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The new voice of Alzheimer's Australia

Integrated Carer Support Service: Regional Delivery Partners

Response from Dementia Australia

May 2018

About Dementia Australia

Dementia Australia (formerly known as Alzheimer’s Australia) is the peak, non-profit organisation for people with dementia and their families and carers.

We represent the more than 425,000 Australians living with dementia and the estimated 1.2 million Australians involved in their care. Dementia Australia works with individuals and families, all levels of government, and other key stakeholders to ensure that people of all ages with all types of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with consumers means that we are an important advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

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UNDERSTAND ALZHEIMER’S
SUPPORT AUSTRALIA

EXECUTIVE SUMMARY

Dementia Australia welcomes the opportunity to provide input to the Department of Social Services consultation on the proposed role and potential options for distribution of Regional Delivery Partners (RDPs) within the recently announced Integrated Carer Support Service (ICSS).

As the peak body representing all people living with dementia and their families and carers, we are strongly invested in the development and implementation of the ICSS. Dementia Australia has made several submissions to the consultation processes, including responses to the draft service concept for the delivery of interventions to improve outcomes for carers, as well as the draft model for the delivery of carer support services.

The National Framework for Action on Dementia 2015-2019, agreed to by all governments across Australia, states that: “Carers should have access to support tailored to their needs in order to effectively respond to and manage the pressures associated with the physical, mental and emotional demands of their caring role.”[1] Dementia Australia is thus disappointed to note that the proposed RPD structure does not align well to the intention of the Framework.

The vast majority of people with dementia living in the community (91%) rely on an informal carer to support them.[2] There are currently up to 1.2 million Australians involved in caring for people with dementia in some way. With the ageing of the Australian population, we are likely to see a steep increase in the number of people with dementia, which has the potential to increase the demand for informal care for this group of people. Carers of people with dementia are often the spouse or child of the person and provide wide-ranging support, including helping with activities of daily living, personal care, and managing behavioural and psychological symptoms of dementia, as well as making difficult decisions about treatment options, use of services, finances, and long-term care.[3]

With the Government’s intention to continue to support community based aged care, as well as the announcement of $1.6 billion in funding as well as an additional 14,000 higher level home care packages, the reality is that more and more people with complex needs will continue to remain in community, and as such will be supported by their informal carers, who themselves will have their capacity stretched..

To enable people with dementia to live at home for as long as possible – which meets their preferences and is also cost-effective for the health and aged care systems – it is critical that their carers are well supported. Research to date suggests that specialist and structured interventions that combine information, education, skills training, and psychosocial therapies

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[1] National Framework for Action on Dementia, 2015-2019, p 14.

[2] Australian Institute of Health and Welfare. Dementia in Australia. Canberra: AIHW, 2012 Cat. no. AGE 70.

[3] Brooks D, Ross C, Beattie E, *Caring for Someone with Dementia: the economic, social and health impacts of caring and evidence-based support for carers.* (2015) Report for Alzheimer’s Australia.

led by qualified professionals and delivered over a period of time, with active participation by carers, tend to show the most positive improvements in carer outcomes. Consumers report, and the literature concurs, that provision of support and education for carers, such as that provided by Dementia Australia, significantly increases their capacity to care for the person with dementia at home for longer. This is true for both regional/rural and metropolitan carers.

Diluting the focus on meeting the needs of carer groups will have a subsequent impact on the ability of carers to continue to support people with dementia living in the community. In Dementia Australia's view, limiting access to carer support and services to those accessible through the Carer Gateway is not an appropriate approach to address the specialist, unique needs of carers of people living with dementia.

Thus Dementia Australia remains fundamentally opposed to the fragmentation of the needs of a carer from that of the person living with dementia, which will only add further barriers to access. Carers of people with dementia need specialised support services, which are specific to caring for a person with dementia. Mainstream approaches to education, counselling and other interventions will not meet the needs of many carers of people with dementia. Mainstreaming service delivery to deliver 'low cost' services remains central to the proposed RDP model, and, as such, we do not think this will meet the unique needs of families and carers of people living with dementia.

