary for economic or social participation in the community, under section 24 of the NDIS Act,¹⁶ 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.

¹⁰ 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

¹¹ 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

¹² 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=e746b9940ff39c130ae617dcfc6e8157d8f9a7f1a5457687eb1f263bcdcedcfff844c3e409e294529dfcf62b0751ab0b2eea560efe07170ac67fdd7f8355c19684d65df31ec8db03fbbb5750816b330a33baed14619fde79> as at 4 June 2018

¹³ 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

¹⁴ 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

¹⁵ 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

¹⁶ See NDIS Act, above n 2, s.24(d)

Furthermore, as reports continue to emerge about shortfalls in care staff needed to make NDIS supports a reality,¹⁷ the issue of labour force constraints in this area are widely recognised.¹⁸ While the NDIA devotes part of its Annual Report to ‘assistive technology’¹⁹ 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.²⁰ Such technological investment could relieve many of the heaviest and most complex aspects of care, while giving assurance to carers (those whose role Ms Young 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.²¹ Ultimately, from the point of view of government it is the cost-savings that could result from investment in technology that needs to be considered.

Clinging to disability

Until recently, this author 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

¹⁷ See e.g.: [Dan Conifer](http://www.abc.net.au/news/2017-02-25/ndis-report-warns-major-cities-not-prepared-for-implementation/8303276), “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.

¹⁸ 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

¹⁹ See National Disability Insurance Agency, Towards an ordinary life: *NDIS Annual Report 2015-16*, Commonwealth of Australia 7., 34-35

²⁰ 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.”

²¹ See for example, the webpage of Australian paraplegic speaker and campaigner Amanda Boxtel, 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.

Cochlear implants,²² 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."²³ 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)".²⁴ 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'.²⁵ 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:

(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.²⁶

²² 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

²³ *Ibid*, 135-6.

²⁴ 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

²⁵ 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.

²⁶ 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,

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.²⁷

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.²⁸ 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 illegitimate²⁹

The real conundrum

it is fair to say that this author is yet to be convinced by the concept of disabling social processes 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

<http://s3.amazonaws.com/academia.edu.documents/7383443/Meekosha%202006.pdf?AWSAccessKeyId=AKIAIWOWYYGZ2Y53UL3A&Expires=1489440202&Signature=eE%2FE3Un1tZPaA%2FkNVlwi98VA2wA%3D&response-content-disposition=inline%3B%20filename%3DWhat_the_hell_are_you_An_intercategoria.pdf> as at 14 March 2017

²⁷ 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.

²⁸ See *ibid.*, 3.

²⁹ See *ibid.*, 12-13.

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 New South Wales (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 1943.³⁰ 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”.³¹

This press release is important for several reasons. Firstly, it acknowledged that ADHC provided for 70% of disability and aged care support in NSW.³² Secondly, it confirmed that the outsourcing of human services was being followed in other jurisdictions.³³

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:

(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.³⁴

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

³⁰ 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

³¹ 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

³² See *ibid*

³³ 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

³⁴ 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

government.³⁵ 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 personal hygiene skills, and increased success in making independent transportation arrangements.³⁶

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.³⁷

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

³⁵ 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.

³⁶ 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

³⁷ 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>>

and burdensome'.³⁸ 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.³⁹ This broadly corresponds with international evidence suggesting that in comparable jurisdictions, where self-management is as low as 11 percent.⁴⁰

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."⁴¹ Otherwise, there were clear reports of a system overwhelmed and a market that was failing.⁴² Despite the many formal representations to the contrary,⁴³ the States and the Commonwealth have held belligerently to a market forces model.⁴⁴

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 43 variously say, great uncertainty has been created, some 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-

³⁸ Ibid., 374

³⁹ See *ibid.*, 380

⁴⁰ 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

⁴¹ See *ibid.*

⁴² 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

⁴³ 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

⁴⁴ 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

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.⁴⁵

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.⁴⁶ 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.⁴⁷

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 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. In his comments on *Freedom from Want*, during his *Forgotten People* broadcasts, Sir Robert said:

⁴⁵ Bo'sher, above n 40.

⁴⁶ 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

⁴⁷ 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

*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.*⁴⁸

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.*⁴⁹

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 quoted above knew what poverty and armed chaos could do to society. While their 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 McClelland Royal Commission into Institutional Responses to Child Abuse and Neglect.⁵⁰ 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.⁵¹

⁴⁸ 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

⁴⁹ 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

⁵⁰ 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

⁵¹ 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

Despite these lessons, 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.⁵²

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.⁵³ 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 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 amputees⁵⁴ 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

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

⁵² Wallace above n 34, 44

⁵³ 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

⁵⁴ 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

confined to wheelchairs may find freedom of movement in exoskeletons. These are currently widely used by industry.⁵⁵ 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,"⁵⁶

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 recently in the Sydney Morning Herald⁵⁷ 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.⁵⁸

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."

⁵⁵ 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

⁵⁶ *Ibid*, 19

⁵⁷ 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

⁵⁸ 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 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

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.⁵⁹

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.⁶⁰

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 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.⁶¹

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 partly funds the second, while largely expecting the first to make up the difference, as many have always done.

⁵⁹ Donald Trump, "State of the Union 2018: Read the full transcript," [CNN Politics](https://edition.cnn.com/2018/01/30/politics/2018-state-of-the-union-transcript/index.html), 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

⁶⁰ See e.g.: Carmel Laragy, "Four Corners: can the NDIS prevent abuse of people with disability?" [4 Corners](https://theconversation.com/four-corners-can-the-ndis-prevent-abuse-of-people-with-disability-75286), 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

⁶¹ *Harriton v Stephens* [2006] HCA 15 at 122 (Kirby J.).

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.

