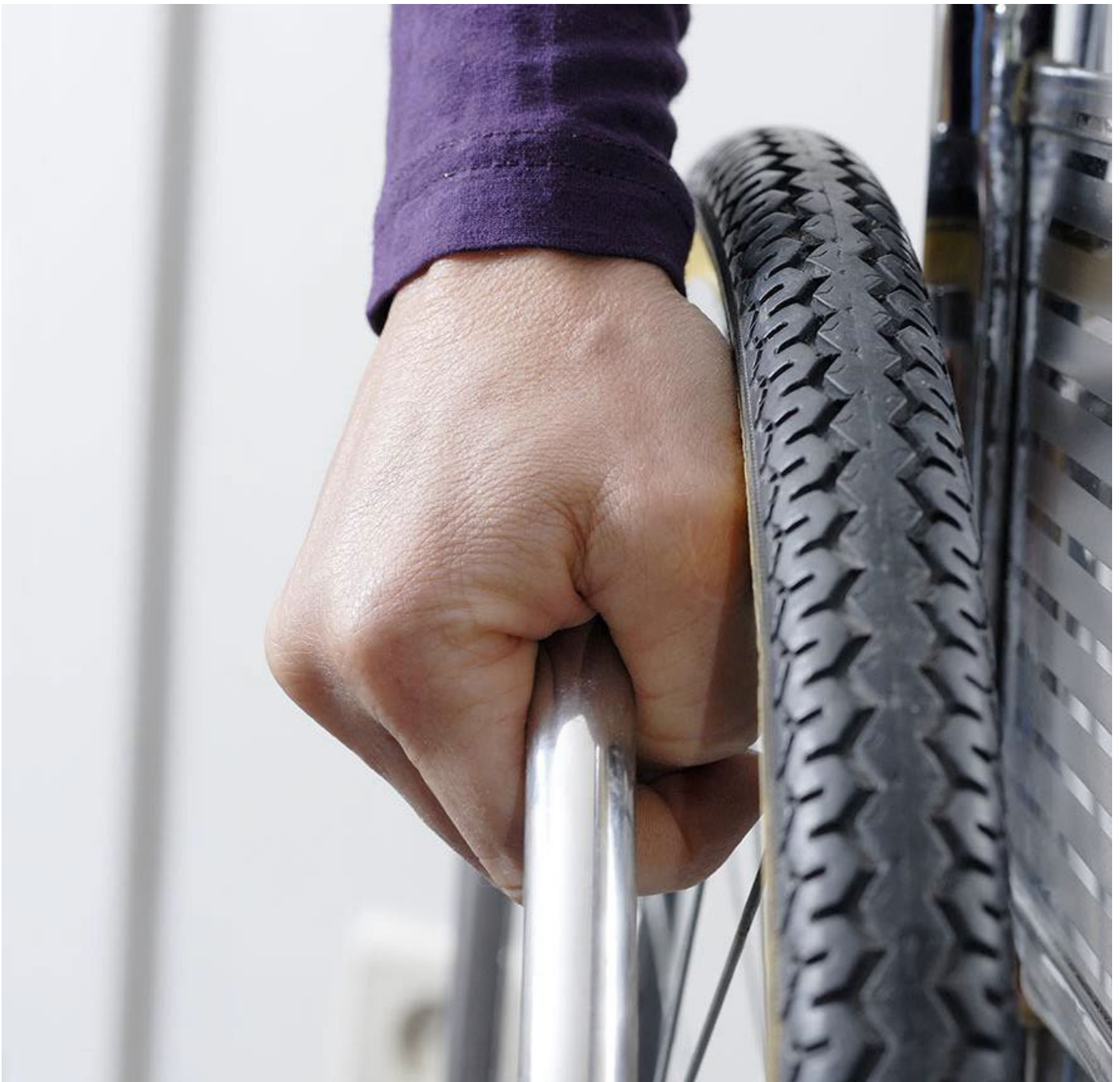


Aged Care Act Exposure Draft

Submission to Key Issues Paper



About the Exposure Draft

The Aged Care Act Exposure Draft is a proposal to replace the existing Aged Care Act 1997. The proposed Act aims to create a rights based legislative framework to regulate aged care with a greater focus on safety, health and wellbeing of older persons.

The exposure draft for the new Aged Care Act brings in stronger regulatory powers, improved transparency, and a much-needed rights-based framework. SCIA commends many changes in the current draft. However, we wish to highlight additional measures that need to be incorporated into the Act to ensure that the desired safety, health, and wellbeing of older persons, particularly older persons with disability, can be delivered.

Reflecting the needs of our members, SCIA would like to raise the following three key issues for consideration.

1. The importance of advocacy and representation being incorporated into the Act.
2. Explicit reference of disability in the Act, laying a foundation for and parity with the NDIS for people with disability over 65
3. The importance of acknowledging in the ACT the critical importance of assistive technology in enabling capacity and independence for people with a disability.

About Spinal Cord Injuries Australia

SCIA has been providing a dedicated advocacy service for people with spinal cord injuries and similar disability since 1967.

We currently employ 200 staff across services nationwide including 13 staff dedicated to our Policy and Advocacy work in New South Wales, metro, and regional areas.

SCIA provides specialty knowledge in Spinal Cord Injury and similar neurological conditions, and broader knowledge and experience across physical disability. SCIA was founded by people with acquired spinal cord injury in 1967. Today people with disability still largely lead our organisation.

