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MEDIA RELEASE

DEMENTIA CARE IN AUSTRALIA “DOES NOT MEET HUMAN RIGHTS”

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AUSTRALIA “does not currently meet the human rights of people with dementia to timely and accessible health services of appropriate quality or to participation in health care decisions”, according to members of the National Institute for Dementia Research Special Interest Group in Rehabilitation and Dementia.

Writing in the *Medical Journal of Australia* today, the authors wrote that Australian services for people with dementia are “fragmented, challenging to navigate and hard to access”.

“Dementia is the leading cause of disability, the second leading cause of death in Australians aged over 65 years, and the leading cause of death in women in Australia,” they wrote.

“In 2020, it is estimated that Australia will spend \$8.1 billion on health care and \$3.8 billion on social services for people with dementia, with a further \$6.1 billion in lost productivity and earnings.

Australia’s last National Framework for Action on Dementia (2015-2019) has lapsed. Despite the National Framework, “it can be difficult for people with dementia to obtain a diagnosis, there are limited health and social services for early dementia, including post-diagnostic support, and existing services are often poorly coordinated”.

“Services face workforce shortages and gaps in worker knowledge and skills related to dementia,” the authors wrote.

Variable delivery of best-practice dementia care by memory clinics, acute hospitals, primary care, and community and residential aged care was a barrier to quality care, “perhaps because the role of each of these is unclear”.

The authors identified principles which should apply to models of service delivery for dementia. The models should:

- have an overarching objective to maintain positive health and wellbeing of people with dementia, their care partners and families;
- recognise dementia as a disability, consistent with the World Health Organization Convention on the Rights of Persons with Disabilities, and promotes autonomy, social participation and rehabilitation;
- take into account the cognitive disability of people with dementia in accessing support and being a partner (along with their families) in planning care through supported decision making;
- be delivered by a multidisciplinary workforce with knowledge and skills around dementia;
- be accessible for all people with dementia and care partners;
- be ongoing, cost-effective and economically sustainable;
- be needs-based, not capped according to central budgets;
- be integrated for seamless experience for people with dementia and care partners, within and across primary, acute and subacute health care, aged care and social services; and
- be evidence-based.

The authors also identified models of service delivery for dementia, including the self-directed approach; case management; primary care chronic disease management; shared and stepped care; a specialist team approach; and, navigator and care pathways.

“None of the models of service delivery that we identified in Australia or overseas appear to sufficiently meet the principles above,” the authors wrote.

“There is no clear recognition that dementia is both a social and a medical issue.

“Recognition of dementia as a disability is only apparent in the self-directed care model. The models also do not sufficiently consider the needs of the person with dementia and care partners together. Barriers to all the current models are the poor dementia knowledge and the tendency to stigmatise people with dementia by many health and aged care professionals.”

The authors called for the development of a new National Framework which “should include the development of a model of service delivery that considers accessible pathways to diagnosis and effective and seamless ongoing support of health and wellbeing throughout the course of dementia”.

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