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Other

Amanda Boxtel <http://www.amandaboxtel.com/index.html>



Symposium organising team:

Associate Professor Jen Smith-Merry. Director, Centre for Disability Research and Policy, The University of Sydney

Dr Ellen Stewart. Chancellor's Fellow, Usher Institute, University of Edinburgh

Professor Gwynnyth Llewellyn, Centre for Disability Research and Policy, The University of Sydney

Dr Tanya Riches, Centre for Disability Studies, The University of Sydney

Cherry Baylous, PhD student, Department of Media and Communications, The University of Sydney

Public Involvement in Health Service Research – International Symposium

**Thursday February
21st, 2019**

The University of Sydney,
Faculty of Health
Sciences

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 – Associate Professor Jenifer Smith-Merry, Director, Centre for Disability Research and Policy & Dr Ellen Stewart, Chancellor’s Fellow, The University of Edinburgh |
| 9.30am – 10.15am B020 | <p>Morning Panel - Wellbeing, Health & Youth Panel: Making 'Healthy Publics' Together Chair: Jen Smith-Merry</p> <p>Introduction and Overview Kate Steinbeck, Director, Wellbeing Health & Youth, NHMRC Centre of Research Excellence (CRE) in Adolescent Health (USyd) – Medical Foundation Chair in Adolescent Medicine, University of Sydney</p> <p>Adolescent Health Research Commission Betty Nguyen, Western Sydney University</p> <p>Health Literacies Rachel Skinner, University of Sydney</p> <p>Knowledge Translation Fiona Brooks, University of Technology Sydney</p> <p>Ethics of Engagement Julie Mooney-Somers, Sydney Health Ethics, University of Sydney</p> <p>People, Places and Platforms Teresa Swist, Institute for Culture & Society, Western Sydney University</p> |
| 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 | <p>Parallel Session 1: Chair Ivy Yen Health Consumers' Experiences of Involvement in Health and Medical Research Anthony Brown and Janelle Bowden Health Consumers NSW and Research4Me</p> <p>A snapshot of consumer and community involvement in translational health research – where are we now and where can we go next? Angela Todd, Sydney Health Partners University of Sydney</p> |

| | |
|---------------------------|---|
| | <p>Inclusive consumer-driven health services research – Enhancing public involvement in test result management, communication and follow-up Maria R. Dahm, Maureen Williams, Centre for Health Systems and Safety Research, Macquarie University</p> |
| 10.45am – 11.45am T207 | <p>Parallel Session 1: Chair: Ellen Stewart Co-designing a text message program to support women’s health after breast cancer treatments Anna Singleton, Westmead Applied Research Centre, University of Sydney</p> <p>What’s our experience really worth? Finding a middle ground between “tokenistic” versus “used & abused” consumer contribution Catherine Maguire</p> <p>Patient participation in health research: Biocitizenship and the perpetual politics of knowledge Patti Shih, Australian Centre for Health Engagement Evidence and Values, University of Wollongong.</p> |
| 10.45am – 11.45am T208 | <p>Parallel Session 1: Chair: Gwynnyth Llewellyn Occupational Therapists’ perceptions of consumers providing feedback to learners completing practice education Thomas Bevitt, University of Canberra</p> <p>Identifying and integrating patient and caregiver perspectives in clinical practice guidelines for percutaneous renal biopsy Talia Gutman, University of Sydney</p> <p>Pathways to Preventive Care for People with Severe Mental Illness: An Innovative approach to co-design Peri O’Shea and Karen Fisher, UNSW Social Policy Research Centre</p> |
| 11.45am – 12.45pm T203 | <p>Parallel Session 2: Chair: Jen Smith-Merry Workshop: From aspiration to implementation: What does it take to embed authentic engagement in research practice? A panel presentation and dialogical workshop</p> <p>Chérie McGregor, Tegan Scheffe, Megan Dutton, Dan Hermans (Sunshine Coast Mind and Neuroscience Thompson Institute) with community partners Rosie Williams and Jocelyn Culpitt.</p> <p>Tegan, Megan, Dan, Rosie and Jocelyn will be on video conference.</p> |
| 11.45am – 12.45pm T207 | <p>Parallel Session 2: Chair: Carol Porteous What would grandma say? Adam Johnston, Macquarie University</p> <p>Families are first responders Gabrielle Carey, University of Technology Sydney</p> <p>Enabling action? Participatory action research with women with disabilities in the Philippines and Australia Cathy Vaughan, Sarah Khaw, Liz Gill-Atkinson, Vaskiliky Kasidis, University of Melbourne</p> |
| 11.45am – 12.45pm T208 | <p>Parallel Session 2: Chair: Martin Raffaele Nothing about us without us: consumers shaping research Elisabeth Kochman, Murray McLachlan, Cancer Voices NSW</p> <p>Agents of Change: Public Involvement in Dementia Research Lenore De la Perrelle, Ian Gladstone, Flinders University</p> |

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| <p>11.45am – 12.45pm T110</p> | <p>Parallel Session 2: Chair: Stephanie Luz Mantilla Filling the Gap- Improving Oral Health Outcomes for People with Cerebral Palsy Karen Lansdown, University of Sydney</p> <p>STELLER: Supporting the translation into everyday life of lived experience research Anne Honey, Katherine Gill, University of Sydney</p> <p>The importance of patient and public involvement across the continuum in health technology decision-making Sally Wortley, University of Sydney</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: Jen Smith-Merry</p> <p>Katherine Gill, Richard Schweizer, Bradley Foxlewin, Anne Honey and Nicola Hancock</p> |
| <p>2.30pm – 3.30pm T203</p> | <p>Parallel Session 3: Chair: Nicola Hancock Reflecting on research and lived experience Robert Pedlow</p> <p>The insights from two types of expertise on disability: scientific and lived Shane Clifton, Nicola Fortune, Gwynnyth Llewellyn, University of Sydney</p> <p>Collaboration with consumers, carers and other stakeholders: Lessons for mental health policy, services and research Michelle Banfield, Amelia Gulliver, Alyssa Morse, The ACT Consumer and Carer Mental Health Research Unit, The Australian National University</p> |
| <p>2.30pm – 3.30pm T207</p> | <p>Parallel Session 3: Chair: Cherry Baylois Choice or coercion in childbirth: a room with a view Marjan Khajehei, University of Sydney</p> <p>How to engage with consumers to reduce medication errors and harm? Alison Vickery, Kerin O'Halloran, Australians for Safe Medicines</p> <p>The Patient's Voice. A qualitative study embedding person centred care with outpatients in chronic and complex care Jane Bradshaw, University of Tasmania</p> |
| <p>2.30pm – 3.30pm T208</p> | <p>Parallel Session 3: Chair: Sarah Chan Listen! Exploring why the character trait of 'listening' is absent from virtue ethics mental health practice frameworks Bè Aadam</p> <p>CP Quest: Community and researchers together for cerebral palsy research Isabelle Baldé, Shannon Clough, Sarah McIntyre, the University of Sydney</p> <p>Public involvement in dementia research in Australia: personal reflections and political realities Jane Thompson</p> |
| <p>2.30pm – 3.30pm T110</p> | <p>Parallel Session 3: Chair: Karen Wells The SWASH survey of lesbian, bisexual and queer women's health: How community shaped and sustained a 22-year collaboration. Julie Mooney-Somers, Sydney Health Ethics University of Sydney</p> |

