



Analysis of Dementia
Programmes funded by the
Department of Social
Services

Final report

30 September 2015

Disclaimer

Inherent Limitations

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The findings in this report are based on a qualitative study and the reported results reflect a perception of participants who attended consultation workshops between 13 April 2015 and 14 May 2015 and/or who provided written submissions between 13 April 2015 to 31 May 2015, but only to the extent of the sample surveyed. Any projection to wider personnel and/or stakeholders is subject to the level of bias in the method of sample selection.

No warranty of completeness, accuracy or reliability is given in relation to the statements and representations made by, and the information and documentation provided by, service providers, advocacy and peak organisations clinicians, carers, people with dementia, the Australian Government, and State Government stakeholders consulted as part of the process.

KPMG has indicated within this report the sources of the information provided. We have not sought to independently verify those sources unless otherwise noted within the report.

The findings in this report have been formed on the above basis.

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Key messages

The Department of Social Services funds a number of activities to support people affected by dementia. Funded activities range from peak body awareness raising and policy advocacy activities, to education and training (for the health and aged care workforce as well as the families of people with dementia), support and advisory services for providers and carers, and, in some circumstances, assistance for people with dementia via clinical care and time-limited case management and coordination services.

In addition to these established services, a number of pilot and trial initiatives have also been funded to explore new service models and approaches that can better meet the needs of particular consumer cohorts or respond to particular settings.

This analysis considers the effectiveness, coordination and alignment of these activities which provide additional support to complement the wide variety of services delivered to people with dementia through the Commonwealth Home Support Programme, Home Care Packages, residential care and respite care.

What is working well?

Carers and consumers value the information and support services, particularly where these services are delivered in a face-to-face mode and especially during the earlier stages of dementia. The skills and dedication of workers are also valued.

Family and carer education and training services are well-received and are reported by participants to be beneficial in helping them provide better care.

Workforce education and training services are generally considered to be beneficial by those who are able to access them.

What could be improved?

There is a lack of national consistency and coordination of workforce education and training services. This increases complexity and makes programme administration less efficient. Allocating responsibility to Dementia Training Study Centres (DTSCs) for coordinating a more consistent and aligned national approach would be beneficial.

There are unmet needs within some consumer cohorts: people from Aboriginal and Torres Strait Islander backgrounds; people from culturally and linguistically diverse backgrounds; those with younger onset dementia; people in rural or remote areas with poor health literacy and poor access to primary care; people at risk of homelessness; those who are financially and socially disadvantaged and who have a range of (diagnosed or un-diagnosed) co-morbidities for which they are not receiving treatment, and people who identify as lesbian, gay, bisexual, transgender and/or intersex (LGBTI).

Many stakeholders advocate for a 'one stop shop' for dementia care to reduce system complexity for carers and consumers and to improve access and efficiency. Potentially, this could be through MyAgedCare or a similar portal.

Where is the duplication/overlap?

There is duplication in support services for people affected by dementia (National Dementia Support Programme (NDSP) and Home and Community Care (HACC) Dementia Advisory Services). It also appears that in some areas HACC is also being used to provide services that overlap with Dementia Behaviour Management Advisory Services (DBMAS) or filling a perceived general gap for case management or key workers.

There is duplication between the Dementia Education and Training for Carers (DETC) programme and the education and training elements of the NDSP. Essentially the same services are provided under different programmes and with no apparent formal organisation across the programmes to maximise coverage.

What are the gaps and emerging issues?

The key gap across most of the programmes and services is regional, rural and remote accessibility. It may be necessary to reconsider the way funds are allocated to ensure coverage is maximised.

There is an ongoing need to promote earlier detection in the primary care sector.

There is still a demand for support in managing severe behaviours. In the longer term, more attention could be given to developing sustainable dementia care capability within the aged care sector to decrease reliance on these services and ensure dementia competencies are incorporated into core business.

What opportunities are there for consolidation of programmes and services?

A number of consolidation opportunities are identified for consideration:

- consolidate elements of HACC Dementia Advisory Services with the NDSP and/or DBMAS to provide clear support programmes with national coverage and common performance measures
- remove the education and training activities from the NDSP and combine it into the DETC programme with national coverage and common performance measures
- remove the systematic advocacy and awareness raising activities from the NDSP and consolidate it with the Dementia Community Support Programme (DCSP) into a single dementia advocacy and awareness raising programme, separate from service delivery funding
- consolidate the Service Delivery Pathways Programme (SDPP) within the Developing Innovative Methods to Respond to Neurodegenerative Disease (DIMRND) into the NDSP
- consolidate the Acute Care – environmental design project into DTSCs
- expand the role of DTSCs to include national coordination of all dementia education and training programmes, with a view to combining these into a single programme with common performance measures

It is also suggested that a comprehensive evaluation strategy be implemented for the integrated DBMAS and Severe Behaviour Response Teams (SBRTs) programme due to commence in 2016-17.

Need for of an overarching framework

There is widespread agreement on the need for a more structured approach to the design, development and funding of dementia programmes and services. The current suite of initiatives is complex, particularly for consumers, with some areas of duplication as well as areas of inconsistent service delivery and coverage.

The majority of stakeholders support the development of an overarching national framework to guide dementia programme and service funding. In addition to articulating the overall objectives for dementia care, such a framework should articulate the range of services accessible to consumers in the community – irrespective of where they live or their special needs – and expected dementia competencies for health and aged care professionals. Programmes and services could then be funded to align with the framework and drive more consistent service coverage and performance monitoring.

Development of clear objectives linked to intended outcomes for dementia support programmes would also complement the National Framework for Action on Dementia 2015-19 recently agreed by Commonwealth and State/Territory Health Ministers, which provides an overarching framework for dementia policy across Commonwealth and State/Territory health and aged care systems.

Glossary and abbreviations

| | |
|-----------------------------|---|
| AA | Alzheimer’s Australia, a dementia service provider and peak body |
| Acute care workforce | Refers to clinicians and support staff working in hospital settings |
| Aged care workforce | Refers to personal care workers (sometimes called ‘formal carers’) or clinicians working in aged care settings, such as home care or residential care |
| Allied health workforce | Refers to health professionals other than medical practitioners, dentists, nurses and pharmacists (i.e. speech therapists, occupational therapists, social workers) |
| BPSD | Behavioural and psychological symptoms of dementia |
| Carer(s) or family carer(s) | Refers to the carer (sometimes called an ‘informal carer’) and/or family of a person with dementia who may use programmes or services described in this report |
| Case management * | Refers to a collaborative process of assessment, planning, coordination and review of supports for an individual consumer and their carer/s and or family within the health and/or social services sectors, facilitated by a professional support person working within that sector |
| Consumer(s) | Refers to a person with dementia who may use programmes or services described in this paper |
| Clinician(s) | In this report, a generic reference to health care professionals, including medical practitioners (specialists and general), nurses, and allied health |
| CRCC | Commonwealth Respite and Carelink Centres |
| DBMAS | Dementia Behaviour Management Advisory Services |
| DCE | Dementia Care Essentials |
| DETCs | Dementia Education and Training for Carers |
| Department, the | Department of Social Services, the Australian Government agency which funds and/or administers the programmes and services described in this report |

| | |
|------------------------|---|
| DIMIRD | Developing Innovative Methods to Respond to Neurodegenerative Disease |
| DTSC | Dementia Training Study Centres |
| GP(s) | General Practitioner(s) |
| HACC | The Commonwealth HACC Programme (formerly Home and Community Care; will become part of the Commonwealth Home Support Programme from 1 July 2015) |
| Key worker(s) * | A professional support person who provides a single point of contact and assists in coordinating and linking into a range of services for an individual consumer and/or their carer(s) and family |
| LGBTI | Lesbian, gay, bisexual, transgender and/or intersex |
| NDIS | National Disability Insurance Scheme |
| NDSP | National Dementia Support Programme – Building Capacity in Dementia Care |
| Primary care workforce | Refers to clinicians working in community and diagnostic settings, such as general practitioners |
| PWD or PLWD | People with dementia, or people living with dementia |
| SBRTs | Severe Behaviour Response Teams |
| YOD | Younger Onset Dementia |

* A note on ‘key worker’ and ‘case manager’ terminology: The distinction between the role and functions of a key worker and a ‘traditional’ case manager is sometimes unclear. Often, the terms are used interchangeably, or the term key worker is used to describe otherwise standard case management practice that is more consistent with contemporary principles such as person-centred approaches and consumer-directed care. The literature, however, does distinguish between these two roles, with the key worker having an increased ‘outward-focus’ in coordinating services across agencies and sectors, and acting as the central contact point for the consumer.¹ The key worker is sometimes described as a ‘primary case manager’.²

¹ Mukherjee, S., Beresford, B. and Sloper, P. (1999) *Unlocking Key Working: An analysis and evaluation of key worker services for families with disabled children*, Community Care into Practice, Bristol: The Policy Press.

² Trute, B. and Hiebert-Murphy, D. (eds.) (2013) *Partnering with Parents: Family-centred Practice in Children’s Services*, University of Toronto Press.