People with disability make up 35% of our employees and a further 25% of employees have a close family member with disability. Over 50% of our board have disability and we represent 3000 members across Australia who have spinal cord injury or neurological condition and their family.

Spinal Cord Injuries Australia (SCIA) welcomes the opportunity to provide a submission for the Aged Care Act Exposure Draft on behalf of the many people with spinal cord injury and similar physical disability over the age of 65 who use our services.

Include a provision for advocacy and representation in the Act.

It is essential that the role of independent advocacy be written into the Act.

Advocacy is essential to any system of services and supports that are designed to assist people to a life of full inclusion and participation. Whenever a service or system is created, advocacy support should be made available to the people for whom the service is constructed and particularly to those who are most at risk within it¹.

People over 65, particularly those with a disability can face multiple points of vulnerability within the aged care system.

Many people with disability aged over 65 who are isolated in aged care facilities experience systemic discrimination without a family member, friends, or an advocate to look in on them and ensure that they are being cared for appropriately². Additionally, people with disability over the age of 65 can be isolated within their communities from financial and other abuse from perpetrators that include family members, partners, and institutions other than aged care or disability service providers³.

Therefore, information and advocacy services should be made available in each state and territory to educate and protect those over 65, particularly those with a disability. Vulnerable groups should also be acknowledged in the legislation. Advocacy services should be made available to people over 65 who experience increased isolation or prejudice because of their race, disability, culture, incarceration, economic and or social disadvantage, gender and gender identity, and sexual orientation.

Recommendation: Whilst the existing and outgoing Aged Care Act included provisions for a national advocacy program, the exposure draft does not. SCIA calls for the role of advocates and associated funding to be identified in the Act.

Explicit reference of disability in the Act to ensure a foundation for parity with the NDIS for people with disability over 65

Many people who acquire a disability over the age of 65 enter the aged care system not because of frailty or ill health as outlined in the Act but because they have a disability. This is often an acquired disability, exemplified by people who acquire a spinal cord injury over the age of 65.

The government has mandated all people who acquire disability on or after the age of 65 years obtain support for their disability from the aged care system and therefore, disability should be explicitly mentioned in the Act.

The legislation must recognise the specific needs of people over 65 with complex disability as opposed to those who are frail or sick. As previously articulated in our response to Consultation Paper 1, the legislation must recognise the specific needs of people over 65 with complex disability because service provision in support of this cohort will be substantially different and must be fit for purpose in recognition of disability needs.

¹Disability Advocacy Network Australia. Submission on the National Disability Advocacy Framework July 2022 pp20-21

² Ibid p64

³ Australian Government. Australian Institute of Family Studies Research Report No. 35. Elder abuse Understanding issues, frameworks and responses Rae Kaspiew, Rachel Carson and Helen Rhoades pp34-36

Whilst it is acknowledged that funding will be addressed in the Support at Home program to start in 2025 and an opportunity to comment will be provided closer to the time, the importance of parity cannot be understated.

The current level 4 Home Care Package for high needs support is \$53,268.10 a year⁴. It is estimated that the proper care for a person over 65 with quadriplegia costs more than 200,000 a year⁵. Trying to manage with this significant funding gap pushes families into hardship, means retirees need to return to work to support their loved one, become full time carers or accept substandard support.

Recommendation: Include in key concepts and definitions of the Act that disability is a reason to access aged care alongside the existing terms of frail, sick and ill.

Recommendation: To end the discrimination that limits older persons with complex disability to substandard support, ensure parity with the NDIS for supports is included in the Support at Home program.

Access to assistive technology should be explicitly mentioned within the Act.

Access to AT is a human right and should be clearly recognised in the legislation.

The Act outlines a rights-based approach and a commitment to the safety, health and wellbeing of older persons and yet, the independence and quality of life of some people with disability aged over 65 is being compromised because they are unable to access assistive technology (AT), aids, and other supports.

AT products are sought to address daily living problems across over twenty domains including mobility and transfers, driving, self-care, self- management and monitoring, housework, cooking, communication, seeing and hearing, and lifting and carrying.

Whilst funding is outside of the scope of the existing draft, it remains critical to mention the role of AT for people with complex disability.

Recommendation: Explicitly mention the role of assistive technology in the Act.

Recommendation: Prioritise funding for AT as an early intervention for people over 65, recognising its critical role in promoting independence and quality of life for those with complex disability.

Conclusion

The above recommendations represent the priority issues for SCIA members with disability who are over the age of 65 when considering the Aged Care Act Exposure Draft. A more comprehensive outline of the broader issues facing people with disability in the aged care

⁴ Myagedcare Home Care Packages <https://www.myagedcare.gov.au/help-at-home/home-care-packages>

⁵ End the 'do nothing' decade for seniors with disabilities. Joint media statement Australian disability & aged care organisations. COTA for older Australians. <https://www.cota.org.au/news-items/end-the-do-nothing-decade-for-seniors-with-disabilities>

system can be found in our previous submission, Submission to Consultation Paper 1.

On behalf of those we support, we believe that it is critical for the above recommendations to be prioritised and incorporated into the Act to immediately remove the discrimination that means older persons with disability in the aged care system have fewer opportunities for a full and healthy life compared to people with a disability who are under 65.