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| | <p>What instructions are available to health researchers for writing lay summaries? A Scoping Review. Karen Gaaney, School of Public Health, University of Sydney</p> <p>Consumer & Community Involvement at Telethon Kids Institute: our journey – our success Anne McKenzie AM, Telethon Kids Institute</p> |
| 3.30pm – 3.45pm T107 (ground floor) | Afternoon tea |
| 3.45 – 4.45pm T203 | <p>Parallel Session 4: Chair: Shane Clifton</p> <p>Organisational approaches to public involvement in health research – perspectives from a local health district and medical research institute.Karena Conroy, Sydney Local Health District & The George Institute for Global Health</p> <p>Successfully Participating in General Societies when Living with a Neurological Disability Martin Raffaele, the University of Sydney</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 Nicole Scholes-Robertson, Centre for Kidney Research</p> |
| 3.45 – 4.45pm T207 | <p>Parallel Session 4: Chair: Ellen Stewart</p> <p>Principles and strategies for involving patients in research in chronic kidney disease: report from national workshops Talia Gutman, Sydney School of Public Health, University of Sydney</p> <p>Using video-reflexive methods to optimise infection prevention and control: A collaboration between researchers, patients, family members and healthcare professionals Mary Wyer, Gary Armstrong, Tegan Dawson, Westmead Institute for Medical Research and the University of Sydney</p> |
| 3.45 – 4.45pm T208 | <p>Parallel Session 4: Chair: Ivy Yen</p> <p>Sharing power with communities in health research priority-setting: Developing a ethics toolkit for engagement practice Bridget Pratt, University of Melbourne</p> <p>A shock to the system: service-user lead research using lived experience knowledge to inform ECT practices Karen Wells, University of Sydney</p> |
| 3.45 – 4.45pm T110 | <p>Parallel Session 4: Chair: Carol Porteous</p> <p>Consumer and community involvement in health research – what do consumers say about how to do this? Angela Todd, Sydney Health Partners University of Sydney</p> <p>Lived Experience Evaluation – Keep It Real! Danielle Brennan, Eloise McKimmon and Natasha Malmstrom, Brisbane North Primary Health Network</p> <p>Consumer and Community Engagement in Research in South Western Sydney: Insights from the SWSLHD Consumer and Community Participation Unit Lynda Johnston and Stefanie Leung, South-west Sydney Local Health District</p> |
| 4.45pm – 5.30pm T109 | <p>Wrap up & Conference close Chair: Jen Smith-Merry</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

Kate Steinbeck, Director, Wellbeing Health & Youth, NHMRC Centre of Research Excellence (CRE) in Adolescent Health (USyd) – Medical Foundation Chair in Adolescent Medicine, University of Sydney

Adolescent Health Research Commission

Betty Nguyen, Western Sydney University

Health Literacies

Rachel Skinner, University of Sydney

Knowledge Translation

Fiona Brooks, University of Technology Sydney

Ethics of Engagement

Julie Mooney-Somers, Sydney Health Ethics, University of Sydney

People, Places and Platforms

Teresa Swist, Institute for Culture & Society, Western Sydney University

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

Anthony Brown and Janelle Bowden Health Consumers NSW and Research4Me

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?

Angela Todd, Sydney Health Partners University of Sydney

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

Maria R. Dahm, Maureen Williams, Centre for Health Systems and Safety Research, Macquarie University

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

Anna Singleton, Westmead Applied Research Centre, University of Sydney

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

Catherine Maguire

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

Patti Shih, Australian Centre for Health Engagement Evidence and Values, University of Wollongong.

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

Thomas Bevitt, University of Canberra

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

Talia Gutman, University of Sydney

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
Peri O'Shea and Karen Fisher, UNSW Social Policy Research Centre

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

Chérie McGregor, Tegan Scheffe, Megan Dutton, Dan Hermans (Sunshine Coast Mind and Neuroscience Thompson Institute) with community partners Rosie Williams and Jocelyn Culpitt.

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?

Adam Johnston, Macquarie University

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

Gabrielle Carey, University of Technology Sydney

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

Cathy Vaughan, Sarah Khaw, Liz Gill-Atkinson, University of Melbourne

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

Elisabeth Kochman, Murray McLachlan, Shirley Baxter, Cancer Voices NSW

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

Lenore De la Perrelle, Ian Gladstone, Flinders University

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

Karen Lansdown, University of Sydney

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

Anne Honey, Katherine Gill, University of Sydney

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

Sally Wortley, University of Sydney

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 Protheses 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

Katherine Gill, Richard Schweizer, Bradley Foxlewin, Anne Honey and Nicola Hancock

Parallel Session 3:

Reflecting on research and lived experience

Robert Pedlow

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

Shane Clifton, Nicola Fortune, Gwynnyth Llewellyn, University of Sydney

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

Michelle Banfield, Amelia Gulliver, Alyssa Morse, The ACT Consumer and Carer Mental Health Research Unit, The Australian National University

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

Marjan Khajehei, University of Sydney

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 mucus, 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?

Alison Vickery, Kerin O'Halloran, Australians for Safe Medicines

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

Jane Bradshaw, University of Tasmania

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 3 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

Bè Adam

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 papers 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

Isabelle Baldé, Shannon Clough, Sarah McIntyre, the University of Sydney

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

Jane Thompson

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.

Julie Mooney-Somers, Sydney Health Ethics University of Sydney

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.

Karen Gainey, School of Public Health, University of Sydney

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

Anne McKenzie AM, Telethon Kids Institute

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.

Karena Conroy, Sydney Local Health District & The George Institute for Global Health

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

Martin Raffaele, The University of Sydney

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

Nicole Scholes-Robertson, Centre for Kidney Research

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

Talia Gutman, Sydney School of Public Health, University of Sydney

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

Mary Wyer, Gary Armstrong, Tegan Dawson, Westmead Institute for Medical Research and the University of Sydney

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

Bridget Pratt, University of Melbourne

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

Karen Wells, University of Sydney

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?

Angela Todd, Sydney Health Partners University of Sydney

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!

Danielle Brennan, Eloise McKimmon and Natasha Malmstrom, Brisbane North Primary Health Network

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

Lynda Johnston and Stefanie Leung, South-west Sydney Local Health District

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 humidity crib 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 humidity crib 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 at 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 when funds were dispersed, and 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's 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://novaajs.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’s 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/Oc96053a2976b98f54000000.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 38

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 Divine, 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 unfavourable 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-theproblems-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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PUBLIC INVOLVEMENT IN HEALTH RESEARCH

“What would Grandma say?”