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1 Introduction

KPMG was engaged in March 2015 by the Department of Social Services (the Department) to conduct an analysis of dementia programmes and services funded by the Department. The analysis is intended to inform future dementia programme and policy development by the Australian Government. This document is the final report for the project.

1.1 Background

On 11 September 2014, the then-Assistant Minister for Social Services, Senator the Hon Mitch Fifield and the then-Minister for Health, the Hon Peter Dutton MP held the inaugural *Ministerial Dementia Forum, Dementia Care – Core Business for Aged Care*. The forum was attended by 69 participants from across Australia representing service providers, clinicians, carers, people with dementia and the Australian Government. The purpose of the forum was to identify what is needed to improve the provision of dementia care in aged care settings, while remaining within the current funding envelope.

The Ministerial Dementia Forum – Options Paper³ captured the recommendations from the forum and presented future policy options for the Australian Government. Participants were of the view that most dementia programmes were effective, but that there were challenges in accessing them, particularly in regional and rural communities, and there were differing levels of awareness about them. Concerns were also raised about potential overlaps between some programmes.

One of the recommendations arising from this discussion was that a stocktake and analysis of currently funded dementia programmes and services should be undertaken to inform future policy initiatives. It was recommended that this analysis be undertaken with a view to: consolidating and improving the alignment of those programmes that are most effective; considering strategies to make them more widely available; and identifying gaps in support. This project arises from that recommendation.

1.2 In-scope programmes and services

The following programmes and services, and nine ‘sub-programmes’ or projects within those funded programmes and services, were in scope for the analysis:

- Dementia Training Study Centres (DTSCs)
- Dementia Behaviour Management Advisory Services (DBMAS), and the following sub-programme:
 - DBMAS Information Technology Project
- Dementia Education and Training for Carers (Commonwealth Respite and Carelink Centres)

³ Available online at: <https://www.dss.gov.au/our-responsibilities/ageing-and-aged-care/older-people-their-families-and-carers/dementia/ministerial-dementia-forum-options-paper>

- Dementia Care Essentials (Registered Training Organisations)
- National Dementia Support Programme
- Dementia Community Support Programme
- Service Delivery Pathways Programme, and the following sub-programme:
 - Responding to Neurodegenerative Disease Project
- Younger Onset Dementia Key Worker Programme
- Home and Community Care (HACC) Dementia Advisory Services
- The Timely Diagnosis of Dementia in Primary Care initiative, and the following sub-projects:
 - Detect Early Project
 - Primary Care education scoping project
- Improving Acute Care Services for People with Dementia; and the following sub-projects:
 - Acute Care education scoping project
 - Dementia in Acute Care – environmental design
 - Promoting the National Safety and Quality Health Service Standards as they relate to the care of people with cognitive impairment
 - Medicare Locals scoping study.

1.2.1 Interaction with other government-funded dementia activities

These in-scope programmes and services interact with other Australian Government-funded dementia activities (including those funded by the Department of Health and its auxiliary agencies) as well as care for people affected by dementia delivered in acute and sub-acute settings (primarily the responsibility of state and territory governments) and primary care. Those other activities are not specifically within scope for this analysis, but it is important to understand how they interact.

The Department of Social Services and the Department of Health collaborate closely on overall dementia policy and the whole-of-government response to dementia-related issues. This was confirmed through interviews conducted with staff from both agencies for this project. There is a clear complementarity of and delineation between the types of activities that each agency funds:

- The programmes and services funded by the Department of Social Services mainly focus on the delivery and/or improvement of quality dementia care in community and aged care settings for people directly affected by dementia.
- The activities funded through the health portfolio focus more on dementia as a population health issue and in the context of dementia as a national health priority. This includes collection and reporting of data relating to prevalence and incidence

(through the Australian Institute of Health and Welfare) and research efforts in dementia prevention and risk reduction (through the National Health and Medical Research Council).

Additionally, it should be noted that people with dementia receive the majority of their support through the Commonwealth Home Support Programme, Home Care Packages, residential aged care and respite care, with more than 50 per cent of residential aged care funding being claimed on behalf of people with dementia.

Any proposed changes to the suite of programmes and services considered in this analysis will need to recognise this interaction with other government-funded dementia activities.

1.3 Project approach

The analysis considered the effectiveness, coordination and alignment of the in-scope programmes and services. This included consideration of:

- programmes, services or overall elements that are working well
- areas that could be improved
- areas of duplication or overlap
- opportunities to consolidate and/or improve the national alignment of these programmes
- any areas where there are gaps in service delivery, programme design and programme implementation, or in responding to current or anticipated needs.

There were three main activities for the analysis. First, an initial stocktake and desktop review was undertaken in March 2015. The Department of Social Services (DSS) provided KPMG with copies of relevant funding agreements, annual reports and performance data, and any available evaluation or review reports. The websites of the various programmes and services were also reviewed, and telephone interviews were conducted with personnel from various areas within the Department responsible for managing the contracts and/or programmes.

The stocktake informed the development of a ‘conversation starter’ paper, which set out preliminary findings in relation to each of the programmes and services. The conversation starter was released in April 2015. This paper formed the basis for the second activity, a national consultation process. Fourteen stakeholder workshops were conducted nationally (two in Sydney and one in every other capital city, as well as one each in Alice Springs, Bendigo, Dubbo, Launceston and Townsville). The workshops were well-attended and included representatives from the current providers of the in-scope programmes and services, aged care providers, health services, industry peak bodies, and consumer representative bodies. There were several consumers and carers in attendance at most of the workshops, who each had direct experience of at least some of the in-scope programmes and services.

In addition to the workshops, written submissions on the conversation starter were accepted for a six week period to 31 May 2015. The written submissions process was

the third key activity for the analysis. A total of 57 submissions were received. A little under half of these were from carers or consumers of the in-scope programmes and services. The remainder of the submissions were from programme service providers, aged care providers, local governments and industry peak bodies.

1.4 High-level summary of key consultation outcomes

The range of issues identified by stakeholders at the workshops and in the submissions was broadly consistent across each of the locations. There was some variation in the types of issues raised by different stakeholder groups. For example:

- dementia services providers were more likely to present additional information to explain how existing services operate and/or complement each other, as well as identifying gaps and challenges
- aged care providers and peaks focussed more on system-level considerations, including overall objectives and outcomes for dementia programmes and services, the lack of and need for performance data and evaluation, and opportunities to streamline and improve current approaches
- carers and consumers tended to focus on the value of face-to-face support services and the challenges of navigating a complex service system.

The majority of stakeholders across all locations were aware of the major funded programmes and services: DBMAS, DTSCs, the NDSP, and HACC Dementia Advisory Services.

There was a lower level of awareness of some of the workforce education and training programmes amongst the target groups for those programmes (i.e. the aged care and health workforce), particularly in the regional workshops where access to these programmes was reported to be lower than in major cities. Aged care sector stakeholders across all locations called for better coordination and promotion of education and training services. Peak body stakeholders also raised questions about inconsistent content and quality across these services.

Very few workshop participants were aware of the various research, pilot and scoping projects, although a great deal of interest was shown in these by aged care stakeholders in particular. There was a consistent call for better dissemination and discussion of the findings of these studies.

There was less agreement amongst stakeholder groups in terms of duplication and areas for improvement. Most stakeholders recognised overlap between the NDSP and HACC Dementia Advisory Services, but there was disagreement about whether this was positive, neutral or negative. Generally, dementia service providers suggested it was a good thing because it facilitated consumer choice, and/or because it allowed for some degree of funds pooling at a local level allowing a more tailored and localised response. However, aged care providers, peak and representative bodies generally suggested that duplication was wasteful and confusing for consumers and primary care practitioners. Carers and consumers did not comment specifically on duplication, but some of them did comment on the challenge of knowing where to go or how to access 'the system'. Whether they argued for or against duplication, however, many

stakeholders called for a 'one stop shop' or centralised entry and information point as the preferred model for delivering services, particularly to people affected by the early stages of dementia.

The need to reconsider service delivery models in rural and remote settings was also consistently raised by dementia service providers and aged care providers. Although some current dementia service providers advocated for centralised, national service models, others suggested partially de-centralised hub and spoke models, based within local health systems and/or local community services. Stakeholders across different groups advocated for a simplified, outcomes-based funding mechanism to promote more flexible, individualised service delivery (rather than hard programme 'silos') which would be a better approach for consumers (being simpler and easier to access), more effective, and probably more efficient.

Many stakeholders from across the different groups highlighted the unmet needs of some consumer cohorts, particularly: people from Aboriginal and Torres Strait Islander backgrounds; people from culturally and linguistically diverse backgrounds; those with younger onset dementia; people in rural or remote areas with poor health literacy and poor access to primary care people at risk of homelessness those who are financially and socially disadvantaged and who have a range of (diagnosed or un-diagnosed) co-morbidities for which they are not receiving treatment and people from LGBTI communities. Broadly, the challenges can relate to one or more of the following issues:

- need for more targeted advocacy and awareness raising within some groups who are not reached by 'mainstream' messaging to increase their understanding of dementia and promote earlier diagnoses
- need for more tailored support responses for groups who are not currently accessing mainstream services
- need for more information, knowledge sharing and good practice discussions around effective approaches for improving access for these groups.