The proposed RDP model does not address the medical complexity and other complexities of managing people with dementia with its greater symptoms, forms and needs in the later and end stages of the disease. Providing adequately for the needs of people with dementia particularly at end of life or during rapid periods of decline is highly specialised, and has to include a need for sound knowledge of other aged care and other comorbidities, but this continues to be under recognised and acknowledged especially in the community setting.

While more recently attention has been paid to this in the acute and residential care environment, with specialised services being tailored for this, such as older person's mental health, dementia palliative services, and the Severe Behaviour Response Team, community care continues to rely on mainstream services to deal with such issues. Few mainstream services in the community have the specialised skills and knowledge to manage this care, and carers are therefore at high risk of being under supported and even provided with inadequate information and advice. This is a concern using a gateway for carers which will have broad and shallow rather than deep and specialised knowledge of dementia.

The proposed model will also result in a sharp decline in the overall number of providers of carer support. With over a 100 organisations currently meeting the needs of a diverse base of carers, moving to either of the options proposed by in the discussion paper (20 or 11 providers) will result in a significant loss of established carer support networks and specialist knowledge. While the paper anticipates that that each RDP would enter into consortium arrangements with a variety of providers engaged through subcontractor arrangements, the lack of focus around ensuring carer need specific service provision will essentially result in the mainstreaming.

Our response to the consultation paper covers the main issues we have with the proposed model, the capacity and capability of the proposed structure to meet the needs of carers of people living with dementia, as well as better alternatives that will meet dementia specialist needs. We propose that the RDP structure facilitate a consortium of specialist providers, who are able to meet the unique needs of carers of people with progressive neurodegenerative diseases. Dementia Australia has for many years provided a range of services to support carers of people with dementia, and brings great expertise to providing these services. It is vital that the expertise of organisations such as ours is built on and utilised in the new RDP structure. The proposed RDP structure must utilise existing networks of specialist providers, who are well established and already link carers in with the specialised supports. It is vital that the capacity developed within specialised service providers is not lost.

BACKGROUND: DEMENTIA AND ITS IMPACT

Dementia is one of the largest health and social challenges facing Australia and the world. It is the leading cause of death of women in Australia, the second leading cause of death in this country and it is predicted to become the leading cause of death within the next five years.[4] Dementia is not a natural part of ageing. It is a disease of the brain and affects a person's ability to function and ultimately to care for themselves. It is a terminal condition that affects people's abilities and memories and has a profound impact on the individual and their loved ones.[5] It is cloaked in stigma and misunderstanding,[6] isolates people with dementia and their carers from social networks,[7] and carries significant social and economic consequences.[8] People living with dementia constitute one of the most vulnerable groups in our society. A wide range of evidence comprehensively demonstrates that the care provided to those living with dementia is worse than the care delivered to any other vulnerable group.

It is estimated that there are more than 425,000 Australians living with dementia and 1.2 million people involved in their care; by 2056 there will be over one million people living with dementia. To put it another way, by 2056 more than 650 people will be diagnosed with dementia every day. These numbers include more than 25,000 people with younger onset dementia, that is, dementia that develops before the age of 65, in people aged from their thirties-to-sixties and more rarely in a person's twenties. One in 13 people living with dementia today lives with younger onset dementia[9].

The cost to our community

The cost of dementia to the Australian economy is already enormous and growing rapidly.

In 2017, dementia is estimated to have cost Australia $14.67 billion. By 2025, the total cost of dementia is predicted to increase to $18.7 billion in today's dollars, and by 2056, to over $36.8 billion.[10] Of this, $5.6 billion is attributable to the estimated loss of income of people with dementia and carers in 2017, a figure set to more than double to $12.8 billion by 2056. Cumulatively, that equates to a staggering total cost of more than $1 trillion over the next 40 years.