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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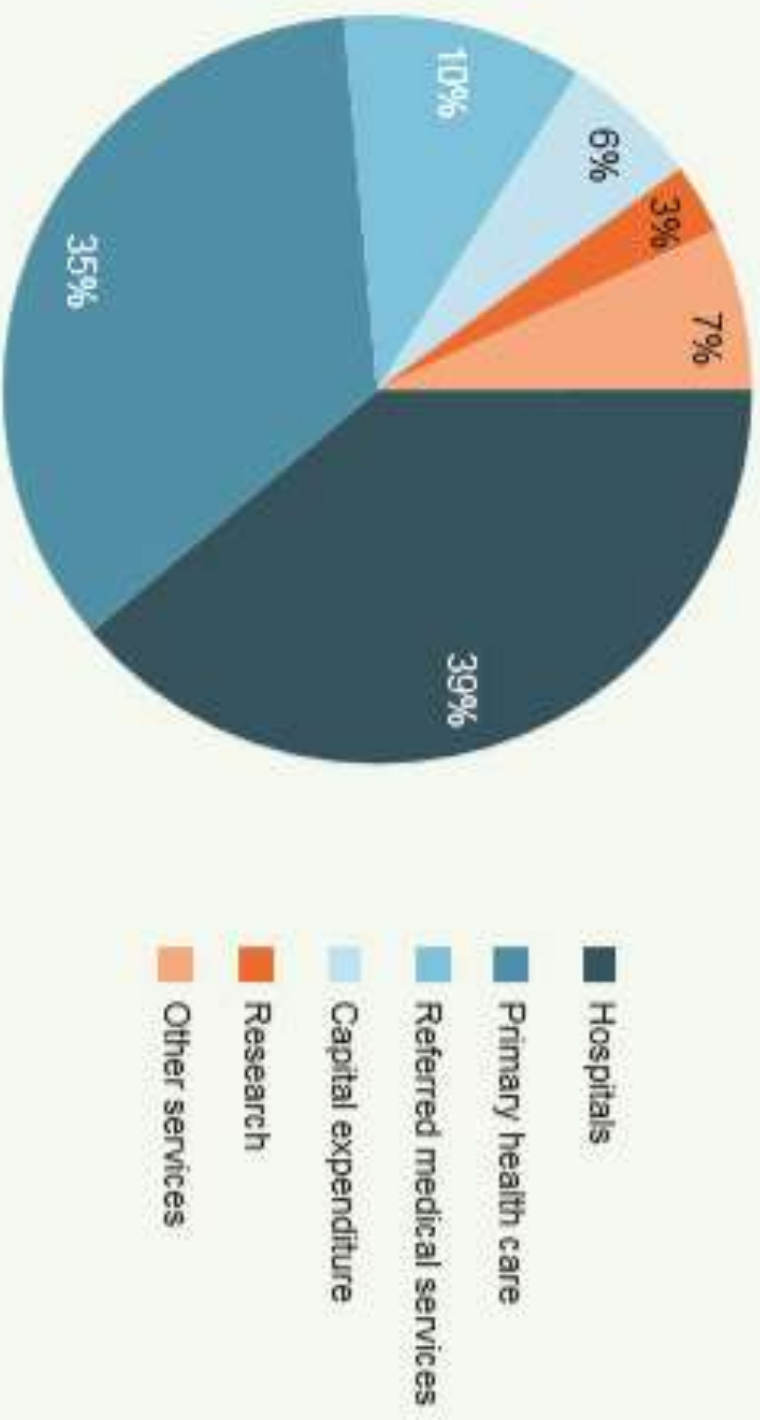
Researchers need to be...

- 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??

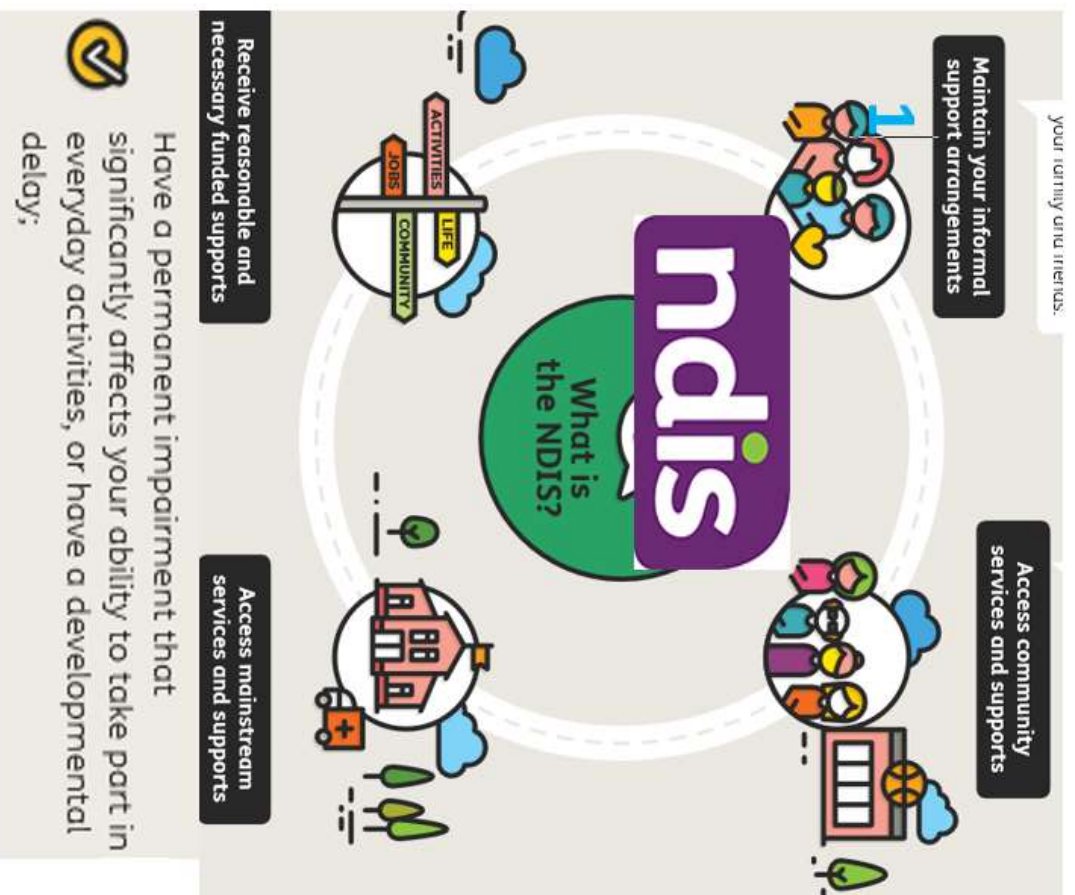
Figure 2.2.6: Proportion of total health expenditure, by broad area of expenditure, 2015-16



Sources: AIHW health expenditure database; Table 52.2.6.

