Acquired disability and support in the Age Care System.

I would like to make two suggestions:

1. That acquired disability be specifically recognised in the Age Care Act as a condition entitling an older person to support in the Age Care System.

This follows logically from The Government establishing the NDIS to care for and improve the lives of disabled Australians and then legislating to prevent those over 65 from entering the Scheme. People who become disabled through accident after turning 65 must therefore be assisted in the Age Care system, as stated by Mr Shorten, Minister for the NDIS. 'Acquired disability' would thus join concepts such as 'illness' and 'frailty' which are specifically referred to or implied in the Act.

The underlying ethos of the Age Care System is to enable aging people to live as normal a life as possible in their own homes for as long as possible.

2. The principle of equity for people with disability should be recognised in the Age Care Act.

The current Age Care system is designed to assist the ill and the frail aged and is inadequate for disabled people who have high care needs.

The Aged Care Royal Commission recognised this and in their recommendation 72[1] entitled *"Equity for people with disability receiving aged care"* stated: *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*.

This recommendation should be the guiding principle in the re-design of the Age Care system to properly and fairly meet the needs of disabled people.

Implementation within the Age Care System could be achieved by identifying those people who would qualify for NDIS support but for their age and then supporting them based on their individually assessed needs. Where this support exceeds the standard Level 4 Home Care Package, an uncapped supplement should be paid.

The amount of the supplement could be assessed in the existing system that determines level of age care funding. Alternatively, assessment could be 'contracted out' to the NDIS assessment team. This later arrangement would readily ensure the equivalent treatment envisioned in the Age Care Royal Commission report (mentioned above).

I am putting forward the above suggestion as the principal carer of my wife, [redacted] I am using her experience (and mine) to illustrate the problem.

[redacted] sustained a spinal injury in a bicycle accident. She was rendered quadriplegic due to damage at C4/C5. Her legs are paralysed, her bowel and bladder functions are impaired and she has limited use of her arms and hands. Otherwise, she is remarkably well, mentally fit and active.

[1] https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-3a_0.pdf

On discharge home from Canberra Hospital in 2013, personal care was provided under Home and Community Care (HACC) at a level clinically assessed, supplemented by some ACT Government services. Carers attended each morning to get [redacted] out of bed, toileted, showered, dressed and into her wheelchair and again each night to help her back into bed. She was allotted approximately 20 hours care each week including 2 hours 'in-home-respite' care and had access to nursing services, some allied health and community transport. With this minimum level of care, [redacted] escaped the fate of being institutionalized in a care facility and was able to live as full a life as possible at home with me, her husband as her main carer.

When the NDIS opened in Canberra, [redacted] was not eligible because she was over 65.

[**Note**: Had [redacted] lived in a State that had a State Disability Service, she would have been eligible for the Continuity of Support Scheme (now DSOA) and funded **according to need**.]

[redacted] is now supported by a Level 4 Home Care Package. This provides personal care to get her up on six mornings each week. Package funds are then exhausted. Care on the seventh morning and every evening falls on me (her 85-year-old spouse/carer) or is at personal expense. There is nothing in the package for any other expense – not respite, nor nursing, nor allied health, nor therapy, nor equipment. This is far short of the support recommended by the Age Care Royal Commission.

Issues for Older People with Disabilities

- Government policy excludes disabled older people from the NDIS and in the absence of other support (e.g. CoS/DSOA or accident insurance), they must rely on the Age Care system.
- The aged care system is planned for the sick or frail aged, not designed for people with significant disabilities.
    - Home Care Packages, including Level 4, may adequately support many frail aged people and many with disability, but do not take into account individual people's clinically assessed needs and are not adequate for those with high care needs resulting from disability.
    - People are currently relying on their families, elderly partners or friends to provide the additional care they need.
    - Current Home Care Packages do not offer the appropriate level of support for care, therapy, allied health and necessary equipment.
- There are significant barriers that prevent people with spinal cord injuries from receiving appropriate support in the aged care system:
    - Many aged care providers do not offer specialist and clinical support e.g. complex bowel & bladder care, pressure injury management, overnight support.
    - Those aged care providers who do accept disabled clients may limit the numbers or decline to take on clients with more significant disabilities (e.g. their staff will not lift paralysed legs onto a bed, citing OH&S).

- Specialist disability service providers tend not to accept clients like [redacted] with a Home Care Package because of inadequate funding and consequently the need to subsidise the significant gap in funding.

- Respite care is not sufficiently funded through Home Care Packages.
- The growth of the NDIS has made it more challenging for those outside the NDIS to access or afford some services, for example occupational therapists and allied health and the costs of equipment and its servicing have risen because of the demand and financial opportunities.

With fair and proper support, people with significant disabilities can live safely at home. Without appropriate support, they will be forced prematurely into residential age care (if a suitable place can be found), a nursing home or into institutional disability care.

Home care is preferable to residential age/disability care because:

It is cheaper.

Less chance of serious infections (Covid, norovirus).

Very few residential age care establishments have the numbers of staff per resident to adequately care for a disabled person with high care needs.

Costs of moving are considerable.

Social connections with friends and neighbours are maintained and family can stay with you when they visit.

Better control of one's life leading to better mental health.

Accommodation in many age care establishments lacks features essential for disabled people who mobilize in a power wheelchair.

In multi-story establishments, disabled people who cannot walk down fire escape stairs have accommodation options limited to the ground floor because lifts do not operate if there is a fire.

Nursing homes are likely to have the physical facilities to accommodate a disabled person with high care needs but, as with any elderly person, should be considered only *in extremis*.