

Submission

- National Disability Insurance Scheme
Saturday 8 October 2022

Submitter Details

Peter William Sutton

I wish to lodge a submission to the Enquiry into the National Disability Insurance Scheme and the National Disability Insurance Agency.

The terms of reference indicate that the inquiry will examine the implementation, performance, governance and expenditure of the scheme.

The scheme should be expanded and widened to include more Australians with disabilities. It is limited in its scope and allows discrimination against older Australians. Disability does not discriminate, its effects and impacts are the same whether the concerned individual is 55, 60, 65 or 70. It impacts the quality of life, agency and dignity of the affected persons, their family and friends. There are huge differences between the supports offered to younger Australians with a disability and those over the age of sixty five.

The National Disability Insurance Scheme was established by the Gillard Government and deliberately excluded those Australians over the age of sixty five years. It was deliberate and wilful discrimination against this older cohort of Australians. I have raised this issue with MP's of both stripes. Coalition MP's were quick to blame Labor who established the NDIS, although, conveniently overlooking the fact, they were in government for nine years. Seemingly they, could have reformed the NDIS and addressed the issues. Labor MP's have pointed out that older Australians can access supports through My Aged Care. There is a huge difference in the quantum and amounts of support available.

To illustrate, an older Australian can receive \$52000 in support and administrative fees are deducted from these packages. A client of the NDIS can receive support of \$120,000. Ageism and discrimination actively exists against mature age Australians in employment, services, finance and should be actively opposed. It sets a poor example to others among the wider community when the Commonwealth can actively discriminate.

The NDIS should be opened up to all Australians irrespective of age.

My Personal Background

I was born in Shepparton, Victoria on February 11, 1964. My parents resided and worked in the small rural community of Yarroweyah, Victoria, a farming area in the Shire of Cobram, which is now part of the Moira Shire.

I received my primary and secondary education in Cobram, until moving to Melbourne for education and employment. I worked over thirty three years in various industries including Banking and Finance, Health Insurance and Retail.

In 2006, I was a pedestrian crossing at a properly designated and legal crossing when I was struck by a motor vehicle, sustaining various soft tissue injuries. I was initially off work for seven months during which time, I underwent a number of treatments including Physiotherapy, Hydrotherapy, Pilates and Feldenkrais.

Over the years my conditions have worsened, and I was forced to leave the workforce in 2018. I am now a Disability Support Pensioner. As an accident victim, I am a client of the Victorian Transport Accident Commission. There are limited supports there. I thus have an individual perspective of Disability. I am 58, and could be eligible for NDIS, given I am under 65.

I also have a different perspective from the fact that I have seen the impacts on older Australians. Growing up, I spent a lot of time with older people, as I knew all four grandparents and their siblings. I knew a sister of my Great Grandmother. My mother developed Diabetes and suffered severe Arthritis requiring hip replacements. She died in 2016, but at that time was experiencing the early stages of Alzheimer's, was largely immobile and received some supports including Meals on Wheels and assistance with cleaning and home maintenance. My father is alive, aged 86 and has some issues.

There is a huge anomaly in the value of supports provided.

I am also a volunteer with Uniting AgeWell, and formerly Uniting VIC/Tas which are agencies of the Uniting Church. I volunteer as part of the Social Support scheme, visiting an older person on a regular basis.

These interactions and experience give me broad insights into the issues around Disability and Ageing.

I am an advocate for Mature Age Australians, and for Various causes impacting social justice and equity issues.

I am a member of a range of organisations including the Combined Pensioners and Superannuants Association, National Seniors Australia and the Council of the Ageing Victoria. I have also signed petitions and disseminated information from the Disability DOESN'T Discriminate Campaign organised by Spinal Life Australia.

This submission is an individual and not on behalf of any organisation or group. These are my perspectives and views.

ISSUES

There is a campaign known as Disability Doesn't Discriminate coordinated by Spinal Life though it is not an issue confined to them. It has also been picked up by seniors groups.

I understand that under the My Age Care scheme, providers giving support to recipients in the home can levy administration fees. These can be quite substantial and reduce the level of support available.