The cost of replacing the informal care of loved ones at home with formal (paid) care at a residential facility is also significant. Across all types of care requirements (not just dementia), Carers Australia estimated that the annual 'replacement value' of informal care exceeded $60 billion per annum.[11]

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[4] Australian Bureau of Statistics (2016). *Dementia: Australia's leading cause of death?* Accessed online.

[5] Mitchell, S. et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine,* 361: 1529-38.

[6] George, D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376: 586-87.

[7] Blay, S. and Peluso, E. (2010). Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2): 163-71.

[8] Access Economics (2003). *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. Report for Alzheimer's Australia. Available: www.fightdementia.org.au/research-publications/access-economics-reports.aspx.

[9] The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2016). *Economic Cost of Dementia in Australia 2016-2056.*

[10] The National Centre for Social and Economic Modelling NATSEM (2016). *Economic Cost of Dementia in Australia 2016-2056*.

[11] Access Economics (2010). 'The Economic Value of Informal Care in 2010', Carers Australia, October 2010, p.3.

The sustainability of carers

Estimates by the Australian Institute of Health and Welfare (AIHW) indicate that 30% of people with dementia lived in residential aged care in 2011, while 70% lived in the community.[12]

The majority of people with dementia want to live at home for as long as possible, and the ability to do so is beneficial both for the person with dementia, and in terms of managing demand on the residential aged care system. People with dementia need access to quality formal care in the community, but the "informal" care provided by family members and other carers is also critical in enabling people with dementia to live well in the community for longer.

When a person begins to experience the symptoms of dementia, their families and friends begin a new and difficult journey of their own. They have to try and cope with the emotional impact and implications of a diagnosis, come to terms with and manage the changes they see in their relative/friend, provide emotional and practical help on a daily basis, and make difficult decisions about treatment options, use of services, finances, and long term care. Some may have work, children and other family commitments to cope with as well.

The vast majority of people with dementia living in the community (91%) rely on an informal carer to support them, and more than one in five (22%) rely solely on informal care and do not access any formal care services. About 9 in 10 people with dementia living in the community were receiving care from one or more carers, and about two-thirds of these carers were women, with half of carers of people with dementia were 65 and over. Around 42 % of main carers of a person with dementia were the spouse/partner and 44 % were the son or daughter.[13]

There are a significant number of Australians providing informal unpaid care to people with dementia, and most of these are the spouse or adult child of the person with dementia.[14] The increasing focus on home care as opposed to residential care, while aligned with consumer preferences, is likely to lead to increased demand for support in the community. The highest level home care packages provide only 14 hours per week of care. This is likely to be insufficient for many people with dementia as their condition advances, and additional informal care will be needed.

However, the sustainability of informal care is an issue of concern. While the number of people with dementia will continue to increase, there are concerns that the future availability of carers is under threat due to ageing of the population (already, half of all carers for people with dementia are aged over 65); workforce constraints; changing family structures; and a

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[12] Australian Institute of Health and Welfare (2012) *Dementia in Australia.*

[13] Brooks D, Ross C, Beattie D for Alzheimer's Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers.* Alzheimer's Australia Numbered Publication 42, pp 7-8.

[14] Brooks D, Ross C, Beattie D for Alzheimer's Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers.* Alzheimer's Australia Numbered Publication 42, pp 7-8.

reluctance to provide informal care. It is estimated that by 2029 there will be a shortage of over 94,000 full time equivalent family carers.[15]

If we are to achieve an aged care system that supports people to live in the community for as long as possible, then carers are an essential part of the equation. Most people with dementia rely on informal carers to supplement formal care, as often the hours available even at the highest level of home care package are simply not sufficient to support a person with dementia to stay at home. In order to provide people with choice over where they receive care, there is a need for not only a good system of home care but also a comprehensive, evidenced-based approach to supporting informal carers of people living with dementia.

Currently there are a range of supports and services available for carers including information, education and training, psychosocial therapies, case management approaches, social support groups, respite care, and multi-component programs that combine these. Research suggests that structured multi-component and individualised psychoeducational[16] and psychosocial interventions[17] led by qualified professionals, over a period of time and with active participation by carers, tend to show the most positive improvements in carer outcomes. However, even with the supports currently available, many carers find it difficult to access the supports they need when and where they need them.

