DEPARTMENT OF HEALTH

REDESIGN OF DEMENTIA CONSUMER SUPPORTS

Submission

15 November 2017
ABOUT ACSA

Aged & Community Services Australia (ACSA) is the leading aged care peak body supporting over 700 church, charitable and community-based, not-for-profit organisations. Not-for-profit organisations provide care and accommodation services to about one million older Australians.¹

ACSA represents, leads and supports its members to achieve excellence in providing quality affordable housing and community and residential care services for older Australians.

Aged care providers make a significant $17.6 billion contribution to the economy by producing outputs, employing labour, paying wages and through buying goods and services.² This is akin to the contribution made by the residential housing, beef and dairy industries. In many regional and rural areas aged care is the largest employer, which is where the majority, if not all, providers are not-for-profit.

ACSA members are important to the community and the people they serve, and are passionate about the quality and value of the services they provide, irrespective of their size, service mix or location.

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4.1 INFORMATION QUESTIONS

4.1.1 QUESTION ONE

Given the existence of an information line for several years and the continued ongoing low dementia literacy rates, are there additional supports that the information line and website can better leverage to increase dementia literacy in the community?

Ongoing promotion of the information service is needed, including through mainstream and culturally specific media to ensure awareness of the information line is available when needed by people. People will often only take in information when it becomes meaningful to them, so ensuring ongoing promotion of the existence of the information line is important. Promotion of the line should be targeted to different audiences so they recognise relevance for them. All people seeking diagnosis or newly diagnosed with a dementia should be provided contact details for the informational line so they can make contact as early as possible.

The information line should be available for extended hours, recognising that often carers may be seeking information beyond traditional business hours. The services of the information line needs to be easily accessible and appropriate for all therefore access to the Translating and Interpreting Service should be widely promoted. Access to culturally appropriate and bilingual staff should be available on the information line.

4.1.2 QUESTION TWO

Noting the outreach services outlined at 3.4, are there further considerations needed to better support:

- consumers with low IT literacy or lack of access to IT infrastructure?
- special needs groups, especially with people with low literacy levels, from Culturally and Linguistically Diverse backgrounds or from regional, rural and remote areas to have equity of access to these core information supports services?

Whilst ACSA supports the concept of pop-up clinics to ensure necessary expertise is made available in rural and remote areas, how these are introduced to an area will be important. Partnering with local services, health professionals and communities may make these more appropriate for the particular area and therefore more acceptable to the population. Ensuring cultural safety particularly for Aboriginal communities will be important. Designing these services with the recognition that a one size fits all model will not work will be important. Ensuring follow up and ongoing access to information between visits of the pop-up clinic are available will help to support ongoing engagement and improve outcomes. Working in conjunction with local health and aged care providers would help to build local capacity and support for consumers, families and carers between visits of the pop-up clinic.

Balancing online, telephone and face to face support should be an integral design feature to address various information needs in our community. Building supports that recognise varying levels of IT literacy and access to IT infrastructure up front will minimise people missing out. The Redesigned Dementia Consumer Supports must consider strategies that foster equity of access for everyone regardless of where they live and which take account of the unique needs across the population.
4.2 AWARENESS QUESTIONS

4.2.1 QUESTION THREE

The Australian Government has providing support for dementia awareness and stigma reduction activities for over a decade. However, less than 30 per cent of those people living with dementia who access Australian Government funded dementia consumer supports programs, heard about the supports from a health professional.

Noting the proposed awareness activities outlined at 3.3, given the continuing low rates of dementia literacy among health professionals are there other specific supports that would encourage self-management, independence and reablement to ensure people recently diagnosed with dementia connect to the available support services early?

Dementia education and awareness should be included in all Allied Health, medical and nursing curriculum to provide a solid basis for future campaigns. Targeting primary care practitioners as a core source of advice initially is supported. However, whilst this is likely to improve people being directed to supports they need, help to challenge negative attitudes people may have towards support services and facilitate better interactions moving between health and aged care, it is questionable whether this campaign will significantly influence community attitudes as proposed. To this end, ACSA is pleased to see an evaluation of the campaign is planned.