Some participants from the dementia services and aged care sectors were aware of the current projects underway to address these special access issues and they suggested that the results had been encouraging, but that there was simply not enough capacity to meet the demand in this area.

The main area where there were notably differing views expressed in the workshops related to DBMAS. Some stakeholders were critical of DBMAS, others felt that it was very effective. These differences were not related to location or stakeholder group. Combined with the lack of national data and outcomes evaluation evidence for these services, it is difficult to analyse the reasons behind these divergent views.

There was a similar level of consistency in the written submissions. Almost half of the submissions were from carers and consumers, who shared their personal experiences and insights. These submissions were overwhelmingly positive in terms of the quality of support services and resources. Many of the submissions also highlighted the inherent vulnerability of living with dementia, which for some led to feelings of confusion and isolation. Ease of access and timely referral into appropriate services and networks were identified as critical supports. Face to face contact was also particularly valued.

Key themes in the submissions from other stakeholders related to: effectiveness and access to education and training, including the need for improved national consistency and reduced duplication in this area; problems with accessing support service, education and training and clinical care in some regional, rural and remote areas; the need to expand awareness raising (particularly for special needs groups); the benefits of key worker and case management approaches; the need for better performance monitoring and data collection, and the need for a national framework.

Some submissions also addressed the issue of interfaces with other sectors, particularly mental health, which was considered to be ineffective in most jurisdictions.

The importance of respite and carer support programmes was also highlighted as a critical component of dementia care. Stakeholders emphasised that it is not possible to consider the effectiveness of the in-scope programmes and services in isolation from respite and carer support services. Issues such as a reported lack of respite options for people affected by younger onset dementia and those from Aboriginal and Torres Strait Islander backgrounds have an impact on both the demand for and the effectiveness of many of the in-scope programmes and services.

1.5 Structure of this report

This report is set out in four parts:

- Section 1 – introduction, background and project approach (this section)
- Section 2 – understanding the current state
- Section 3 – considerations for the future suggested actions.

2 The current state

This section outlines the analysis findings in terms of what is working well, what could be improved, duplication and overlap, and gaps and emerging issues.

2.1 Context for the analysis

Four pertinent contextual issues were identified during this analysis. These issues are inter-related and frame all of the findings set out in this report.

- First, there is widespread agreement across all stakeholder groups about the need for a more structured and strategic approach to the design, development and funding of dementia programmes and services. The current suite of initiatives is complex, particularly for consumers, with some areas of duplication (coordination and delivery of education and training services, support services in some areas), and areas of inconsistent service delivery and coverage (DBMAS and support services outside of metropolitan areas). The majority of stakeholders agree that there is a **need for clear objectives linked to intended outcomes** to guide programme and service funding. In addition to articulating the overall objectives for dementia care, such a framework should articulate the range of services accessible to consumers in the community, irrespective of where they live or their special needs, and expected dementia competencies for health and aged care professionals. Programmes and services can then be funded to align with the framework to drive more consistent service coverage and performance monitoring.

The programmes and services administered by (the Department) have developed over time, as needs and opportunities have been identified. The result of how programmes and services have developed is that there is duplication in many areas, which is confusing for those trying to navigate them, including people with dementia, their families and services providers. (*Submission 41 – aged care provider*)

Most of the current funded programmes and services already share common broad objectives (improving quality of life for people affected by dementia; improving quality of care or building care capacity; enhancing service linkages or improving inter-service collaboration; and indirectly to improve quality of life or quality of care), but there are few meaningful performance indicators to measure progress against these objectives, either within or across the various programmes and services.

An overarching framework could also set clear, agreed objectives and (ideally) outcomes-based performance measures for dementia programmes and services. This would aid in monitoring and evaluating performance, and in assessing and prioritising future funding allocations.

- The second issue relates to **sector interfaces**. To be effective in supporting improved outcomes for people affected by dementia, programmes and services cannot function as silos of expertise. They must interface effectively with a range of other services and sectors to provide coordinated, responsive and individualised responses for consumers and carers. This includes primary care (general practice, allied health, community health), community and residential aged care, acute care (hospitals) and sub-acute care (including mental health, community nursing, palliative care), and potentially also the disability sector (particularly in relation to

people affected by younger onset dementia). Improving the interfaces has been the subject of several recent research and scoping studies. According to the bulk of stakeholders who participated in this analysis, there remains much more work to be done to ensure that the interfaces operate optimally. It is possible that the way in which dementia programmes and services have historically been funded – as siloed or discrete programmes mostly based in the community sector, with output-based performance indicators and little formal review or evaluation – may not support effective interfaces, nor give adequate recognition to the negative impacts of ineffective interfaces on the in-scope programmes and services.

- The third issue relates to the increasing prevalence of dementia, and the anticipated increase in service demand. This raises the question of the **appropriateness of existing service models and responses**, in terms of both fitness-for-purpose (that is, whether existing responses that have been designed to meet the needs of the current generation of people affected by dementia will be sufficient to meet the needs of the next generation, as well as a projected increased volume of clients) and sustainability.
 - There was general agreement by stakeholders that some form of face-to-face support was needed by the majority of people affected by dementia, especially in the earlier phases. This was particularly emphasised by carers and consumers as well as some aged care providers. Current efforts of some programmes to provide remote service delivery have been met with variable reports of success by stakeholders. In addition, although there was much evidence of consumers and carers valuing current support service models involving support groups and peer support, a small number of stakeholders from dementia services, aged care providers and health services questioned the effectiveness of these services for people living in regional and rural areas. Some of these stakeholders also questioned the appeal of those delivery models to younger consumers and carers.
- The fourth and final issue relates to how dementia care can be framed as core business for aged care. This raises a question of whether the current approaches are effective in building sustainable capability in the aged care workforce, but there is also a question about the **need for cultural change** in parts of the aged care sector so that dementia capability, including behaviour management, is accepted as part of core business and an essential in-house capability, rather than a discrete expertise or specialty area.

Services such as DBMAS take a traditional approach based on the medical model to “managing behaviours”. While this approach of “managing behaviours” rather than preventing behaviours continues, there will always be a need for a “reactionary” service. A paradigm shift towards a preventative approach through improved person-centred services is required. (*Submission 54 – peak body*)

2.2 Categories of programmes and services

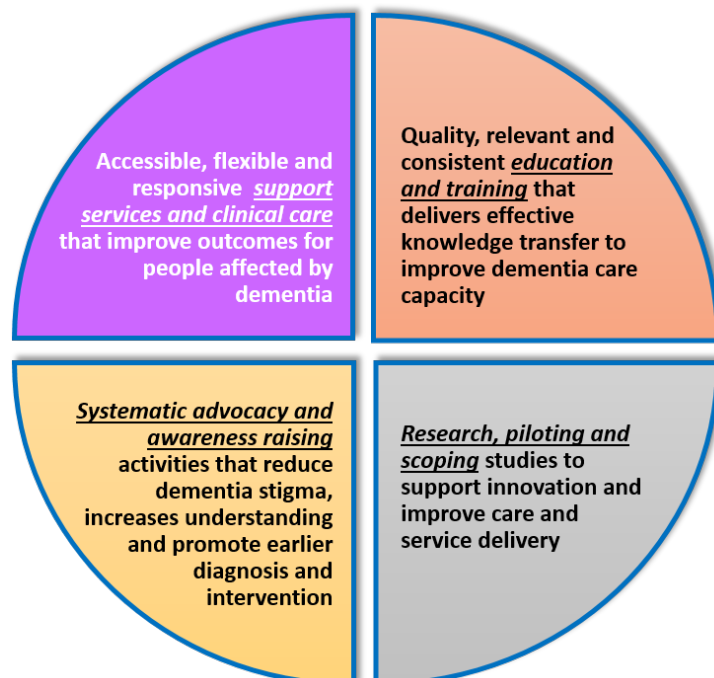
The current suite of funded programmes and services can be categorised into four key service categories. There was widespread agreement from all stakeholder groups that these categories are both an accurate reflection of the current arrangements, and an appropriate general structure. The four categories are:

- systematic advocacy and awareness raising
- support services and care for people affected by dementia
- education and training (aged care and health professionals, carers and families)
- research, pilots and scoping studies.

There was consistent feedback from the consultations that the common objectives for each of these service categories should be to improve quality of life for people affected by dementia, and/or improve the quality of care for people with dementia.

A number of stakeholders suggested that these categories should be clearly linked to intended outcomes, to drive improved programme design and performance measurement. Figure 1 (right) reflects this outcomes-focused service category structure.