The Disability Doesn't Discriminate campaign has informed me that although some Australians with significant disability are participants in the My Aged Care Scheme, the level of annual funding is approximately \$52,000 per year. Once the administration fees charged by service providers are taken into account (often 40% of the value of the package) participants are left with very little funding to support them. On the other hand, if these people were not actively discriminated against in the basis of age then they would be eligible to participate in the NDIS, and receive tailored financial support. Again the Disability Doesn't Discriminate campaign has informed me that this could be in the vicinity of \$150,000 per year with no administration fees charged.

These

These are the facts. In 2013, the then Labor Government deliberately amended the Age Discrimination Act to enable the NDIS to exclude people over the age of sixty five from the scheme.

ONE IN FIVE Australians live with a disability.

Forty Four and a Half Percent (44.5%) of those with a disability are over the age of 65 years.

A person with a spinal injury over the age of 65 receives just \$52,000 in funding support. By contrast a client of the NDIS receives as much as \$165,000, about three times as much.

I will provide below information published by National Seniors in 2021.

The Royal Commission into Aged Care recommended that those people with significant disabilities, receive at least as much support as provided by the NDIS. Recommendation 72.

Older Australians are likely to face the double whammy of discrimination from both Ageism and Discrimination in respect of their disability. They are less likely to work and able to fund their own care needs. We know from the figures of those on Jobseeker that the largest cohort are those individuals over fifty.

Items such as mobility aids are expensive. Motorised scooters for example can cost well over \$14000.

I am not currently on the NDIS, though, I am unable to work due to an ongoing back condition. As I am ageing, my conditions are worsening. Accompanying this, is the very real anxiety and fear that I will require home modifications, which I can't afford. I am finding it more difficult, with such simple tasks to get on and off the toilet without modifications.,I think I will soon need to instal bats and handles. I find it more difficult to get out of a bath now. The way I travel now is changing.I rely on public transport to get around. I can travel by train, they are close to the platform, ride smoother and have no large steps. I avoid buses now, and will not use them. There is a large step up or down,, between the vehicle and the ground. Transport options are changing.

If I drop an item, it is increasingly hard to bend down and pick items up. The use of mechanical aids will eventually be needed.

Support in the home and for ageing in place, is essential for personal agency, for self determination and personal dignity. To maintain independence in the home is important for self esteem and mental health. This will require for some, supports. Whether this is provided by My Age Care, or NDIS is irrelevant. What is relevant is the huge disparity in supports available.

In the event that these supports are not provided there are a number of other implications. One of these, is that care falls back on to other family members. This creates a feeling of anxiety or worry that they are a "burden". This feeling can lead to Depression and Anxiety, or the loss of a will to live. A secondary consequence, is that family members to whom, this responsibility falls become resentful, angry and bitter. This can lead to physical and mental elder abuse. A third consequence is economic and impacts the wider economy and civil society. Personal carers may need to reduce hours at work, require more time away or cessation of work altogether.

It is better to provide adequate supports at home.

From personal experience, my paternal grandmother lived in her own home independently until her early 90's. She had some support receiving cleaning assistance from the local council an hour or two per week and she received meals on wheels for lunch. She was still able to prepare her own breakfast and a light evening meal. She went into an aged hostel. She declined in age care. She was well cared for, receiving decent meals and was clean, but she wasn't as happy. She confided in me, that " I didn't want to come in here, but it would stop the family worrying about me."

My maternal grandmother used to say she wanted to die early, because she did not want to be a burden. My mother died in October 2016, the sixth anniversary is approaching on the 22nd. She was willing to die, as she too, did not want to be a burden.

Adequate supports enabling independence and dignity should be a right. It is not fair that there are such large anomalies.

In many cultures, older people are perceived respectfully and valued. Their contributions recognised. Our mature age Australians built this country, they raised children and families, some served their communities with distinction as volunteers, or in the armed services. We need to look after them.

Instead of seeing them, as human beings, they are commoditised and distilled down to dollars and cents. The narrative is of " financial sustainability" or of " costs to the budget ". We have substituted humanity for dollars. We used to value people. We have become an Economy instead of a society.

To illustrate this point, I will use Peter Costello, as an example. He served as the Member for Higgins, Deputy Leader of the Liberal Party, and long-standing Treasurer of Australia. He oversaw unprecedented growth in revenues due to the mining boom. Rather than invest in our people, he built in structural budgetary problems by creating the problems we are dealing with today, thanks to the combination of capital gains tax discounts, negative gearing and refund of imputation credits. He introduced the principle of Intergenerational reports. These were undertaken on the basis of " long term sustainability of Commonwealth Finances" These reports have consistently highlighted the increasing cost of age care and the reducing pool of taxpayers.