Clearly, the care needs of people with dementia in the community are met by a diverse group of people. The implementation of My Aged Care and the challenges encountered have raised concerns around many of these variations in carer experience. Consumers report issues faced in dealing with an online system and teasing out complex issues such as differentiating the client from the carer– is there one primary carer? Or are their multiple carers? What’s the definition of carer in the context of dementia?

Another aspect that needs to be considered in the development of the ICSS is the need for carers of people living with dementia to access supports and services once their loved one has moved into permanent residential care. It is unclear whether the current model of RDP’s will be able to support carers in this situation. Whilst residential care can provide relief for some family carers and some aspects of the caring role, Dementia Australia recognises that the role of being a carer and that the stress associated with caring does not stop when a person enters residential care – in fact the carer stress can actually just change focus.

It is also important to remember that it is hard to predict the trajectory of need for support for families and carers of people living with progressive neurodegenerative conditions. Most of the time, carers that reach out to Dementia Australia via the National Dementia Helpline are

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15 Brooks D, Ross C, Beattie D for Alzheimer’s Australia (October 2015). *Caring for someone with dementia: The economic, social, and health impacts of caring and evidence based supports for carers.* Alzheimer’s Australia Numbered Publication 42, pp 7-8.

16 Psychoeducational interventions refer to interventions that include elements of education, skills training, information and advice about available services and resources, and require active participation by carers.

17 Psychosocial interventions refer to interventions that focus on identifying and modifying carer’s beliefs and developing new strategies to help cope with caring demands.

facing a crisis situation, with an escalating need for support to enable them to continue to care for the person with dementia at home.

It is critical that effective supports are in place to provide carers with strategies and resources to cope with the demands of caring, as well as practical support and respite. Such supports will help to mitigate the negative impacts of caring, and increase carer well-being and the sustainability of the caring role. Indeed, the National Framework for Action on Dementia 2015-2019, agreed to by all governments across Australia, states that: “Carers should have access to support tailored to their needs in order to effectively respond to and manage the pressures associated with the physical, mental and emotional demands of their caring role.”[18]

We are therefore disappointed to note that the proposed RPD structure would instead mainstream carer service provision, making it harder for carers of people with dementia to access the dementia specialist support that they require to address their unique needs.

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[18] National Framework for Action on Dementia, 2015-2019, p 14.

RESPONSE TO ISSUES RAISED IN THE CONSULTATION PAPER

Key issues with the approach to structuring the service areas.

Most people with dementia and their families prefer that the person with dementia remain living at home for as long as possible. Carer support is a critical factor which currently enables 70% of people with dementia to live in the community. The increasing focus on home care as opposed to residential care, while aligned with consumer preferences, is likely to lead to increased demand for support in the community. The highest level home care packages provide only an average of 14 hours per week of care. This is insufficient for many people with dementia as their condition advances, and additional informal care is needed. Already there are significant threats to the sustainability of this carer support and we face a looming shortage of carers. The impacts of caring are substantial, and while some carers experience positive impacts, many carers experience negative effects on their emotional, psychological, and physical health, social activities, ability to work and finances.

Carers of people with dementia need specialised support services, which are specific to caring for a person with dementia. Mainstream approaches to education, counselling and other interventions do not meet the needs of many carers of people with dementia.

In order to ensure that carers of people with dementia have access to the support they require there is a need for services that have a specific level of understanding and training in dementia and dementia care. These cannot be provided by mainstream service provision through My Aged Care or the Carer Gateway, or indeed the proposed mainstream, RDPs. Dementia Australia's experience and consumer feedback has shown us that it is not realistic to expect contact centre staff or any other mainstream care provision staff to have this level of understanding around dementia specialist needs and support requirements.