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

NDIS in a page – Positive + / Negative -



Have a permanent impairment that significantly affects your ability to take part in everyday activities, or have a developmental delay;

'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?' Heike Fabig, mother

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

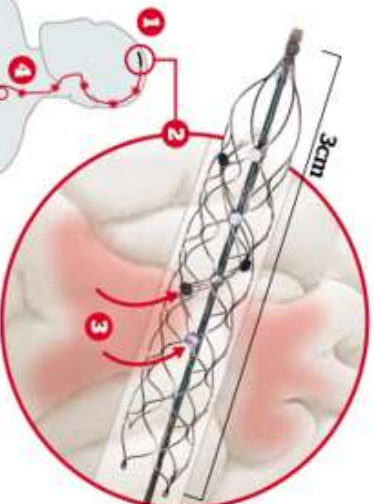
118 Functions of the Agency

(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



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 vein ...
- 4 ... to a wireless transmitter between the skin and ribs.
- 5 That transmitter sends the commands wirelessly to the exoskeleton or to a wheelchair.

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/>

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.,)

WHAT THE NDIS IS NOT DOING



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



CAREER AWARD

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



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/>

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

“What would Grandma say?”



QUESTIONS?

'Dance with the one that brung

ya, Ronald Reagan, 40th US President



**WHAT IS COMMUNITY
ENGAGEMENT? Or...**
**Could you make the public
love the *Vacanti* mouse?**



EnableNSW Advisory Council appoints new members

Seven positions have been filled on the EnableNSW Advisory Council (ENAC), including a special appointment to guide EnableNSW through major national reforms such as the establishment of Local Health Networks.

ENAC facilitates the involvement of key stakeholders including clinicians and consumers of EnableNSW in the development of strategic policies, plans and initiatives in the provision of disability support services.

Of the seven new appointments, two were existing members who have been reappointed for a second term, with the other five joining the Council for the first time.

Now appointees include:

- Ms Hoopy Chapman – CEO of the Independent Living Centre NSW
- Mr Adam Johnston – Consumer and Director on the board of the Cerebral Palsy Alliance (formerly The Spastic Centre)

- Ms Kristin Albrecht – Associate Director of Community Health Services at Prince of Wales Hospital
- Ms Barbara Mersen – Public Affairs Director of Southern Cross Community Health

- Ms Leanna Harvey AM – Registered Nurse with more than 35 years in the health and disability sectors (reappointed for second term)

- Associate Professor Karen Walters – Paediatric Respiratory Physician and Head of the Respiratory Support Service at the Children's Hospital at Westmead (reappointed for second term).

- The Council had also welcomed Adjunct Professor Annette Symes as a special appointee to assist Council in its consideration of the implications of a number of national health reforms including the new Local Health Districts.



EnableNSW ENAC Members

Back row (standing) (L-R): Ms Judy Harwood, Ms Barbara Mersen, Ms Kaitlin Kloubert, Ms Bronwyn Scott, Mr Allan Marmbery, A/Professor Karen Walters, Ms Robyn Chapman, Ms Tonina Harvey, Dr Chris Paulson, Ms Lesley Gild



THE BENCHMARK GROUP
excellence in education

Statement of Attainment

Adam Johnston

Course in Consumer Leadership

Course Code: 22095VIC

These competencies were completed as part of the above course:
VU20263 - Engage as a consumer in a health care service
VU20264 - Promote consumer engagement
VU20265 - Promote consumer leadership


Bruce Greaves
General Manager

November 2015 BSG008


Drew Sutherland
CEO



A Statement of Attainment is issued by a Registered Training Organisation (RTO) to an individual who has completed one or more units of competency from nationally recognised qualifications in a course. This Statement of Attainment is recognised with the Australian Qualifications Framework (AQF) and is a record of the individual's achievement.

Health Issues Centre, Vic <http://healthissuescentre.org.au/>

'Community engagement' is...a planned process with the specific purpose of working with identified groups of people, whether they are connected by geographic location, special interest, or affiliation or identity to address issues affecting their well-being.

***What is Community Engagement?* Dept. of Environment and Primary Industries (Vic)**

EnableNSW Advisory Council appoints new members

Seven positions have been filled on the EnableNSW Advisory Council (EWAC), including a special appointment to guide EnableNSW through major national reforms such as the establishment of Local Health Networks.

EWAC facilitates the involvement of key stakeholders including clinicians and consumers of EnableNSW in the development of strategic policies, plans and initiatives in the provision of disability support services.

Of the seven new appointments, two were existing members who have been reappointed for a second term, with the others free joining the Council for the first time.

New appointments include:

- Ms Hoopyn Casparian – CEO of the Independent Living Centre NSW
- Mr Adam Johnston – Consumer and Director on the board of the Carotid Palsy Alliance (formerly The Spastic Centre)

- Ms Kristin Alnohoru – Associate Director of Community Health Services at Prince of Wales Hospital
- Ms Barbara Mearns – Public Affairs Director of Southern Cross Community Health

- Ms Emma Harvey AM – Registered Nurse with more than 35 years in the health and disability sectors (reappointed for second term)

- Associate Professor Karen Walters – Paediatric Respiratory Physician and Head of the Respiratory Support Service at the Children's Hospital at Westmead (reappointed for second term).

