Dear Commissioners,

**RE: Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services**

Thank you for the opportunity to provide further input to the Productivity Commission’s (*the Commission’s*) draft report on Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services (*the Report*).

Alzheimer's Australia is the peak body providing support and advocacy for people living with dementia, their families and carers in Australia. The issues raised by the Commission through this study are therefore very relevant to our consumers.

As noted in the Report, the human services sector plays a vital role in the wellbeing of the Australian population, but it is facing significant challenges due to the increasing demand associated with an ageing population, the impact of new technologies, and new and more complex service supply and demand. Alzheimer’s Australia is therefore supportive of the objective of the Commission’s Report to find innovative ways to improve the efficiency and cost-effectiveness of human services, and to target services to those most in need, so that access and quality can be maximised.

Overall, Alzheimer’s Australia is broadly supportive of the recommendations made by the Commission in their draft report. In particular, we note and provide further commentary on the following issues:

**Government involvement in human services**

We strongly agree with the Commission’s view that “Governments will (or should) always have the role of system stewards. This role incorporates a range of functions that help to ensure service provision is effective at meeting its objectives, including policy design, regulation, oversight of service delivery, monitoring of provider performance, and developing ways for the system to learn and continuously improve.”

The significance of this role has been underlined in recent times across the residential aged care sector, with disturbing reports emerging of consumer right violations in formal residential aged care
services. With a Government Review into the regulatory framework across residential aged care, as well as a Senate Inquiry into the effectiveness of the aged care quality assessment and accreditation framework underway, the cost of neglecting this role is significant to both consumers and Government.

**Informed User Choice**

We are particularly pleased to note the Commission’s recognition that there are circumstances where user choice may not be appropriate (such as the example cited of a person in the advanced stages of dementia choosing a health practitioner). It is worth emphasising, however, that even when user choice is not appropriate, a focus on the users themselves can be achieved through other approaches, such as increasing ‘user voice’ and co design to ensure a person’s (or community’s) preferences are taken into account when others make decisions on their behalf.

As noted in our submission to the Commission’s Issues Paper,¹ people living with dementia, their families and carers, along with other vulnerable and marginalised groups in society, are likely to have even poorer health literacy, and diminished capacity to identify the services they need in a market-driven system. They are also likely to have difficulty in interpreting available data relating to service quality, and in using this effectively to make informed health care choices, even where service choice is actually available.

But genuine user choice for people with dementia can be delivered when consumers are enabled to be partners in the decision-making process. A comprehensive advocacy framework is therefore a critical element to support the implementation informed user choice across the human services sector. Alzheimer’s Australia considers it vital to ensure consumers are supported, empowered and have their rights protected throughout the reform process. Investment in the education, training, and quality infrastructures will therefore be crucial to supporting the genuine implementation of informed user choice, particularly where choice is more limited, including in rural and remote areas.

**Caring for people at the end of life**

We support and endorse the Commission’s recommendation that State and Territory Governments be required to substantially increase the availability of community-based palliative care.

Being able to access appropriate end-of-life care is a critical factor in a more dignified death and a defining feature of quality care. Alzheimer’s Australia thus strongly supports the Commission’s recommendations that aged care facilities need more staff with the skills to lead and coordinate end of life care for residents, and that consumers be provided with more information to help them select aged care facilities that deliver high quality end-of-life care.

Further, we recommend that residential aged care standards should require aged care providers to encourage residents to complete advance care plans as soon as appropriate. Consumers have told us that this is an important area that needs action:

Consumer Views on End of Life Care

“There is a need for advanced care health directive at the time of diagnosis so the person can still be involved in how they die. I cared for my aunt and you wonder would she have wanted to die like this. If she had directives would it be like this?”

We agree with the Commission’s recommendation that reforms are needed to increase the rate and quality of advance care planning. Moreover, we recommend that providers should also work with residents and their families/carers to develop a palliative care plan; as well as support staff to receive additional training on: palliative care support; the legal rights of people at the end-of-life and, by extension, the ways in which advance care plans can and should be honoured.

