

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Via Submissions portal/email

RE: Aged Care Bill 2024 [Provisions]

Down Syndrome Australia (DSA) is pleased to provide this submission on the Aged Care Bill 2024 [Provisions], as referred to the Community Affairs Senate Committee on 16 September 2024.

Down Syndrome Australia was established in 2011 as the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change and provide a national profile and voice for people living with Down syndrome. Our vision is an Australia where people living with Down syndrome are valued, reach their potential, and enjoy social and economic inclusion.

For the first time, people with Down syndrome can expect to reach 60 years of age, with 1 in 10 living to 70 years¹. As a result there are new issues of concern to people with Down syndrome and their supporters which are related to ageing, as well as health concerns with progressive and terminal conditions like dementia. Not all people with Down syndrome will be diagnosed with dementia, but the rates are approximately 50%, due in part to the biomechanical results of the triplication of chromosome 21¹.

There are many reasons that a person with Down syndrome might live in residential aged care before the age of 65. This includes medical reasons, and the availability of safe and appropriate housing in the community. There may also be financial or family reasons why a person with Down syndrome might be in residential aged care. DSA supports these options where it is an informed decision which is made by the individual and their supporters.

DSA has been undertaking policy and advocacy work related to aged care due to the historic prevalence of young people with Down syndrome in residential aged care. DSA is a member of the Younger People in Residential Aged Care and Young Onset Dementia groups run by the peak body, Young People in Nursing Homes National Alliance. DSA has been committed to the practice of supporting members of our community to return back into safe living options in the community.

DSA understands that Younger People in Nursing Homes National Alliance has made a submission to the Senate Committee about the proposed changes to the Aged Care Act contained in this Bill. We endorse this submission and direct the Committee members to the details and potential impact on people with disability.

¹ Down Syndrome and Dementia: A Guide for Families. <https://www.downsyndrome.org.au/wp-content/uploads/2020/02/DSA-DA-guide-for-families.pdf>

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Australia's national voice for people with
Down syndrome and their families.

To summarise, DSA is concerned about the apparent reversal of Government policy to place younger people in residential aged care to more appropriate community housing options. People with disability should be provided with opportunities to live in the community, safely; and maintain the option to transfer into aged care at a time of their choosing, funded under NDIS arrangements. These funding arrangements would provide people with individual disability supports and access to the community which is age and disability appropriate.

There are significant inconsistencies across the recommendations of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability and the Aged Care Royal Commission; and the potential outcomes of this legislation in its current format. The proposed changes weaken safeguarding arrangements for vulnerable people, and establish a lower-barrier entry pathway into aged care for people with disability compared to home and living options in the NDIS.

Finally, there is no definition or eligibility criteria for the 'homelessness' or 'risk of homelessness' pathway for placement in residential aged care or access to home care, and no requirement for supported decision-making for people with disability who are assigned this designation. It is not possible to know the implications of this omission and the way that it might be applied in practice.

DSA encourages the Committee to understand the impact of this proposed legislation on the human rights of people with disability. There are significant inconsistencies with Government policy and human rights principles.

For more information, or to arrange appearance at a public hearing, contact:

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