Figure 1: Categories of dementia programmes and services

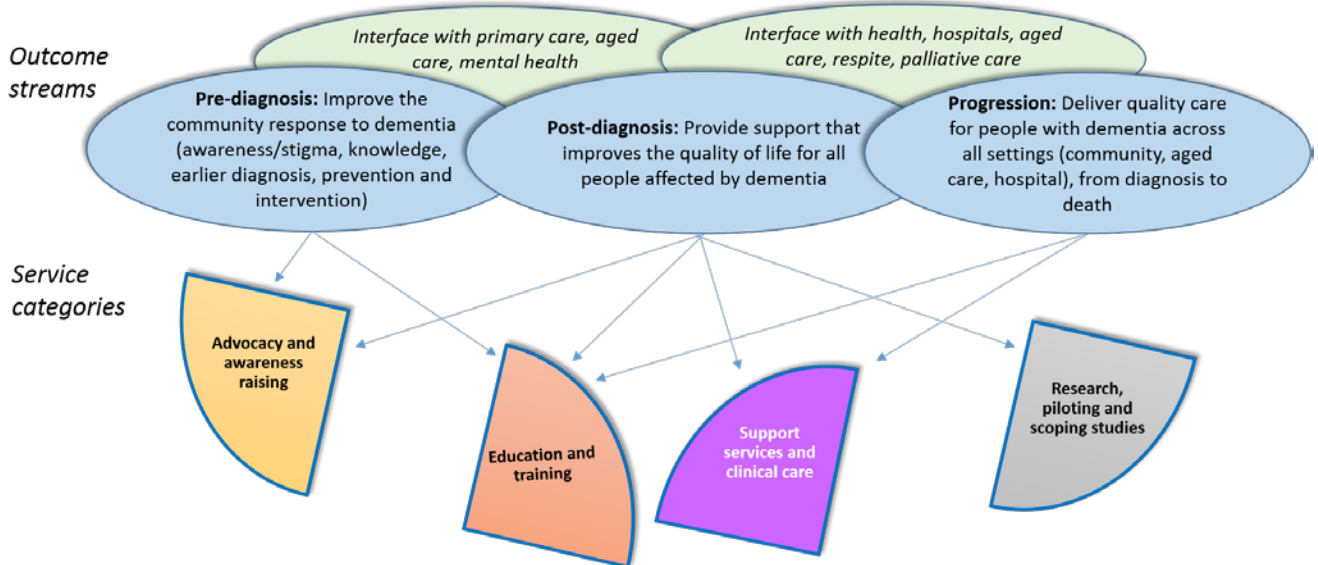


Source: KPMG

Several submissions suggested that it would be helpful to place the service categories into a broader structure of policy or outcomes ‘streams’, which also highlights the critical sector interfaces. Such a model should first articulate *why* the government funds particular dementia programmes and services and *what* it aims to achieve by doing so, before then organising *how* they will be delivered and *who* will deliver them.

Figure 2 provides such a model, linking the service categories from Figure 1 (the ‘how’) to particular outcomes streams (the ‘why’). Several suggestions were made by stakeholders as to how these streams could be organised. The approach adopted in this proposed model is to organise the interlinked outcome areas to dementia phases.

Figure 2: Proposed dementia 'outcome streams' linked to service categories (showing critical service interfaces)



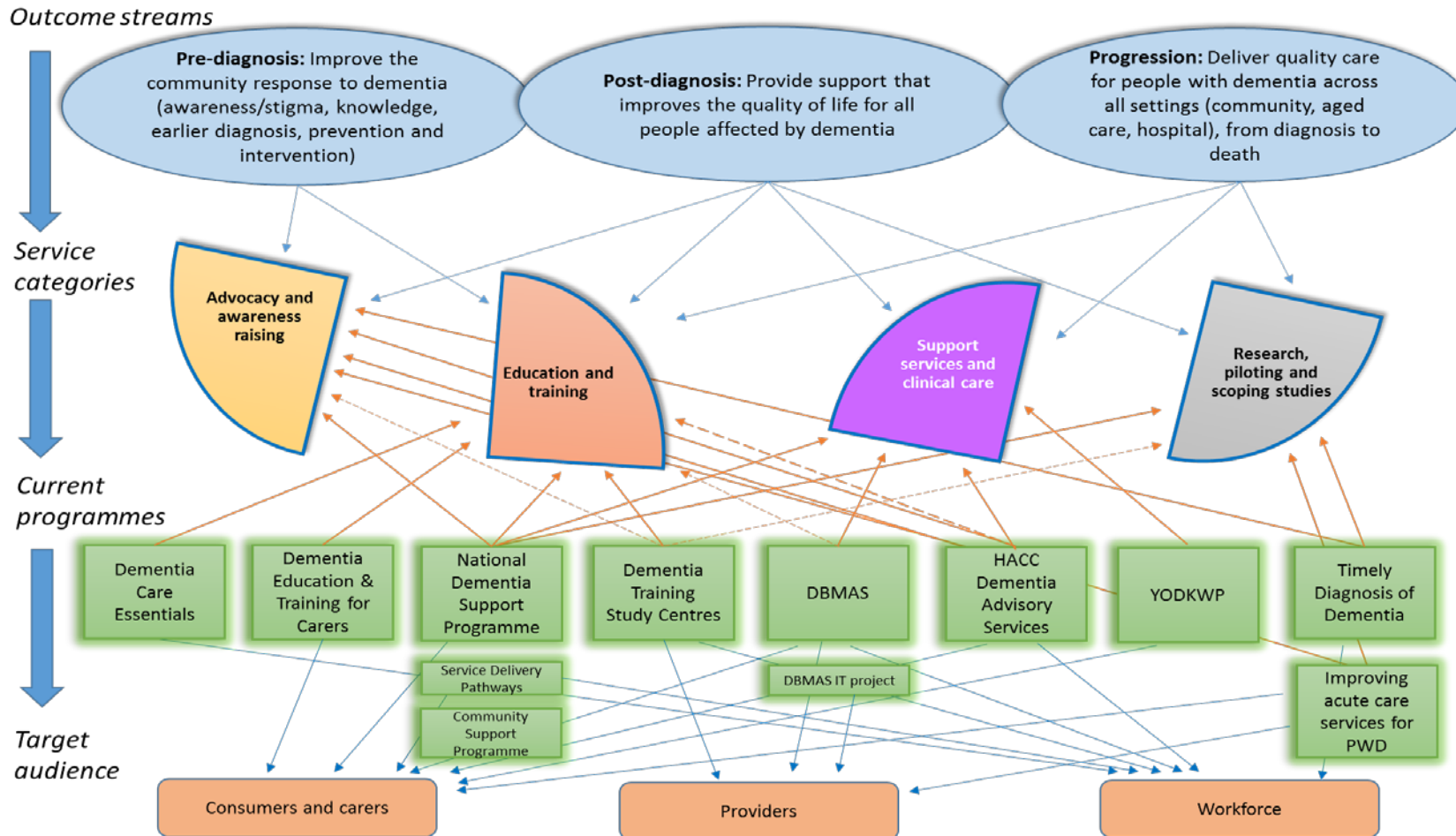
Source: KPMG

The model could provide a broad framework for (a) ensuring that funded programmes and services are clearly linked to specific policy objectives which are articulated as intended outcomes (recognising that these are impacted by the effectiveness of sector interfaces), and (b) linking outcomes to the categories of programmes and services that are funded by the Department.

The existing programmes and services can be mapped to this model, which helps to illustrate potential areas of duplication and overlap, as well as the gaps. Figure 3 over the page provides such a map. Table 1 on the pages following provides an updated version of the activities matrix from the conversation starter. Together these demonstrate the following points identified by the analysis:

- There is duplication in support services for people affected by dementia (NDSP and HACC Dementia Advisory Services). Only in NSW does it appear that HACC has been used to deliver services in areas where the NDSP does not have a regular presence, particularly rural areas. In Queensland, there are two organisations funded to provide a dementia helpline and shopfronts. It also appears that in some areas HACC is also being used to provide services that overlap with DBMAS, or filling a perceived gap for case management.
- Although there is no duplication of education and training services across the in-scope programmes and services, because most target slightly different groups (the exception being Dementia Education and Training for Carers and the NDSP which both provide training for informal carers), there is a lack of national consistency and a lack of national coordination for these services which increases complexity for the target cohorts and makes programme administration less efficient.
- The overall service structure is complex. For example, a number of minor initiatives could be rolled into the NDSP to reduce the service system complexity and simplify reporting and monitoring arrangements.

Figure 3: Mapping current programmes and services to service categories and outcome streams



Source: KPMG

Table 1: Summary matrix of in-scope programmes and services

| | Education/training (health workforce) | Education/training (aged care workforce) | Education/training (families/carers) | Support for people affected by dementia | Research and pilot programmes | Advocacy and awareness raising | Other (e.g. IT and infrastructure) |
|---|--|---|---|--|----------------------------------|-----------------------------------|--|
| Dementia Training Study Centres (DTSCs) (2013-16) | ● | ● | | | ● | ● | |
| Dementia Behaviour Management Advisory Services (DBMAS) (2013-16) | ● | ● | ● | ● | | ● | |
| DBMAS IT Project (2014-15) | | | | | | | ● |
| National Dementia Support Programme (NDSP) (2013-16) | | | ● | ● | | ● | |
| Dementia Community Support Programme (2012-2017) | | | | | | ● | |
| Service Delivery Pathways for special needs groups (2011-16) | ● | ● | ● | ● | ● | ● | |
| Responding to Neurodegenerative Disease (2012-16) | ● | | ● | | ● | | |
| Younger Onset Dementia Key Worker Programme (2014-16) | ● | ● | ● | | | ● | |
| Dementia Care Essentials (2011-16) | | ● | | | | | |
| HACC Dementia Advisory Services (2012-18) | | ● | ● | ● | | | ● |
| Timely Diagnosis of Dementia in Primary Care (2014-17) | | | | | ● | | |
| Detect Early Project (2014-15) | ● | | | | | | |
| Improving Acute Care Services (2013-17) | ● | | | | ● | | |
| Dementia Education and Training for Carers (2014-17) | | | ● | | | ● | |

Source: KPMG

2.3 Specific observations of in-scope programmes and services

2.3.1 Dementia Training Study Centres (DTSCs)

DTSCs provide courses, workshops and seminars for continuing professional education for dementia health care professionals and students at a tertiary level, as well as assisting universities with curriculum development.