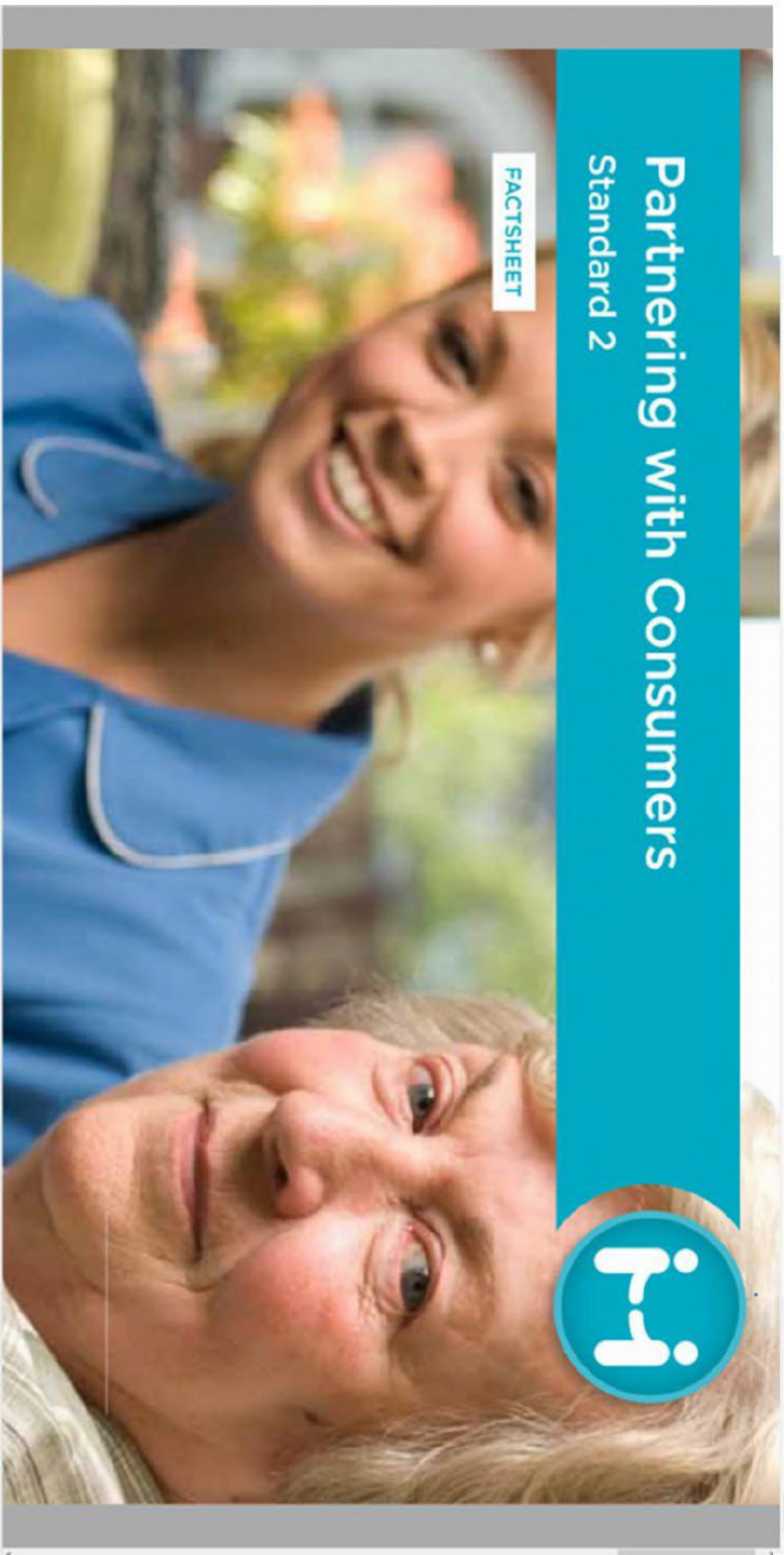
The Council had also welcomed Adjunct Professor Annette Symes as a special appointee to assist Council in its consideration of the implications of a number of national health reforms including the new Local Health Districts.



e-news ENAC Members

Back row (standing) (L-R): Ms Judy Jarwood, Ms Barbara Mearns, Ms Elaine Moulden, Ms Bronwyn Scott, Mr Alan Moriarty, Dr Professor Karen Walters, Ms Betsy Chapman, Ms Terrie Harvey, Dr Chris Paulus, Ms Lesley Gild

Front row (seated) (L-R): Mr Adam Johnston, Mr Hoopyn Casparian, Mr Steven Johnston



