

SUBMISSION TO THE EXPOSURE DRAFT OF THE NEW AGED CARE ACT

8 MARCH 2024

This submission was developed and is supported by a consortium of peak organisations and individuals, whose members and networks represent over 700,000 people living with a diverse range of chronic conditions and disabilities (including families, friends and carers), all of whom have a vested interest in strengthening the aged care system in Australia.

These organisations and individuals include:

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| Speech Pathology Australia | Parkinson's Australia |
| Spinal Life Australia | Emerge Australia |
| Fragile X Association of Australia | Epilepsy Foundation |
| Huntington's Australia | Epilepsy Australia |
| Leukodystrophy Australia | Myasthenia Alliance Australia |
| MS Australia | Polio Australia |
| Queenslanders with Disability Network Ltd | Motor Neurone Disease Australia |
| Brain Foundation | Ms Robin Vote |
| Mito Foundation | Ms Lesley Forster |
| Muscular Dystrophy Foundation Australia | Mr Peter Willcocks |

Introduction

The consortium supports the intent of the new aged care Act to focus on the safety, health and wellbeing of older people and put their needs and preferences first through measures that include:

- Embedding a rights-based approach by introducing a Statement of Rights, complying with international conventions, introducing independent system oversight and allowing for equitable access through a single assessment framework
- Empowering individuals through revised nominee arrangements, increased system transparency, a new complaints management framework and support and funding for aged care advocacy
- Enforcing obligations on aged care providers and the aged care workforce
- Introducing a Statement of Principles to guide decisions, actions and behaviours required under the new Act, a legal framework to improve supported decision making and increased protection for whistleblowers.

Issues and concerns

The main concern for the consortium is the means by which a person's needs are assessed to take into account their individual life circumstances.

In particular, we are concerned about the powers of the System Governor that allow for the use of a computer program to automatically determine decisions relating to the classification of individuals and for prioritisation of accessing aged care.

The focus of classification and prioritisation should not be solely on ageing. Decision-making should consider the disability needs of those accessing aged care and ensure the wishes and preferences of older people are included in the design of such decisions. It is difficult to imagine that an individual's preferences can be determined by an algorithm. This process should allow for oversight by a panel of qualified clinical experts that can apply evidence-based practice to the decision-making.

Too much emphasis is placed on capacity and function during the single assessment process. We recommend a process that includes greater flexibility and review to support people manage episodic and progressive conditions. Due to the changes in how case management is to be provided we recommend that the assessment process includes guidance on a reassessment timetable.

The use of computer program decision-making and artificial intelligence system process should be designed to build transparency and confidence. We recognize AI as a valuable tool to augment decision making but AI must not replace human oversight and final decision-making. The exposure draft of the Aged Care Bill 2023 does not provide security of governance for the safe use of such systems.

In her recent opinion piece “Let’s not elevate brain tech over our humanity”, regarding human rights and neurotechnology, Human Rights Commissioner, Lorraine Finlay, observes, “There is a pressing need to ensure that proper safeguards are in place to protect human rights” and further “we must ensure that our government and regulators prioritise human rights. Humanity always needs to be placed above technology”.¹

The recommendations of the Aged Care Royal Commission² encourage the use of technology in a variety of ways, such as in recommendation 109 regarding ICT Architecture and investment in technology and infrastructure, though these uses have a focus on improving service provision, improving quality of life and data and information sharing, rather than as envisaged in the draft Aged Care Bill for classification and prioritisation to access the aged care system.

To ensure that governance of AI has a human centred approach, the legislation needs to define an independent panel of experts to review decisions and outcomes. This panel would include health and disability experts with skill sets in ageing, independent advocates, older people directly affected by decisions made and most importantly systems analysts who can respond to questioning by members of the panel.

Progressive Neurological Pathway

For those ageing with a progressive neurological condition, we recommend that the Aged Care Bill contain a pathway that better meets the needs of those living with these conditions that includes specific consideration of eligibility, assessment, timeliness of access and a level of funding required for multidisciplinary care for complex needs.

The pathway would set out specific requirements such as for the clinical assessor workforce, using detailed evidence-based guidance to identify needs, an enhanced funding classification (compared to frail aged) and expedited review pathways.

¹ <https://humanrights.gov.au/about/news/opinions/lets-not-elevate-brain-tech-over-our-humanity>

² <https://www.royalcommission.gov.au/aged-care/final-report>

Recommendations

In response to these issues and concerns, the consortium urges the Australian Government to ensure that the new Aged Care Act clearly makes certain that:

- The pre-assessment process identifies chronic health conditions and disability type supported by documentation.
- The pre-assessment process identifies people from special needs groups.
- The formal assessment process reflects pre-assessment data collection with services recommended, including the establishment of a progressive neurological pathway.
- People are assessed as individuals by trained health professionals with expertise in aged care and disability needs who are able to identify individual supports that can be tailored to address an older person's individual needs, including the flexibility to support people to manage episodic and progressive conditions.
- The decisions made by computer programs must not be taken as a final decision made by the system governor.
- Information and analysis provided by computer programs is used to assist assessors to make their recommendations provided the tool itself is subject to governance by experts in the field of aged care, disability, special needs groups and systems management.
- The use of computer programs is subject to expert oversight, regulatory safeguards, audits and reporting.