Observations from the initial stocktake were that it was unclear to what extent DTSCs collaborate or are aligned with the other programmes and services involved in education/training for the health workforce, and that there was little published or reported information about the effectiveness of DTSCs, or of their perceived value by stakeholders (although output data and some training outcomes data are reported in their annual reports to the Department).

The consultations provided some additional information about the DTSCs. The services provided are valued by stakeholders in major cities, whereas those in regional areas reported that although the services were considered to be of good quality they were more difficult to access from regional, rural and remote areas, despite increased use of remote service delivery. Longer lead-in times and a consolidated, national list of training opportunities promoted well in advance were suggested to remediate this. The adoption of a more nationally consistent approach for DTSCs generally was also advocated.

The Dementia Training Study Centres are an excellent resource for health professionals. Consolidation of all education under their umbrella would reduce duplication, ensure quality and a more consistent approach. Currently there are five DTSC's across Australia, each with their own focus. A review of education on the DTSC website indicates that programs are not national, rather they are specific to each state. A national approach would provide consistency in resources and education. (*Submission 54 – peak body*)

The DTSCs have begun moving to a more collaborative and nationally consistent form of operating (including collection of outcomes data) and are attempting to work more closely with other programmes and services. The DTSCs recognise that there are opportunities for further enhancements in this area. A submission from the DTSC leadership group also proposes an approach for measuring effectiveness not only of education and training programmes, but of all of the in-scope programmes and services, based on four stages of knowledge transfer.

Focussing on outcomes might lead to a totally different way of looking at the relationships between services, particularly if a common outcome could be agreed on. Why not consider the possibility that all of these services and programmes have a common goal – to transfer knowledge in the service of improving care to people with dementia. Pathman et al (1996) has suggested a simple four stage model of the transfer of knowledge that has been generated from research or the evaluation of practice. The first stage involves raising *Awareness* of the new knowledge. Unless practitioners (or consumers) are aware of a new/better way of doing things they cannot put it into practice. This is followed by *Agreement*, because without agreement that the new way is better nothing will change. Once agreement is reached the possibility of *Adoption* is opened up and, if resources and authority to change are present, practice can be changed. Once adoption has been achieved the new practice can become accepted good practice, business as usual, and its *Adherence* supported by the development of policies, QA processes and, sometimes, regulation ... (to date) there simply has not been enough attention given to the Adoption

and Adherence stages. Too many programmes and services content themselves with Awareness raising and Agreement. (*Submission 29 – DTSC leadership group*).

2.3.2 Dementia Behaviour Management Advisory Services (DBMAS)

Dementia Behaviour Management Advisory Services (DBMAS) provide advice and support to those caring for people with dementia, with the focus on people experiencing severe behavioural and psychological symptoms of dementia. Services may include clinical advice over the phone, assessment, care plan development and short-term case management, mentoring and education and training.

The initial stocktake noted that there was little published or reported evidence of DBMAS's effectiveness (the services have been in operation for eight years now, although some of the providers have changed), and that its current performance reporting focuses on outputs rather than outcomes. It was also noted that there was considerable variability in how the different DBMAS gather user feedback and review outcomes. Furthermore, service delivery appeared to be inconsistent in each jurisdiction.

At the workshops, some aged care stakeholders were very supportive of DBMAS and considered it an essential service; others considered that it provided non-individualised and generic advice and/or had strayed into other areas of operation – such as general training – outside of its intended scope. It was difficult to isolate these comments to a particular jurisdiction, however those outside of major cities were more likely to say that DBMAS was ineffective because it took too long to respond.

Written submissions provided equally divergent views of DBMAS effectiveness:

... the degree of impact and therefore perceived benefits of services such as DBMAS varies across Australia, and sometimes even within a localised geographic region. While we support the principle that services should vary to meet the needs of the local population, we do not believe there should be any variation in the level of impact or benefits. (*Submission 52 – national aged care provider*)

The DBMAS service is a highly disjointed, non-collaborative, inconsistent, poorly targeted and offers tax-payers an extremely poor return on investment. (*Submission 47 – clinician with experience across several jurisdictions*)

DBMAS provides a crucial source of advice and support not only to (service providers) but also to (our) consumers and their families/carers. Twenty-four hour support is highly valued and an essential resource. As a phone base support program they do not offer home visits. Home visits could be a good add on to the current 24 hour phone support service. (*Submission 30 – HACC/dementia services provider*)

Services such as DBMAS have not been able to attend to community home assessments either at all or in a timely manner. The priority appears to be residential care. (*Submission 27 – aged care provider*)

(Residential aged care providers) report a preference to seek advice from state funded mental health services over DBMAS. Reasons cited included improved case management which often extends to specialised training for care givers. This feedback (from our member organisations) was consistent from both metropolitan and regional members... (Furthermore), rural members report when they do utilise DBMAS there is a significant time lag from referral to action... DBMAS (is considered to be) of most benefit when used to manage psychological and

behavioural symptoms of dementia at the lower end of the spectrum.
(*Submission 38 – peak body*)

One of the written submissions questioned the continuing relevance of service approaches structured around a medical model focussed on ‘managing’ people with dementia, suggesting that this approach and the accompanying clinical language was inconsistent with person-centred practice and bio-psycho-social⁴ informed models of care (although it should be noted that DBMAS practitioners who attended the workshops described their approaches as being strongly informed by bio-psycho-social theory). This does raise some interesting questions about how dementia care is framed – indeed, who the ‘client’ is – and the extent to which person-centred approaches are genuinely applied for people with dementia (as well as their carers), and even the applicability of reablement-informed methods in dementia care. This is an area which was not discussed in great detail during this analysis, but was cited as a particularly important consideration by those stakeholders with interests in younger onset dementia. Put simply, individual dementia care needs differ and a service system which directs most of its resources to the front end (i.e. information, support and advice on diagnosis and in the very early stages of dementia), and to managing severe behaviours for those in advanced stages is not only missing a significant proportion of those in need of support, but it is also potentially missing opportunities to implement a range of earlier interventions and care strategies that could negate the need for crisis interventions at the tail end.

An enabling wellness approach is often not considered as an option for people who have been diagnosed with dementia ... a person with dementia is and continues to be a valued member their community. (*Submission 47 – dementia services provider*)

DBMAS will be integrated with SBRTs from 2016-17 following a year-long first phase in which stand-alone SBRTS will act on referral from DBMAS. It is also suggested that a comprehensive evaluation strategy be implemented for the integrated DBMAS and SBRTs programme.

A review will ensure that its service offerings and delivery models remain relevant and responsive in the current environment, that there is consistency and equity of access and service delivery across locations, and that there is a focus on building sustainable dementia care capacity in the aged care workforce.

For regional and remote areas, accessing DBMAS services in a timely manner is difficult. A regional Aged Care Facility recently waited over two months for a site visit and review despite the frequency and severity of the resident’s behaviours... The workforce requires education on how to provide dementia friendly environments, meet the needs of people with dementia, the provision of person-centred care and other psycho social strategies to reduce behaviours. Only then will the industry move away from the task focused care that is predominant. (*Submission 54 – peak body*)

⁴ A bio-psycho-social model is the interaction between one's genetic makeup (biology), mental health and personality (psychology), and sociocultural environment (social) that contribute to health or illness. Source: Boundless. “The Biopsychosocial Model.” Boundless, 03 Jul. 2014.

2.3.3 DBMAS Information Technology Project

This one-off project aims to enhance the national capacity of DBMAS to provide services via videoconferencing platforms. This enhanced capacity will lead to improved access to DBMAS services, in particular from clients from rural and remote settings.

No substantive information about this project's effectiveness was obtained, although a small number of stakeholders with first-hand knowledge of the project considered that it was important and effective.

2.3.4 National Dementia Support Programme

The National Dementia Support Programme (NDSP) provides funding to Alzheimer's Australia to operate a range of consolidated programmes and services to support people with dementia and their carers and families. This includes the national dementia helpline and referral service, dementia and memory community centres across a variety of metropolitan and regional locations around Australia, early intervention support, non-clinical advice, counselling and professional support, education and training, and dementia advocacy and awareness raising. The programme was evaluated in 2007.

Observations from the initial stocktake were that Alzheimer's Australia (AA) collected and reported significantly more sophisticated output and outcomes data than the other in-scope programmes and services (for the NDSP and the other programmes and services that they administer). In addition, the NDSP and several other AA-administered programmes and services have also been subject to review and evaluation over the years. In terms of performance monitoring, evaluation and reporting, this programme provides a model for others.