The current Labor Government remind us, that Australia has a Trillion Dollar yet. There is an opportunity here, to repeal the legislated Stage 3 Tax Cuts. The savings could be used to properly fund the NDIS, including equality of support and treatment for older Australians by creating parity.

I will refer directly to the Royal Commission

- “Equity for people with disability receiving aged care. By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions.”
- Annual reporting to Parliament by the Disability Discrimination Commissioner and the Age Discrimination Commissioner. By 1 July 2024, the Disability Discrimination Commissioner and the Age Discrimination Commissioner should be required, as part of the new National Disability Strategy, to report annually to the Parliament on the number of people receiving aged care with disability who are aged 65 years or older and their ability to access daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those available under the National Disability Insurance Scheme.

The Beatles famously sang “Will you still need me, will you still feed me, when I’m sixty four.” It seems rather apt.

There is a coalition of groups aligned together advocating for this reform. These include Council of the Ageing Australia, Forward Ability Support(formerly Paraquad NSW), National Disability Services, Physical Disability Council of NSW, Spinal Cord Injuries Australia, Spinal Life Australia, Spinal Cure Australia.

These groups issued a joint statement on 1 June 2022.

I will quote at length from that statement.

“We cannot wait for the Disability Royal Commission or other reviews to be complete before tackling this issue. The new Albanese Government can act now to deliver equality and fairness for people over 65 with disabilities.”

The statement continues,

“ These are the facts:

1. If you acquire a disability after you turn 65, there is no disability support available to support your care.
2. If you were eligible for the NDIS during your life but were not accepted before you turned 65, you are not eligible for any Federal Government disability support.
3. People with disabilities over 65 must rely on Home Care packages that are currently capped at \$52,000 each. However, the proper care for a 65+ year old person with quadriplegia costs more than \$200000 per year.
4. Funding and care shortfalls are currently met by family members who leave their jobs to become carers and sell their homes to fund support.
5. The current gap in funding places unbearable pressure on older partners who have their own care and support. They now spend their time fighting for funding in a complex system that should empower and support them. “

I made those points earlier in my submission. There is a real economic cost due to this. In Economics we use the term Opportunity Cost. That is the cost of another valuable alternative. In this case, the extra cost of funding NDIS for older Australians weighed up against the lost productivity and family costs, as carers surrender work opportunities to assume care of older relatives.

In 2011 the Australian Government published Social Policy Research Paper No 43. This paper examined the costs of caring and living standards of carers. The paper in its introductory statement stated, “ Informal carers are people who provide unpaid help, support or assistance to family members or friends with disability, chronic illness, mental illness, other illness or alcohol and other drug problems. Recent estimates suggest that around 16% of adult population provide informal care.”

It is clear that without financial support through My Age Care or NDIS much of the burden falls upon family members.

The report goes on “ ____ Thus it is likely that many will encounter the challenges of competing demands of caring and paid employment. The evidence suggests that, given limited alternative care arrangements, many carers adapt to their caring role by reducing or leaving employment.”

It is clearly evident that age discrimination exists from the Commonwealth in its treatment of older Australians with disabilities.

The disparities must be addressed immediately to remove this inequity and inequality. Either NDIS must be expanded to include older Australians or My Age Care arrangements amended to reflect parity with benefits received on the NDIS.

Disability and illness does not discriminate on the basis of age. The Age Discrimination Act must be amended to remove these ageist and discriminatory aspects.

Further discrimination is allowed and sexism encouraged as care responsibilities largely fall back on women. It may be that expansion of supports may still see women in those care roles, though paid.

I believe this submission is lodged in accordance with the Terms of Reference. The actual terms are limited, however, at c it says “ any other relevant matters”.

Those terms refer to “ the impacts of NDIA **capability** (my emphasis) and culture on the experiences of people with disability and NDIS participants **trying to access information, support and services within the agency.**”

I am happy for this submission to be published in whole or in part, and to be shared or disseminated with relevant stakeholders including other Commonwealth departments, Members of Parliament and Senators to facilitate policy discussion and debate.

Peter Sutton