Case Study: Carers of Person with Dementia interactions with My Aged Care

Over a period of a few weeks, three separate carers commenced the process and had been blocked at the My Aged Care contact centre screening and been advised that they do not have sufficient needs to access CHSP services and are not approved for a RAS assessment. One client was advised if they still wanted to access the support group they would need to pay for it privately, as they did not qualify for CHSP funded services.

When Dementia Australia staff investigated this with My Aged Care they were advised the client was '*not needy enough'* and so they could not have a RAS assessment. Even after Dementia Australia staff explained that the carers support group was an entry level service for carers to reduce the risk of stress and breakdown of the caring role, to maintain wellbeing, and assist them with strategies for managing a person with dementia, they were advised that unless the carer was experiencing carer stress and there was potentially an imminent breakdown of the caring role, they did not qualify for services.

In addition, the capacity building component of the information provision and the local level advocacy provided by Dementia Australia cannot be replicated by My Aged Care, the Carer Gateway or the RPDs. Given that this support is provided through the journey of the client and/or their carer it would also appear unrealistic that this role could be taken on by any mainstream service provider.

The flexibility around service provision that has been offered by Dementia Australia has also been noted in the evaluation of some of our flagship programs:

> *Clients taking advantage of the counselling service offered by Alzheimer's Australia particularly appreciate the fact that it is offered at no fee, through a number of channels (face-to-face, phone, and even Skype in some jurisdictions), and that there seem to be few, if any, waiting lists. This is seen as being in stark contrast to other counselling services or access to psychologists offered through the health system (where only a specified number of sessions is able to be bulk-billed).*
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> *NDSP Revitalised: Report by Hall and Partner, 2015*

Feedback from consumers on Dementia Australia services indicate that many carers highly value specialised education targeted to their specific issues and needs. Education was ranked third, after peer support and respite care, in a Dementia Australia consumer survey asking carers which supports had been the most useful to them. As one consumer commented:

> *Initially the [Alzheimer's Australia] "Living with Memory Loss" course was very helpful. It assisted with ideas of what to do in the home environment to support my Mum with dementia. The systems my sister and I have instigated are very detailed and required a lot of work and discussion on our part because there is not one size fits all with calendars, signs, prompting mechanisms, visitors book, and other processes but they all worked really well as long as everyone was on board with our needs.*[19]
> *Carer perspective on specialised support*

Another consumer comment highlights the importance of specialised and relevant education:

> *"[Carer education] is vital in that the Carer needs specialised education and training in order to manage dementia, especially behavioural issues in the FTD [fronto-temporal dementia] area. I found that once I was educated more and learnt new skills to manage my husband's dementia issues, I was more in control and acceptance of the situation came about more quickly. Different dementias need different training, e.g. my husband has Fronto Temporal Dementia, with Semantic and Behavioural*

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[19] Alzheimer's Australia (2016) Consumer Survey (unpublished).

> *variants. This meant comprehension of the language was deteriorating, as well as socially unacceptable behaviour; this requires a different level of training compared with someone with Alzheimer's disease, where there is more of a memory loss. It is also important for hands on Carers to share their experiences in conjunction with a professional educator."*
>
> *Carer perspective on specialised support*[20]

Again, the importance of support groups has also been highlighted in the evaluation of Dementia Australia carer support programs like the NDSP:

> *Participants in carer support groups viewed them as very helpful, in terms of the emotional support they offer and also in the way they allow participants to benefit from the experiences of others through the sharing of useful tips, strategies and local information.*
>
> *NDSP Revitalised: Report by Hall and Partner, 2015*

Carers of people with dementia have also highlighted: the positive impact of the information and education provided through the programs such as the NDSP; the support in referrals and gaining access to specialist services; counselling and advice; social and therapeutic activities for the person with dementia; and establishment of social connections for themselves and the person with dementia.

Thus the ICSS should continue to remain responsive to the need for joint services for the person with dementia and their carer, and preferably for the whole family. A separation across service delivery often does not work well for carers of people with dementia, which is why Dementia Australia has developed services that include both client groups, that is, people with dementia and their carers.

