



(A SUB-COMMITTEE OF PATH Inc.)

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**Senate Inquiry Planning Options and Services
for People Ageing with Disability**

About *Dare to Care*

Dare to Care is a disability advocacy group concerned with the needs, rights, interests and aspirations of people with disability in the Nepean and surrounding areas, including Penrith, Blue Mountains and Hawkesbury. Our focus is the adequate and quality provision of respite care and supported

accommodation to adults with disability, particularly but not exclusively people with intellectual disability and cognitive disability.

As a sub-committee of PATH Inc, **Dare to Care** comprises parents and carers, people with disability and others concerned with the unmet need for respite and supported accommodation for people with disability in Penrith and surrounds. All of the parents and carers in our group are aged between mid-40s to 80 years old, and our adult children with disability are mostly mature adults in their middle years.

Dare to Care can be contacted via PATH Inc PO Box 1288, Penrith NSW 2750.

Our contact person is our secretary Joyce Bellchambers at:

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Dare to Care reviewed and considered the Inquiry's Term of Reference:

Access to planning options and services for people with a disability to ensure their continued quality of life as they and their carers age, and to identify any inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers.

This submission constitutes our feedback to the Inquiry.

Unmet demand and escalating need for supported accommodation

Dare to Care is aware of the huge unmet demand for supports to people with disability who are ageing. The lack of available, appropriate, quality and responsive supported accommodation in NSW for people with disability is a major source of anxiety for them and their families and carers as they all grow older. No amount of individual planning can compensate the uncertainty faced by people and their families if the resourcing and supply of supported accommodation does not address existing and predicted unmet demand. **Dare to Care** often receives reports of distressing hardship due to the lack of accommodation and supports and the diminishing capacity of ageing carers to continue to provide essential assistance.

Self-directed support funding

Dare to Care endorses the move away from traditional funding mechanisms to self-directed support funding for all people with disability regardless of their level or type of support needs. Self-directed support funding will give the person and their family control over the supports they prefer and require, and will help to customise supports to suit the needs of the individual, taking into account their lifestyle, culture, background and personal preferences to simply live a good life.

Self-directed support funding must be provided universally, accompanied by choices of associated administrative supports: Technical Assistance (experts in disability and programming to advise on options for adults) and Financial Intermediary (a mechanism to conduct financial management, contracting, recruiting, employment and accountability obligations). The degree to which the person and their family uses these administrative supports is the decision of the person and their family. Independent monitoring of the funding is regularly undertaken.

Inadequacy of existing services

Dare to Care is concerned at the eligibility, quality and availability of existing supported accommodation services in NSW.

The only real eligibility for accommodation services in NSW is at crisis point where the person with disability has nowhere to live, for example where the primary carer is no longer able to provide care (being incapacitated or deceased) or where the often loving carer has reached the point of no longer coping or where the support needs of the person have escalated etc.

The mushrooming demand for supported accommodation in relation to the insufficient supply has resulted in a vacancy management approach to existing services. Compatibility is no longer a determining measure to find suitable placements for people with disability. Also, the supported accommodation responses largely involve the provision of group homes, regardless of their appropriateness.

Dare to Care opposes a one-size fits all approach, considering it to be tragically unresponsive, unnecessarily cumbersome, unsuitable for some and therefore needlessly expensive. People with disability should be able to make their own choices, reflective of the choices of people without disability of the same age but with the necessary supports to exercise those choices.

Dare to Care members were anxious to explain that supports and services to people with disability must have appropriate levels of staff, adequate staff numbers for levels of support needs, with appropriate training, qualifications, expertise and attitudes.

Clear Pathways

The path forward in life-planning for people with disability as they grow older is uncertain and vague. Consequently, it is critical to identify and develop clear pathways for people with disability as they grow older, before crisis occurs, while the valuable support of their carers and loved ones can assist during transitions. In this way, people and families can plan for older ages with confidence and a degree of certainty. **Dare to Care** realises that nothing in life is absolutely certain, but people without disability can loosely plan for their life stages, while currently people with disability who are ageing must reach a critical transition point before knowing or discovering what comes next.

These clear pathways involve the provision of

- information on options to people with disability as they age and as their carers age.
- advocacy to enable the best possible access
- co-ordination between service systems to facilitate seamless and smooth transitions minimizing resulting disruptions and personal intrusions (such as multiple assessments, differing eligibility criteria, burdensome and expensive applications etc.) These coordinated service systems include disability services, health services, aged care, income support,

Quality of Life

The expected quality of life of a person ageing with disability should be at least equal to and certainly no worse than that of others without disability of the same ages. Any specific support and service responses to the needs of people ageing with disability must meet highest disability standards in order that the person can maintain skills and abilities, preserve and improve health, and facilitate a good life.

Similarly, the nature and type of supports to people with disability who are ageing must observe human rights, especially the United Nations International Convention on the Rights of the Person with Disability.

ASAP Research

Dare to Care with the support of PATH Inc received a funding grant to undertake a research project to investigate the needs of people ageing with disability and ageing carers in Nepean and surrounds. **Dare to Care** is pleased to append the entire report as part of this submission. Please refer to the **ASAP Report** attached.

Conclusion

Thank you for the opportunity to contribute to the Inquiry on such an urgent and important issue. Should you require clarification or any further information, please contact Joyce Bellchambers at:

Yours sincerely,

Joyce Bellchambers

For and on behalf of **Dare to Care**

Attachment: ASAP Project by Lynn Houlahan(Dip Welfare, BA (Psych), PG. Dip. (Psych), M Spec Ed, JP)

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