Referral resources should be made readily available to primary care practitioners including GPs and memory clinics. This would allow them to provide resources to people seeking or receiving a diagnosis of dementia to facilitate them accessing the information line as an initial step and as a go-to as their needs change.

Government should work with relevant industry Peak organisations for health and medical professionals, aged care and those representing people with dementia and special needs groups to ensure the campaign is appropriately designed and targeted for maximum effect.

4.2.2 QUESTION FOUR

Are there any other groups which should be included in the targeted awareness and stigma reduction campaign and how should they be prioritised?

Building public awareness through a broader campaign would support and reinforce the work being planned with primary care practitioners and would further the aim of influencing community attitudes regarding the positive contributions people living with dementia can make. ACSA supports the suggestion made in the Final Report of the Ministerial Dementia Forum 2016 – Redesigning Dementia Consumer Supports that such a campaign could ‘include audience-specific
messages that are tailored to different groups’ and ‘should provide a clear, consistent message with key resources free, centralised and accessible’.

### 4.3 OUTREACH QUESTIONS

#### 4.3.1 QUESTION FIVE

*Are there other factors to consider in ensuring services are appropriate and accessible to the most vulnerable or marginalised people living with dementia?*

Carers should be considered in all planning for programs to support people with dementia. Often it is the carer that takes on the role of advocate as the person’s dementia progresses. It is noted that the initial version of the consultation paper said the redesigned services will not include carer supports as these will be available through the Integrated Plan for Carer Supports. In a later version this statement was removed. Regardless of how carer supports are delivered, it will be important to ensure that the unique and changing support and information needs of carers of people with dementia are considered and addressed with supports made available in as seamless and easy to access way as possible.

People with dementia who do not have a carer may need additional support including to navigate the health and aged care systems. Having systems in place to identify people with a diagnosis who do not have a carer or involved family early in their journey would assist.

Specific, culturally appropriate and safe strategies are needed to ensure the Redesigned Dementia Consumer Supports identify and adequately address the needs of Aboriginal and Torres Strait Islander people who are currently not mentioned within the consultation paper.

#### 4.3.2 QUESTION SIX

*Will this model of redesign services embed improved access to services and outcomes for people living with dementia into the future?*

Building in evaluation of the proposed suite of Redesigned Dementia Consumer Supports will be a good, timely way to determine if this model will begin to embed improvements into the future. The multipronged approach proposed looks to provide a solid basis. Designing a system that leverages off existing local networks rather than duplicating has merit. Ensuring that people seeking or receiving a diagnosis are linked in to the appropriate support early and that those supports and interventions are flexible and tailored will be important.

Designing a system that is easy to navigate and works seamlessly for the person with dementia and their family should be the aim. Building information and referral pathways with health, aged care and carer services from the beginning will allow for better integration and therefore easier access.

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4.4 INTERVENTION QUESTIONS

4.4.1 QUESTION SEVEN

Current early intervention supports only reach around 1 per cent of people recently diagnosed with dementia. The combined emphasis of the Information (3.2) and Awareness (3.3) elements of the dementia consumer supports are expected to reach a substantially higher proportion of the diagnosed population. Are there other elements that should be considered in order to increase the proportion of the diagnosed population who will know about and want access to these services?

Supporting awareness campaigns amongst the community and primary care practitioners is likely to increase diagnoses of dementia happening earlier. The benefits gained from an early diagnosis may not be realised if not supported by early intervention supports and information. Providing information about early intervention supports should not be a one-time occurrence. A diagnosis of dementia is a very stressful time when a lot of information is given which can be difficult to absorb. Building in family conferencing and tailored education sessions that ensure the person with dementia and key people in the family have the same information so they can plan, adjust and synchronise their communication will result in better outcomes. Therefore, health professionals need to be skilled up in these areas. Providing information in writing, building in follow-up processes and providing personalised invitations may also assist.