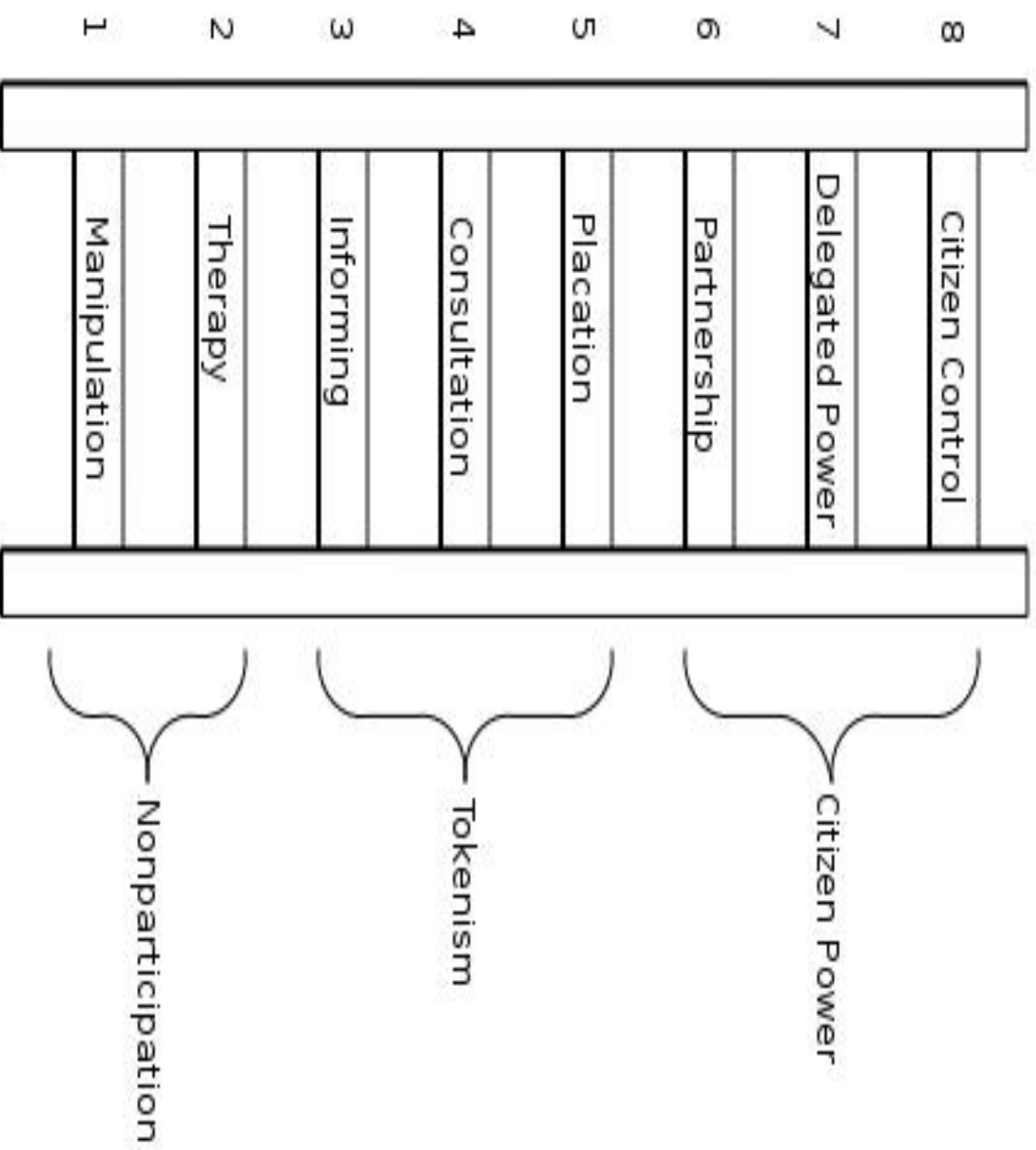
Partnering with Consumers Standard 2



FACTSHEET

**AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE**

A Ladder of Citizen Participation - Sherry R Arnstein



Tony Abbott has not included a science minister in new Cabinet

September 17, 2013

<http://www.news.com.au/>



THE LAW SOCIETY
OF NEW SOUTH WALES



MACQUARIE
University



Health
Northern NSW
Local Health District



HEALTH
CONSUMERS
NSW



Northside
COMMUNITY CHURCH



AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

**If I believe in something, I sell it,
and I sell it hard. – Estée Lauder**

**People don't ask for facts in
making up their minds. They
would rather have one good, soul-
satisfying emotion than a dozen
facts. – Robert Keith Leavitt**

**“CHRISTOPHER REEVE UNDERSTOOD THAT...
EVERYTHING BEGINS WITH HOPE. HIS VISION OF
WALKING AGAIN, HIS BELIEF THAT HE WOULD
BE ABLE TO IN HIS LIFETIME, TOWERED OVER
HIS BROKEN BODY.”**

PATTI DAVIS

© Lifhack Quotes





***“Facts are stupid things —
stubborn things, I should say. ”***



***“If you’re
explaining,
you’re losing.”***

WHO OWNS MY TISSUE SAMPLE, BECAUSE IT ISN'T ME? THE DEBATE WHICH URGENTLY NEEDS MOORE CONSIDERATION

**SUMMARY OF A MASTER OF LAWS THESIS SUBMITTED TO THE
UNIVERSITY OF NEW ENGLAND, ARMIDALE**

BY ADAM JOHNSTON

BA/LIB (MACQ.) DIP LEGAL PRACTISE (COLLEGE OF LAW) LLM (UNE) GAICD

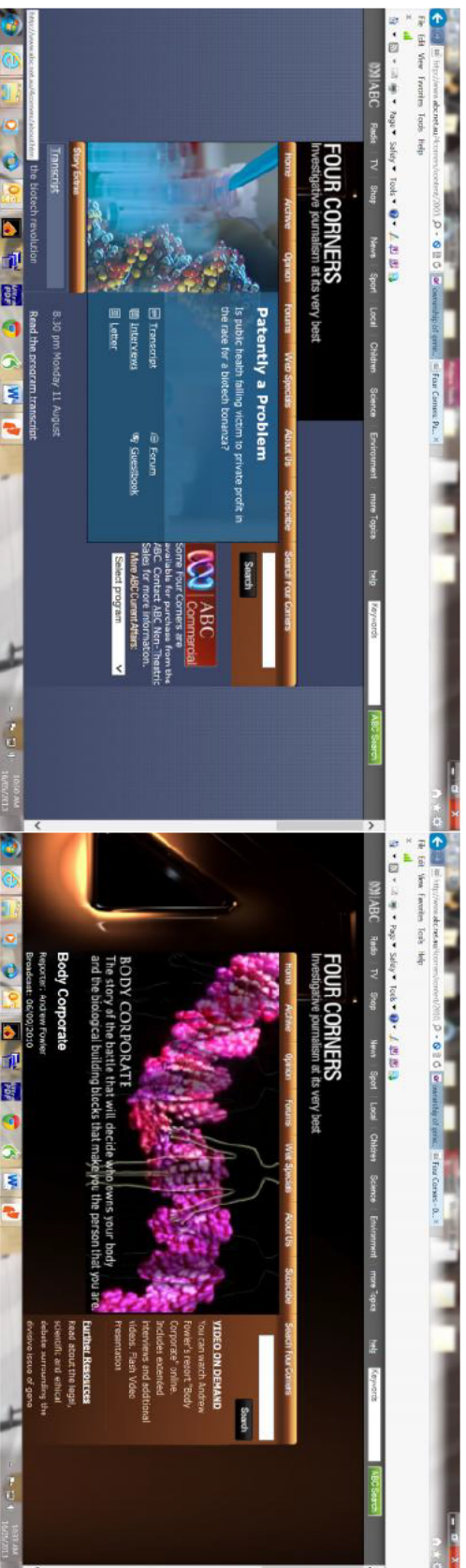


You can see my paper on the Social Sciences Research

Network at: <http://ssrn.com/abstract=1855924>

INTRODUCTION

CAN RESEARCHERS' REALLY SUSTAIN CONTINUING BAD PRESS ABOUT PATENTS?



HOW CAN WE REASSURE POTENTIAL RESEARCH PARTICIPANTS THAT THEY WILL BENEFIT?
A survey of the case law indicates the resistance of jurists to the notion of individuals holding either an equitable or real property right in their body. Precedent, morality and fears about endorsing a form of slavery mean most judges and politicians also reject the idea of paying research participants on a commercial basis, for their tissue samples.
IN A SECULAR WORLD THIS SHOULD CHANGE AND A FEW JUDGES HAVE WRITTEN PERSUASIVE DISSENTING OPINIONS, SHOWING HOW THIS REFORM CAN OCCUR

Aims and Hypothesis: That the common law is capable of supporting the advancement of science, alongside acknowledging an ongoing beneficial interest for those who provide samples to researchers and, that such participants should reasonably expect a return from research successfully applied for clinical benefit



Chronicle / Eric Lusa

The tension between various legal opinions is underlined by these men. Far left: Sir William Blackstone, English Justice of the Common Pleas from 25 June 1770 – 14 February 1780. Left: Justice Stanley Mosk, Associate Justice of the California Supreme Court from September 1, 1964 – June 19, 2001

(Heirs) have no property right in the bodies or ashes of their ancestors, 'nor can [an heir] bring any civil action against such as indecently at least, if not impiously, violate and disturb their remains, when dead and buried'. – Sir William Blackstone, Commentaries on the Law of England 429 (1811)

It does not follow that the researcher who obtains (tissue) must necessarily remain ignorant of any limitations on its use: by means of appropriate recordkeeping, the researcher can be assured that the source of the material has consented to his proposed use of it, and hence that such use is not a conversion. To achieve this end the originator of the tissue sample first determines the extent of the source's informed consent to its use...As the Court of Appeal correctly observed, any claim to the contrary 'is dubious in light of the meticulous care and planning necessary in serious modern medical research' - Moore v. Regents of University of California, 793 P.2d 479 (Cal. 1990) at 204 (Mosk J, dissenting)



**METHODOLOGY
– CONDUCT
LEGAL
RESEARCH VIA
THE INTERNET**

KATE JANE BAZLEY V WESLEY MONASH IVF PTY LTD

[2010] QSC 118 - As executor of her late husband's estate, Ms

Bazley wanted semen preserved as part of the estate. The court accepted not only that the IVF clinic was bailee, but that as long as the estate paid the storage fee, the executor was the bailor.