The consultations indicated that the majority of stakeholders – especially consumers and carers – are aware of these services and consider them to be important and effective. Other stakeholders were generally supportive of these services and the current delivery structures; some of those from outside of major cities indicated a preference for services to be delivered by 'local' community organisations rather than by AA.

The Living with Memory Loss program was so helpful. It has helped me with deal with everyday problems as (my husband's) memory decreases. I also made friends within the group. I praise the support counselling service available through AA - I have called on them a few times and am so grateful for the advice given. *(Submission 1 – carer)*

The Living with Memory Loss Program helped me to better understand what my husband is dealing with and has shown me some helpful ways to respond. The relationships that were built with other couples during the course have been extremely encouraging for both of us, as we realised that our experience is shared by others. It was good to learn about different ways to deal with situations from the others and from the facilitator and to see how we can be better equipped, through education about Alzheimer's to face the future with a more positive outlook and less fear about what is going to happen. Good information was also provided about support services. *(Submission 4 – carer)*

Alzheimer's Australia's Carer Education Course was very helpful. Over three days I learnt a great deal that I was able to apply in my carer role while (my wife) enjoyed being taken for a drive and cared for by a respite carer... Alzheimer's counselling service was a most

needed help. The Alzheimer's Library staff are extra helpful with their own advice as well as finding relevant books. (*Submission 11 – carer*)

Some areas for improvement were identified. One carer suggested that, although AA worked across the dementia spectrum, its name suggested a primary focus on Alzheimer's disease that might be off-putting for people affected by the many other forms of dementia. Some stakeholders also suggested that services delivered under the NDSP were very effective in those locations where it has a physical presence, but less effective in rural and remote areas, partly because of a preference by most consumers and carers for face-to-face services and partly because the state-based AA websites could be confusing – although others considered that the AA websites, and its national website in particular, were important information sites and, at the present time, offered the most extensive mix of Australian resources.

It was not clear from the initial stocktake to what extent AA collaborated with or was aligned to other key services (specifically with DTSCs or DBMAS), particularly in relation to coordinating education and training activities. This remained unclear after the consultation process.

2.3.5 Service Delivery Pathways Programme

This programme is essentially a component of the NDSP and could be incorporated within it – ideally, activities aimed at increasing access for special needs groups should be 'mainstreamed' within the main programme. It was evaluated in 2011.

The stakeholders who were aware of this initiative at the workshops were very supportive of it and reported that it was, anecdotally, successful – but modestly so, given its limited scope.

2.3.6 Dementia Community Support Programme

The name of this programme is somewhat confusing because it does not provide any community support services. Rather, it provides funding to AA to function as a national peak body for people living with dementia.

This programme also essentially operates as a component of the NDSP funding provided to AA, but it is considered appropriate for this funding to remain separate to maintain a clear distinction between service provision and peak body functions: partly to ensure that clear performance indicators are articulated for this function, and partly to allow for the two activities potentially being delivered by separate service providers at some point in the future. In the meantime, the performance indicators for this programme should be reviewed as part of the national framework development.

2.3.7 Developing Innovative Methods to Respond to Neurodegenerative Disease Project (DIMRND)

This programme is also essentially a component of the NDSP and could be incorporated within it.

DIMRID is establishing a number of sustainable national programmes that promote and facilitate evidenced-based dementia case practice in areas of priority to consumers. Five projects are operated by Alzheimer's Australia member organisations. No information was available about its effectiveness at the time of the initial stocktake. No additional information was provided through the consultations. However, some stakeholders did explicitly acknowledge this as an area of need and were supportive of the project. At this stage it is simply too early to assess its effectiveness.

2.3.8 Younger Onset Dementia Key Worker Programme

This pilot programme provides key workers who act as a primary point of contact for people with younger onset dementia, their families and carers. The key worker provides information, support, counselling, advice and helps consumers effectively engage with services appropriate to their individual needs. The programme will transfer to the National Disability Insurance Scheme (NDIS) from 2016-17.

This programme was perhaps the most commonly discussed in-scope programme at all of the workshops. Stakeholder groups agree that people affected with younger onset dementia have historically been a neglected group in dementia care, 'falling through the cracks' of a system where dementia responses have primarily been developed through an ageing and aged care lens. This programme is widely reported to be effective – including by a number of consumers and carers who attended the workshops who explained how having a single, informed point of contact had helped them to: accept the diagnosis; make important life decisions in a timely way; link in to other services; and to help build the confidence to see themselves as still having valuable social contributions to make despite, or because of, their changing circumstances (indeed, several of the consumers with younger onset dementia who attended the workshops to share their stories and insights did so on the encouragement of their key workers).

Many of these consumers expressed some anxiety about the programme's transition to the NDIS, with specific concerns around entry eligibility. These concerns should be considered by government in planning the transition of the programme, and particularly in communicating the changing arrangements to stakeholders.

It should be noted though, that the programme is less than three years old and has not yet been formally evaluated. The programme is currently providing services to around 1,000 of the estimated 25,000 Australians with younger onset dementia.

2.3.9 Detect Early Project

This was a one-off project funded under the Timely Diagnosis of Dementia in Primary Care initiative that was completed on 30 June 2015. It aimed to encourage doctors and other healthcare professionals to look for the signs of dementia in its early stages. It provided education resources and tools to assist with early diagnosis. Available performance data indicates that the programme exceeded its agreed performance targets.

Few stakeholders participating in the consultations were aware of this initiative, but most indicated that there is an ongoing need to promote early detection and diagnosis in primary care. This was particularly emphasised in the regional workshops.

There does appear to be a need for a sustained effort targeting the primary care sector to promote awareness and early detection, preferably with clear performance indicators and data collection. These activities could be rolled into the NDSP, Dementia Community Support Programme or the DTSCs.

2.3.10 Dementia Care Essentials

Dementia Care Essentials (DCE) offers nationally recognised dementia care training to aged care workers throughout Australia and is free to eligible care workers in residential, respite or community care settings or the wider health sector. It is aimed at those care workers who do not have a tertiary qualification.

The initial stocktake found that a variable in the success of this training (as reported in a 2012 programme evaluation) appeared to be where it is supplemented with organisational-level action planning for change, raising the question about the value of providing these services as a standalone intervention rather than as part of a more coordinated effort.

Additional information obtained through the consultations was mixed. Some aged care stakeholders were aware of this programme but few had experience with the training services (it should be noted that several DCE providers also attended the workshops). Some written submissions made reference to the programme and indicated that the services were generally well-received.

Training provided through the Dementia Training Study Centres (DTSCs) and Dementia Care Essentials is of good quality and valued by (our member organisations).
(*Submission 38 – peak body*)

Written submissions also highlighted the lack of national consistency and coordination across all of the training and education programmes, but DCE was particularly identified as needing a more consistent approach.

Nationally, there is no consistency in the quality of the courses or information being taught. There are five organisations delivering Dementia Care Essentials throughout Australia and each organisation uses its own training materials based on the organisations interpretation of the unit descriptor. In Victoria, the CHCAC319A is conducted over three days. In Queensland, it is conducted over one day. This highlights the disparity between Registered Training Organisations (RTO's) and the quality of education that is being funded. Performance reporting has been based on the number of participants completing the course rather than the impact of the program on care practices. To our knowledge, whether the program has improved care worker practice has not been evaluated. A report by C Jones, Griffith University 2014 highlighted that many care staff felt that the education on offer did not translate into practice. The report also notes that the program has not been effective in promoting quality dementia care in Queensland. It is also highlighted that many Personal Care workers are from CALD backgrounds and English is their second language. There is an urgent need for education tailored for these workers.
(*Submission 54 – peak body*)

One of the written submissions suggested that a programme of DCE training should be expanded to MyAgedCare staff and potentially the disability workforce.

2.3.11 Dementia Education and Training for Carers

The Dementia Education and Training for Carers (DETC) programme provides funding to Commonwealth Respite and Carelink Centres to improve the quality of life of people living with dementia, by increasing the competence and confidence of carers through providing courses that enhance their skills or processes that connect a carer to information.

The initial stocktake identified that the range of services provided under this programme overlaps with those provided under the NDSP and DBMAS (and in many instances, services such as training courses which are delivered by Alzheimer's Australia and the DBMAS providers for the Centres).

This overlap was confirmed in the written submissions of Alzheimer's Australia and one of the DETC providers. Both of these organisations suggested that rather than duplicating service delivery, this arrangement allowed for increased coverage and consumer choice.