It is important that the ICSS continue to directly link carers to relevant, targeted education programs, such as those offered by Dementia Australia, to ensure their specific educational needs are met.

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[20] Alzheimer's Australia NSW consumer testimonials (unpublished).

Capacity and capability of organisations to establish and manage a regional presence throughout a large service area, including the ability to lead a consortia-based model, and undertake service area planning.

As mentioned above, Dementia Australia is not confident in the ability of mainstream, providers to meet the needs of our cohort of consumers. This has been evidenced by the roll out of the National Disability Insurance Scheme (NDIS), and the implementation of the Local Area Co-ordinators, that have taken a similar approach to structure as the proposed RPDs.

We have already seen the unfortunate impact of trying to address the needs of our cohort of clients through a broad mainstream, fee for service approach, as has ensued since the roll out of the NDIS.

Case Study, Impact of lack of Dementia specialist knowledge:

The rate of progression of dementia in younger onset dementia can be very rapid, and the current waiting periods through NDIS are a huge issue for key workers and clients of the younger onset of dementia key worker program (YODKWP). In one unfortunate situation, a YODKWP client's condition deteriorated rapidly while he was waiting for appropriate support through NDIS. The client's application was in place as he deteriorated, however, he was hospitalised and needed permanent placement in that time and there was confusion around whether NDIS would support this as they don't have capacity to find permanent placement or whether it should be the aged care system. The feedback from the wife of this client is that NDIS had no understanding of YOD. The client died while waiting for placement.

We have seen many challenges faced by people with Younger Onset Dementia and their carers as they interact with and transition to the NDIS. NDIS rules state that a client's plan must use 10 MBS funded GP psychological counselling sessions before allowing access to any specialised counselling support. For people with dementia, we know that generalist psychologists, who have limited to no dementia knowledge, can only provide a small level of support. Even if clients do work through the 10 general sessions, and get access to specialised dementia counselling, they lose valuable time and energy in that process.

As we have now detailed through several submission to the Department, people with dementia have unique needs and it is essential that they have access to specialised dementia services which cannot be delivered by the mainstream disability, aged care, mental health sector, by the Local Area Coordinators proposed under the NDIS, or the RDPs proposed under the ICSS.

Dementia Australia has been working with clients in NDIS trial sites since the inception of the program. Our experience is that when the NDIS operates as it was originally intended, and participants have the opportunity to exercise 'choice and control' by actively participating in the development of their first NDIS plan, the plan outcomes generally have been positive. However, when the progressive and complex needs of people with neurodegenerative diseases like dementia have been overlooked or insufficiently addressed (e.g. because of a lack of understanding of the disease that leads to an attempt to conduct planning sessions over the phone despite communication or cognition challenges, or the creation of plans that do not address key support needs), the outcomes have been overwhelmingly poor.

Experience to date in the trial sites suggests that people with dementia have difficulty getting through the assessment process and that those in the early stages of the disease are not considered as having a sufficient functional impairment to access services. There are also questions as to how NDIS supports will relate to aged care services and assist people who are already stranded between disability, aged care and community services.

Thus we remain concerned that applying a similar generic approach to the meed the needs of families and carers of people living with dementia, will result in similarly poor outcomes. Our experience with the NDIS has shown the importance of specialist dementia knowledge and we would recommend that the learnings from the rollout of NDIS be considered for RDP, in particular that it is impossible to expect mainstream RDPs to understand the unique needs and individual situations of all carers and disease specific factors, that will play a significant role in supporting carers. This has also been recognised by the Government, with the 2018-19 Budget providing $92.6 million over four years for continuity of support arrangements. This means clients who were earlier deemed ineligible for the NDIS will now be supported to achieve similar outcomes, even if the arrangements for doing that change over time. This includes ongoing funding for programs like the Younger Onset Key Worker Program for people living with dementia.