YEARWORTH AND OTHERS V NORTH BRISTOL NHS

TRUST, COURT OF APPEAL, [2010] QB 1 – Several men

undergoing cancer treatment successfully sued the NHS over its failure to preserve their sperm

PATRICIA COLAVITO V NEW YORK ORGAN DONOR

NETWORK, INC., ET AL., NEW YORK COURT OF APPEALS,

2006 NY INT. 161, 2006 NY SLIP OP 09320, NO. 106 - A

patient awaiting kidney transplant could not assert a proprietary



'Every man has a property in his own person: this nobody has any right to but himself. The labour of his body, and the work of his hands, we may say, are properly his.' - John Locke, "The Second Treatise On Civil Government"

interest in a friend's organ, despite the fact that it has been gifted to him

REGINA V KELLY; REGINA V LINDSAY [COURT OF APPEAL]

[1999] QB 621, 2001 – Body parts were stolen from a lab. The

court rejected the claim they were being used for artist purposes

MOORE V. REGENTS OF UNIVERSITY OF CALIFORNIA, 793

P.2D 479 (CAL. 1990) – The court accepted Mr Moore's consent

had not been sought for research, but rejected his claim for a portion of research earnings

DOODEWARD V SPENCE [1908] HCA 45; (1908) 6 CLR

406, 414 – The High Court found that property existed in the body of

a two-headed baby preserved in a bottle of spirits

NOT PROPERTY

SIR WILLIAM BLACKSTONE - (Heirs) have no property right in the bodies or ashes of their ancestors - Commentaries on the Law of England 429 (1811)

COLAVITO V NEW YORK ORGAN DONOR NETWORK, INC., ET AL., -
Applicant could claim no property right in her late husband's kidney; the court relied on Lord Coke's 18th century dictum 'a corpse has no value'

YEARWORTH AND OTHERS V NORTH BRISTOL NHS TRUST, [2010]
QB 1 AT 21 - '(B)odily parts...which were extracted from the body with a view to their future [use], rather than to their abandonment, retained a functional unity with the body, such that injury to them would constitute physical injury'

MOORE V REGENTS OF UNIVERSITY OF CALIFORNIA, 793 P.2D 479 (Cal. 1990) – (Majority at 72) Human tissue (is) in a class of its own legally (and) all such things of tissue fall into the unique category, regardless of the factual circumstances

(DNA is) like a book with 23 chapters-one for each of our 23 pairs of chromosomes, which make up the gene material (macromolecule) found in the nuclei of cells. Each chapter is divided into sections-genes. You have about 30,000 genes. – James Martin, *The Meaning of the 21st Century*, Random House (2006)

MOORE – (Mosk J, dissenting) (The) researcher who obtains (tissue) must necessarily remain ignorant of any limitations on its use (by) first (determining) the extent of the source's informed consent to its use

PROPERTY

JOHN LOCKE - Every man has a property in his own person: this nobody has any right to but himself - The Second Treatise on Civil Government (1690)

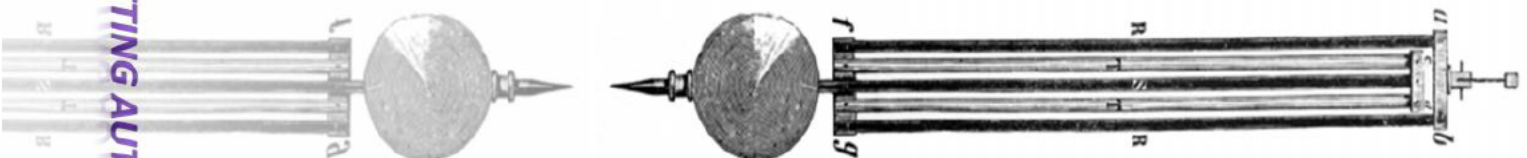
COULD DNA BE LIKENED TO COMPUTER CODE?
YEARWORTH AT 261 - Ownership could involve 'a right to use' without this necessarily being equivalent to a right to possess.

LOTUS V BORLAND INTERNATIONAL, 9 F.3D 807 (1ST CIR. 1995) - Lotus sought to stop the respondent from using its spreadsheet program as a basis for writing other useful related software. The court determined that Borland's programming was of sufficient difference and originality for there to have been no copyright breach.

KATE JANE BAZLEY V WESLEY MONASH IVF PTY LTD [2010] QSC 118 -The court accepted not only that the IVF clinic was bailee of sperm, but that as long as the estate paid the storage fee, the executor was the bailor.

DOODEWARD V SPENCE [1908] HCA 45 - Near the end of his judgement, Griffith CJ suggested that the degree of skill needed to transform the legal status of tissue was not great

FINDINGS: THE PENDULUM OF COMPETING AUTHORITIES & PRINCIPLES



CONCLUSIONS

- Section 32 of the *Human Tissue Act 1983 (NSW)* prohibits research participants being paid on a commercial basis for their services (i.e.: tissue donations)
- However, they may retain common law rights to their tissue, but these claims need to be made before tissue is removed
- As the public becomes more aware of the value of their DNA, more litigants like John Moore will emerge
- For example: **CANCER VOICES AUSTRALIA V MYRIAD GENETICS INC [2013] FCA 65 - <http://www.austlii.edu.au/au/cases/cth/fca/2013/65.html>**
Simone Mitchell & William Doyle of DLA Piper noted that *Cancer Voices* abandoned an argument that human beings are not patentable inventions. While submitting the genes were not patentable, no other ground of invalidity was raised.
<http://www.mondaq.com/australia/x/222116/patent/federal+court+hands+down+decision+of+cancer+voices+australia+v+myriad+genetics+inc>
- This leaves many of my arguments untouched & untested. See: *Who owns you? On Line Opinion, 18/10/10* <http://www.onlineopinion.com.au/view.asp?article=111109>
Reserving the right to protect our genetic code, The Punch, 17/11/10
<http://www.thepunch.com.au/articles/reserving-the-right-to-protect-our-genetic-code/>