As the peak consumer organisation for people with dementia in Australia, Alzheimer's Australia is well placed to be at the forefront of education for carers related to dementia, and as such have a well-developed suite of carer focussed education courses that are well-received and highly recommended. However, barriers remain for some people in (accessing) information on dementia including distance (rural and remote areas), the stigma that remains associated with dementia, denial of the person they are caring for about their diagnosis. As such, it is important to ensure that carers have alternate methods to access carer support and education in relation to dementia which is the critical role of the service offered through the Dementia Education for Carers programme.
(Submission 49 – Alzheimer's Australia)

There are a number of services supporting people living with dementia, but that does not mean that there is a duplication of services. ... Having multiple specialized services supporting carers, and people with dementia, is not a negative. With the increasing number of people being diagnosed with dementia more services may be required, not less. Also as we head towards a more consumer driven service it is important for the consumer to have choice...The DETC program is the only program that is National as it is facilitated by CRCC centres. All centres may not have currently receive funding for the program but it is the ideal portal for the ongoing specialized service and also a good portal for any consolidated or new services, in relation to Carers. As CRCC is Carer focused it lends well to the future in relation to a Carer Portal, where all carer services are centred.
(Submission 37 – DETC provider)

Although there may be a case for having multiple providers of similar services to ensure coverage and offer choice, there is no clear rationale for the funding of these services through two different programmes with different performance indicators.

The benefits of co-locating DETC with respite services were also highlighted in the submissions, as it is reported that many DETC participants were identified when they approached a CRCC in relation to respite services and were then referred into DETC. This points again to the potential for a single 'one stop shop' model for consumers and carers to access dementia care and services, which could perhaps be administered through the CHSP Regional Assessment Services or MyAgedCare, or indeed by an organisation such as Alzheimer's Australia and/or the current CRCC providers.

2.3.12 HACC Dementia Advisory Services

The Commonwealth HACC Programme (previously the Home and Community Care programme, and which has been consolidated into the new Commonwealth Home Support Programme with other entry level services for older people from 1 July 2015) funds a wide range of non-ongoing services to help older people living at home. Under this programme, funding is provided to a number of organisations to deliver 'dementia advisory services'.

The initial stocktake noted that many of the Dementia Advisory Services funded under HACC appeared to duplicate or overlap with the NDSP and DBMAS:

- access to counselling services for people with dementia and carers (which is also funded through the NDSP)
- access to education and training for carers and families (which is also funded through the NDSP, the Dementia Education and Training for Carers programme, and DBMAS)
- a variety of non-specific activities to support dementia care of people with special needs (which is also funded through the Service Pathways Programme of NDSP).

The consultations provided some more clarity around these services. Across jurisdictions, the HACC Dementia Advisory Services seem most frequently to be used as a flexible source of funding for case management or key workers type services to people affected by dementia. Unfortunately, the lack of meaningful data makes it difficult to assess the effectiveness of these services, or their alignment with other services. These are legacy programmes the Commonwealth inherited when New South Wales, Queensland, South Australia, Tasmania, the Australian Capital Territory and the Northern Territory handed control of their HACC programmes to the Commonwealth in 2012.

Therefore there is little, if any, consistency or transparency around the way the current HACC services are funded and distributed. The available information suggests that NSW has the most well organised HACC Dementia Advisory Services and that, at least in rural areas, these seem to be coordinated with NDSP services to ensure maximum coverage and reduce duplication – arrangements which appear to mostly have been developed at the local level over time.

As with the DETC programme, the conclusion of this analysis is that whilst there may be a case for having multiple providers of similar services to ensure coverage and offer choice, there is no clear rationale for funding these services through two different programmes. Furthermore, the lack of performance information for the HACC services and the lack of a consistent approach to delivery of these services does not support continuing with the status quo. However, it should be noted that Alzheimer's Australia put forward a different position in its submission:

Whilst it might appear that there is duplication between these two programs, it is the service *type* (classification of funding) that is duplicated across the two programmes, whereas the outputs are different with separate and distinct outcomes for clients under each of the programmes. The two different funding streams allow Alzheimer's Australia to reach more people with dementia than would be possible under only one of the funding streams. (*Submission 49 – Alzheimer's Australia*)

As these programmes were separately developed by individual states and territories, there is a wide disparity in the level of funding between jurisdictions. Also, the Victorian and Western Australian HACC programmes have not been integrated into the Commonwealth programme.

2.3.13 Timely Diagnosis of Dementia in Primary Care

The Timely Diagnosis of Dementia in Primary Care initiative provides funding for a number of scoping and pilot projects aimed at improving the earlier diagnosis of dementia.

Several projects funded under this initiative that were in-scope for this analysis include:

- Detect Early Project (discussed at section 2.3.9 above)
- Primary Care Education Scoping Project
- Medicare Locals scoping study.

Few stakeholders were aware of these projects, although there was a great deal of interest in them by aged care providers in particular. The programme could be improved by having a more targeted strategic direction.

2.3.14 Improving Acute Care Services for People with Dementia

The Improving Acute Care Services for People with Dementia provides funding for a number of scoping and pilot projects aimed at improving outcomes for people with dementia admitted to hospital, activities that target safety, staff training, environmental design and awareness raising.

Specific projects funded under this initiative that were in-scope for this analysis include:

- Acute Care Education Scoping Project
- Dementia in Acute Care – environmental design
- Promoting the National Safety and Quality Health Service Standards as they relate to the care of people with cognitive impairment.

As with Timely Diagnosis of Dementia in Primary Care, few stakeholders were aware of these projects, although there was a great deal of interest in them by aged care providers in particular. The programme could be improved by having a more targeted strategic direction.

One written submission provided further information about one of the projects (Dementia in Acute Care – environmental design) which highlighted its extensive progress; there may be value in ‘mainstreaming’ this within the DTSCs.

A key question around the other projects is how the results will be disseminated and inform practice and service development, where appropriate. Many stakeholders suggested the need for some form of clearinghouse. Alzheimer’s Australia, the DTSCs and MyAgedCare were suggested sites for such a repository. It would be valuable for

such an initiative to be coordinated with the NHMRC’s new National Institute for Dementia Research.

Over the past three years (this organisation) has supported ten research projects, some of which have been funded by the Dementia Collaborative Research Centre (Consumers and Carers) or peak agencies and others undertaken by Honours, Masters and PhD students. These ten research projects represent significant investment by funding agencies, research teams, students and most particularly carers of people living with dementia. Despite this significant investment, there is little evidence of funding being made available to translate this rich data into contemporary policy or practice. *(Submission 30 – peak body)*

2.4 Discussion

The analysis has identified a number of areas that are working well and has also identified areas for improvement. These are described in the table below.

Table 2: Findings - areas that are working well and areas that could be improved

| Area | What is working well | What could be improved |
|---------------------------------|---|---|
| Service categories | <ul style="list-style-type: none"> Most stakeholders support the current service categories and consider them to be an appropriate catalogue of initiatives. | <ul style="list-style-type: none"> An overarching framework Better alignment of funded services to outcomes Streamlined programme structure with reduced duplication. |
| Education and training | <ul style="list-style-type: none"> Education and training activities are generally well-received. | <ul style="list-style-type: none"> Streamlined programme structure National coordination and consistency Improved rural access. |
| Dementia Training Study Centres | <ul style="list-style-type: none"> Education and training activities are generally well-received Efforts underway to improve national collaboration and outcomes data collection. | <ul style="list-style-type: none"> DTSCs are well-placed to take an expanded role in the national coordination of all education and training activities in a more streamlined service system DTSCs are also well-placed to provide a clearinghouse to promote the dissemination of research and scoping studies (in collaboration with the NHMRC National |

| Area | What is working well | What could be improved |
|--|--|--|
| | | Institute for Dementia Research). |
| Dementia Care Essentials | <ul style="list-style-type: none"> • Targets an identified need (aged care workforce development). | <ul style="list-style-type: none"> • National coordination and consistency • Outcomes data. |
| Dementia Education and Training for Carers | <ul style="list-style-type: none"> • Co-location within CRCCs. | <ul style="list-style-type: none"> • National coordination and consistency • Outcomes data. |
| DBMAS | <ul style="list-style-type: none"> • Services continue to be valued by many aged care providers and family carers. | <ul style="list-style-type: none"> • Improved rural access • Consistent national performance • Ensure there is a comprehensive evaluation strategy for the integrated DBMAS and SBRTs programme. |
| NDSP | <ul style="list-style-type: none"> • Services are highly valued by consumers and carers • Extensive national network and resources • Outcomes data, monitoring and evaluation mechanisms. | <ul style="list-style-type: none"> • Continued work to improve access for special needs groups and primary care • Awareness raising for special needs groups • Improved rural access for face-to-face services. |
| YODKWP | <ul style="list-style-type: none"> • A popular model with consumer advocates. | <ul style="list-style-type: none"> • Ensure that there is a smooth transition to the NDIS. |
| HACC Dementia Advisory Services | <ul style="list-style-type: none"> • Flexible funding to deliver individualised responses. | <ul style="list-style-type: none"> • National coordination and consistency • Outcomes data. |

Source: KPMG

2.4.1 Duplication and overlap

The main areas of duplication and overlap identified are as follows:

- HACC Dementia Advisory Services and the NDSP – these provide similar services under different programmes but do not share common performance indicators.
- DETC and the education and training elements of the NDSP – again, these provide essentially the same services under different programmes and with no formal organisation across the programmes to maximise coverage (although reportedly this does occur to some extent, unofficially) and they do not share common performance indicators.
- The NDSP and Dementia Community Support Programme both provide funding to AA for policy advocacy and awareness raising activities (NDSP funds are directed to state organisations and the Community Support funds are used for national activities). It would be simpler to have all funding for systematic advocacy and awareness services provided through a single programme with consistent performance indicators; it may also be preferable to remove all advocacy and awareness funding from service delivery funding (i.e. separate it from the NDSP).