Dementia Australia thus recommends that the RDP model be amended so that it can leverage the specialist knowledge and existing linkages and networks of specialist consortiums, such as the Neurological Alliance of Australia. The Alliance represents over 850,000 Australians living with progressive neurological or neuromuscular conditions that have no known cause and no cure. This group includes adults and children, carers, families, friends and workmates whose life has been affected by a progressive neurological condition.

How to ensure the breadth and reach of services provided under the proposed service area models, including the incorporation of local service providers.

Dementia Australia proposes that the current RDPs structure be amended to also include a focus on a specialist delivery model. This is vital to address the needs of carers of people living with progressive neurodegenerative diseases, who need disease specific support and services.

Dementia Australia is the leading voice for people living with dementia, their families and carers in Australia. Our trusted position ensures that we understand the needs of people living with dementia and their carers, particularly the specific needs of people from diverse and vulnerable groups. Dementia Australia's significant experience in supporting families of people living with dementia across Australia spans more than thirty years and means our organisational insight is augmented by strong networks that allow us to capture and elevate the consumer voice.

Dementia Australia provides the ‘first line’ response for people living with dementia, carers and families in the community.[21] Our National Dementia Helpline supports people on a daily basis to deal with all stages of dementia and has received over 37,000 calls last year alone, averaging more than 3,000 call per month. Dementia Australia provides evidence-based information and resources, early intervention programs, carer education and support programs with over 8,000 combined sessions delivered over the last financial year.

Dementia Australia’s s services are recognised as effective and highly valuable in supporting carers, and our organisation brings immense experience and expertise to the provision of these evidenced-based services. It is critical that any proposed RDP model within the Integrated Carer Support Service takes a networked approach, linking carers to the specialised services offered by Dementia Australia and other providers, to ensure that the needs of carers are met, and the capacity developed within specialised service providers is not lost.

As such, Dementia Australia is well placed to lead a neurological alliance consortium that focusses on providing disease specialist support to families and carers of people living with a progressive neurological condition. Ten national peak not-for-profit health organisations currently make up the Neurological Alliance Australia (NAA)[22] which is an alliance representing adults and children living with progressive neurological and neuromuscular diseases in Australia. Organisational members include:

- Dementia Australia
- Parkinson’s Australia
- Brain Injury Australia
- Huntington’s Disease Australia
- Muscular Dystrophy Australia
- Muscular Dystrophy Foundation Australia
- MND Australia
- MS Australia
- Spinal Muscular Atrophy Australia
- MJD Foundation

The Alliance draws on a diversity of experience, and each organisation serves as a vital integration point for communities living with these conditions. The Alliances specialist knowledge and care is evidenced based and enables individuals, families and carers to be more connected, resourced and supported. As a consortium, we would collectively be able to bring to the ICSS the specialist skills and support that our vast carer networks will undoubtedly need.

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[21] Original DBMAS model, developed against Brodaty’s triangle, was that DA does lower level BPSD, DBMAS does middle tier and the APMHTs and (now) SBRT does higher order BPSD

[22] The Neurological Alliance Australia is an alliance of not-for-profit peak national organisations representing adults and children living with progressive neurological and neuromuscular diseases in Australia. The Alliance was established in 2010 to promote improved quality of life, coordinated services and greater research investment. The Alliance represents over 850,000 Australians living with progressive neurological or neuromuscular conditions that have no known cause and no cure. This group includes adults and children, carers, families, friends and workmates whose life has been affected by a progressive neurological condition.

CONCLUSION

The proposed Regional Delivery Partner model poses a real risk for carers and families of people living with dementia, as redirecting funding and channelling it to multidisciplinary service providers who can cover ageing, disability and mental health, will result in a breakdown of more specialist provision that our cohort needs.

If we are to support people to live in the community for as long as possible, then carers are an essential part of the equation. Most people with dementia rely on informal carers to supplement formal care; often the hours available even at the highest level of home care package are simply not sufficient to support a person with dementia to stay at home. In order to provide people with choice over where they receive care, there is a need for ensuring specialist service delivery that uses and evidenced-based approach to supporting informal carers of people living with dementia.