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## What would Grandma say? - On Line Opinion

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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 Coberg, Melbourne. Later moving back to her childhood home, in Manly, Jill's daughters grew to adulthood: one would marry and have two children. One of these children, me, would be born three months prematurely and was not supposed to live. A humidicrib and some inspired 1970s intensive care treatment at Manly Hospital would see me through. Grandma would say of me, regarding my resulting disabilities: "at least he was born in the right age". She also related to me a dream



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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 humicrib 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 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.

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 stemming 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

over 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?

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The first issue, however, is to establish: what is health? According to *Black's Law Dictionary*, 1991, health is:

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.

What the term health means in the early 21<sup>st</sup> century as against what it meant in the late nineteenth or early 20<sup>th</sup> 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. People are living longer, but it is far from clear that we are hale or whole. Nor can it be claimed Australia spends that much on research,

with the same AIHW Report suggesting this was just 3 percent of health outlays.

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 to add that this is not a new idea, with consumer bodies, consumer, advocacy and industry collaborations, and clinicians all realising the need and benefits of enacting such policies. While movements for the public to be actively involved and responsible for their own health and wellbeing is positive, we need to examine what has not happened.

This has to be balanced with the reality acknowledged by the [Australian Commission on Safety and Quality in Healthcare](#), that only about 40 percent of Australians have the knowledge required to follow prescriptions and other clinical directions, warnings or messages as intended. Alternatively, this figure could be cited as an argument for more public participation in health research, to build health literacy.

How much has this lack of health literacy lead to the design for the National Disability Insurance Scheme looking acceptable? 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 the details of other non-government organisations who would now provide me with disability support services and be funded by the NDIS. Significantly though, the NDIS Agency would fund nothing it deemed related to my health, as if there was ever a neat dividing line between these two – support and health.

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Other than being the source of funds dispersed when individual plans were approved by the central bureaucracy, State and Federal Governments have largely excised themselves from the public provision of many social services related to disability. 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?

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. All the references to research 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. It is not asking its participants or families (supposedly central to its inception) or the taxpaying public who are funding it, what their view of research is. Do NDIS management fear a series of different answers? Would this upset the quiet, convenient and profitable cartel between the Commonwealth Government, the NDIS and the charitable sector?

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.

For [\\$22 billion annually](#), 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:

**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.

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". People will also be declined because of the need to show the effectiveness of a support to others "in like circumstances". 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 robotics except 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*: Risk is always to be avoided according to Part 5 of the *Rules*, which states:

**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;

It is not as if we lack bright, young researchers ready and willing to take research to the public, but 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. The public also need to pressure politicians to rationalise the number, extent and value of tax expenditures and other subsidies 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.

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 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. We might demand more from an Agency and, a supposedly enhanced, innovative disability sector.

We might also unfavourably critique the lack of ambition in the NDIS, given that supporting a participant's functional

improvement is beyond the Scheme's scope. Yet, I suspect functional improvement is what many participants and families might have expected to be an aim of the NDIS. My Grandma had a clarity on this point four decades ago, which is strangely missing now, in this supposedly enlightened, Informed age.

Neither the NDIS, its charitable partners or government 'got the memo' about the real potential for 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 other providers. 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.

What would Grandma say?

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