Public Hospitals

People with cognitive impairments are high users of hospitals and other health care services. However, people living with dementia who are hospitalised experience worse clinical outcomes and longer lengths of stay as well as a higher likelihood of readmission compared to people without dementia. Not only is this detrimental to the patient with dementia but it also results in a high cost to the health care system.

Alzheimer’s Australia has recommended that dementia should be identified and managed at hospital admission through to discharge. Families and carers should be enabled to be actively involved in the care and support of the person living with dementia and staff should be trained to more effectively communicate with and care for a person with dementia. Physical environments should be made more dementia-friendly and alternatives to psychotropic medications used wherever possible.

While the Commission’s report does not directly address these issues, we are supportive of the proposed information reforms in strengthening and expanding the commitment to public reporting. A jurisdictional move to a general policy of publishing all data on individual hospitals and specialists, unless it would clearly harm the interests of patients, will be a big step towards transparency and informed decision making for all consumers.

Public Dental

Alzheimer’s Australia believes that people living with dementia should be able to access quality dental care from all oral health providers in both the public and private sectors.

We therefore agree with the Commission’s finding that for public dental services to be able to move beyond the short-term focus on urgent care, they need to be able to measure the effectiveness of services in terms of the oral health outcomes of users. We endorse the recommendation that proposed the development of an oral health outcomes framework for Australia.

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Social Housing

The Commission is proposing that governments develop systems to support service planning, evaluation and the identification and sharing of best practice approaches across human services. Alzheimer’s Australia supports the contention that well-designed supply-side approaches are most likely to be effective in meeting the housing needs and preferences of people with disabilities, including people living with dementia. As such, we are supportive of the Commission’s recommendation to reform financial assistance across social housing. This would ensure that those eligible for social housing would be able to choose whether to enter social housing (via a waiting list) or use their financial assistance in the private rental market.

Family and community services

In relation to commissioning of services, Alzheimer’s Australia had previously noted our concern that the introduction of competition and contestability could lead to greater costs associated with tendering and contract management for providers and governments, reducing the resources available for service delivery. There are also concerns that smaller not-for-profit providers who offer valuable specialist services to vulnerable groups may not survive in a market-driven environment.

This concern is partially mitigated by the Commission’s recommendation of a seven year default contract term for Government funded human services. This longer contract tenure would give providers a better opportunity to improve user outcomes while still retaining the benefits of periodic contestability.

Human Services in Remote Indigenous Communities

Dementia remains a significant yet under-recognised issue for remote Aboriginal communities and needs to be taken into account in the provision of human services to these cohorts. In our submission to the Issues Paper, Alzheimer’s Australia had commented on the real lack of service availability for people with dementia and their carers in remote Indigenous communities. This is a gap that we recommend should be urgently addressed through any reforms aiming to improve service delivery and outcomes for these communities.

Therefore we are supportive of the Commission’s proposal of longer default contract terms (ten years rather than seven, with contracts to incorporate safeguards to manage under performance), a greater focus on encouraging collaboration and coordination between providers, and better alignment between tender processes for related services to encourage greater coordination between government agencies. Alzheimer’s Australia also supports that commissioning processes should also have a much stronger focus on developing local capacity, including local employment, community engagement and governance.

Conclusion

Dementia is one of the major chronic diseases of this century. High quality, appropriate and targeted health and human services will continue to be crucial for people living with dementia, their families and carers, and demand will only continue to increase as the prevalence of dementia increases.

We are pleased to note that the Commission’s report has focused on the role that competition, contestability, and improved user choice could play. Our response to the Report focuses on the safeguards that will be needed, to ensure access to high quality services and improved outcomes for people with dementia and their carers who access the human services sector.

We look forward to continuing to contribute to the Commission’s important work in this area. Please do not hesitate to contact us should we be able to be of any further assistance.

Yours sincerely,

Maree McCabe
Chief Executive Officer
Alzheimer’s Australia