2.4.2 Gaps and emerging issues

The key gap across most of the programmes and services is regional, rural and remote accessibility. It may be necessary to reconsider the way funds are allocated to ensure coverage is maximised (i.e. directing more funding to provide more services in this area to cover the increased staffing and travel costs), or to look at more localised approaches to service delivery for some programmes and services.

Many stakeholders point to a need for a ‘single entry point’ for consumers and carers to access dementia support. This would potentially improve access and efficiency.

There remains a need for dedicated efforts to raise awareness and increase access for special needs groups, particularly people from Aboriginal and Torres Strait Islander backgrounds, people from culturally and linguistically diverse backgrounds, those with younger onset dementia, people in rural or remote areas with poor health literacy and poor access to primary care, people at risk of homelessness, and people from LGBTI communities.

There also remains an ongoing need to raise awareness and promote earlier detection in the primary care sector.

There is still a demand for support in managing severe behaviours. It appears that this demand is not being met in many rural areas, as well as in the community aged care sector. In the longer-term, more attention needs to be paid to developing sustainable dementia care capability within the aged care sector to decrease reliance on these services and ensure dementia competencies are incorporated into core business.

A number of stakeholders, particularly larger aged care providers and dementia services providers as well as peak bodies, identified an overall need for better and smarter data collection based on outcomes rather than outputs, with consistent

performance indicators across programmes and services. A more structured approach to programme evaluation and monitoring was also advocated.

A data-led approach should be taken in assessing the existing or desired mix of categories of Department-funded services available to people with dementia. Similarly, we believe that the appropriateness, effectiveness and accessibility of dementia services should be transparently measured and reported... We note the Australian Institute of Health and Welfare identified in a recent report, how important rich and robust data on dementia is to ensuring that policies and service delivery are best meeting the needs of people with dementia... improving dementia data should be made a priority and that data should be made a key element of a national dementia strategy.

(Submission 52 – aged care provider)

An effective programme should be measured based on the outcomes for people with dementia rather than predefined service outputs based purely on number of clients seen or sessions delivered. It should be looking at the impact of programmes on the lives of people with dementia, their carers and families, whether services have met their needs, as well as the impact on communities and populations.

(Submission 49 – dementia services provider)

3 Considerations for the future

This section sets out a series of considerations for the future and suggested actions, based on the analysis findings set out in the previous section.

3.1 A more strategic approach

There is a strong need for a robust national dementia strategy, as well as a framework for determining effectiveness of programmes and services. Without such a strategy, or rich and robust outcome data and evidence, we cannot be certain that dementia programmes and services are as accessible, effective and efficient as they could be for Australians with dementia. (*Submission 52 – aged care provider*)

The current landscape of dementia-related programmes and services has developed in response to emerging need, and requires a new strategic approach in the context of experience, evidence and demographics. (*Submission 41 – aged care/dementia service provider*)

As highlighted earlier in this report, it would be beneficial to have an overarching framework to guide programme and service development and funding. Articulating clear objectives and intended outcomes would form the basis for ensuring the national structure, alignment and consistency of DSS funded programmes and services. This can then underpin outcomes-based performance measurement, and aid in monitoring and evaluating performance.

3.2 Opportunities for programme and service consolidation

The number of services and service providers receiving funding contributes to a lack of consistency in the quality and delivery of services. For consumers, this duplication of services, multiple service providers and the lack of consistency creates confusion on what services to access and how to access them. The number of services could definitely be consolidated to provide more consistency and reduce confusion amongst consumers. (*Submission 54 – peak body*)

The suite of programmes and services has a high level of complexity and lacks focus, which is confusing for those trying to navigate them, including people with dementia, their families and services providers. The objectives of this suite of programmes and services are not clearly articulated. (*Submission 41 – aged care provider*)

Currently the delivery of education can be confusing as different organisations offer training to a variety of audiences and certification end points. A standardised directory that is accessible from each service website detailing what education each organisation offers would be helpful. This should include specific detail re self-directed learning modules to degree level. (*Submission 30 – dementia services provider*)

A number of opportunities exist to consolidate and streamline programmes and services:

- consolidate elements of HACC Dementia Advisory Services with the NDSP and or DBMAS to provide clear support programmes with national coverage and common performance measures. Given the diverse funding of HACC Dementia Advisory Services, this would need to be considered over the longer term in conjunction with

the integration of the CHSP into the new care at home programme from 1 July 2018.

- remove the education and training activities from the NDSP and combine them into the DETC programme with national coverage and common performance measures
- remove the systematic advocacy and awareness raising activities from the NDSP and consolidate them with the Dementia Community Support Programme into a single dementia advocacy and awareness raising programme
- consolidate the Service Delivery Pathways Programme and DIMRND initiatives into the NDSP
- consolidate the Acute Care – environmental design project into DTSCs
- expand the role of DTSCs to include national coordination of all education and training programmes, with a view to combining these into a single programme with common performance measures
- improve the targeting and strategic direction of the Timely Diagnosis of Dementia in Primary Care and the Improving Acute Care Services for People with Dementia programmes.

It is noted that the funding periods for the majority of in-scope programmes and services expire over the next two years.

3.3 Maximising coverage and enhancing services

There needs to be a universal pathway in Australia for referral of those with ongoing memory loss/suspicion of dementia or diagnosis of dementia.

(Submission 30 – dementia services provider)

There is a need for dementia key workers for people with dementia of all ages to provide a consistent point of contact on the specialist needs of people with dementia during the course of the disease. In the first instance this should be targeted on those people with dementia from special groups including CALD, Indigenous communities, LGBTI, the homeless and those living alone. *(Submission 42 – dementia expert)*

It may be beneficial to assess whether a ‘one stop shop’ style initiative would be possible for all Commonwealth funded dementia services, programmes and grants. This would also potentially allow for more successful dissemination of research and therefore assist in delivering evidence based best practice. *(Submission 44 – peak body)*

Consolidation of programmes and services will assist to maximise coverage by streamlining the service structure. Additional measures will also be needed to improve coverage. This could include:

- mandating specific performance targets and measures for the delivery of services in rural, regional and remote areas to which providers will be held accountable
- developing common performance measures for programmes to allow better monitoring of activity and outcomes across locations

- improving access through a 'one stop shop' entry point for dementia care, perhaps through MyAgedCare (noting that arrangements will need to be made for those affected by younger onset dementia), RASs or CRCCs.

3.4 Recommendations and suggested actions

Table 3: Suggested actions

| Area | Suggested actions |
|---|--|
| <p>1. Develop clear objectives linked to intended outcomes for the Department's dementia programmes</p> | <ul style="list-style-type: none"> • Design and articulate common objectives and intended outcomes for dementia programmes and services (the outcomes model at section 2.2 of this report may provide a starting point for this) • All systematic advocacy and awareness services funded from a single service • Address inequality of support of PWD including those living in regional and remote Australia, and those from CALD, LGBTI and Indigenous communities. |
| <p>2. Streamline the programme structure and consider options to maximise coverage</p> | <ul style="list-style-type: none"> • Consolidate and simplify the existing programme structure (the suggestions at section 3.2 of this report can be a starting point): <ul style="list-style-type: none"> – address areas of duplication and overlap – consolidate elements of HACC Dementia Advisory Services with the NDSP and/or DBMAS to provide clear support programmes with national coverage and common performance measures – remove the education and training activities from the NDSP and combine them into the DETC programme with national coverage and common performance measures – remove the systematic advocacy and awareness raising activities from the NDSP and consolidate them with the Dementia Community Support Programme into a single dementia systematic advocacy and awareness raising programme |

| Area | Suggested actions |
|---|---|
| | <ul style="list-style-type: none"> – consolidate the Service Delivery Pathways Programme and DIMRND initiative into the NDSP – consolidate the Acute Care – environmental design project into DTSCs – expand the role of DTSCs to include national coordination of all education and training programmes, with a view to combining these into a single programme with common performance measures – improve the targeting and strategic direction of the Timely Diagnosis of Dementia in Primary Care and the Improving Acute Care Services for People with Dementia Programmes – ensure that the website already funded under the NDSP provides information on all support available to PWD and their carers, including links to MyAgedCare.gov.au, and is promoted to consumers. |
| <p>3. Monitor progress and consider new service model development</p> | <ul style="list-style-type: none"> • Develop consistent performance indicators for programmes (linked to intended outcomes) • Monitor performance against the new, consistent KPIs • Ensure a rigorous evaluation strategy is in place for the integrated Dementia Behaviour Management Advisory Services and Severe Behaviour Response Teams due to commence in 2016-17. |
| <p>4. Develop a clearing house to translate results of successful research into enhanced practice</p> | <ul style="list-style-type: none"> • Ensure service providers are aware of evidence to support the introduction of new practice and researchers are aware of matters previously investigated • Expenditure within the current funding envelope should be guided by evidence of best support to PWD and their carers. |

Source: KPMG