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The new voice of Alzheimer's Australia

Specialist Dementia Care Units

A response from Dementia Australia

January 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 consumers, all levels of government, and other key stakeholders to ensure that people with 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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EXECUTIVE SUMMARY

Dementia Australia welcomes the opportunity to provide input to Department of Health’s consultation on Specialist Dementia Care Units (SDCUS).

More than 50% of people in Commonwealth-funded residential aged care settings have dementia and better management of all elements of behavioural and psychological symptoms of dementia (BPSD) is urgently needed across the aged care sector. This is evidenced by the recent Ministerial and Senate Inquiries on the subject of quality of residential aged care, including serious concerns about access by people with BPSD to quality care, both within mainstream services and in specialised services.

First and foremost, Dementia Australia urges the Government to consider carefully the myriad issues that may impact on the success – and quality – of the SDCUs. People impacted by dementia have long raised concerns about the consistent accessibility of quality dementia care, including appropriate supports for people exhibiting BPSD.

And while most people with whom we consulted highlighted the need for better management of BPSD, they remained very concerned about the ability of mainstream aged care services to appropriately manage the specialist and unique needs of people with dementia more broadly and BPSD in particular.

While we offer specific responses to the discussion paper, Dementia Australia would like to emphasise the broader context within which we provide this feedback:

- That the SDCUs cannot be developed in isolation from broader aged care reforms;
- That the service model for SDCUs needs to be underpinned by clear pathways into and out of the units, and including linkages into and out of acute care and psychogeriatric/neuro-cognitive services;
- That staff training and education about dementia more broadly and BPSD specifically, needs to be a focus for the aged care sector as a whole and not isolated to SDCUs;
- That a piloted approach is taken to ensure that the service model can be appropriately tested, evaluated and improved before a broader rollout.

Dementia Australia looks forward to working with Government further on the design of SDCUs and collaborating with a broad range of stakeholders to ensure that people living with dementia, including those with very severe BPSD, are able to access quality care services.

BACKGROUND

There are more than 425,000 Australians living with dementia. By 2025, the number of people with dementia is expected to increase to more than 530,000. Without a medical breakthrough, the number of people with dementia is expected to be 1.1 million by 2056.1 Dementia is the second leading cause of death of Australians, contributing to 5.4% of all deaths in males and 10.6% of all deaths in females each year.[2]

The need for specialist dementia care units (SDCUs), as noted in the consultation paper, stems from an "identified gap in the ability of the aged care and the broader health system to provide appropriate care for the small minority of people (estimated as up to 1 per cent of people with dementia) with very severe behavioural and psychological symptoms of dementia (BPSD)."

However, it is important to consider SDCUs within a broader context. Arguably, the ability of the health and ageing sectors to appropriately support people with dementia expressing any level of BPSD, as described by Brodaty, Draper and Low, is variable. This is despite the fact that most people with dementia will experience BPSD at some stage during the course of their illness.[3] BPSD can include depression, anxiety, apathy, agitation, hallucinations, verbal and physical aggression, screaming, sexual disinhibition and other disinhibited behaviours.[4] These symptoms require sophisticated responses from services and staff across all aged care settings, including home care, residential care and psychogeriatric or neuro-behavioural units.

According to Australian experts,[5] at any one time 40 percent of individuals with dementia in the community may have no BPSD, 30 percent are estimated to have mild BPSD and 20 percent moderate BPSD. The care and support required for individuals with milder symptoms of BPSD differ from that required by individuals with more severe symptoms. 10 percent of individuals with dementia have severe to extreme BPSD, which equates to approximately 42,000 individuals in Australia.[6]

The causes of BPSD are not always clear but changes in behaviour may be triggered by biological, psychological, social or environmental factors. As noted, in the consultation paper, there is a view among some stakeholders that BPSD is not necessarily due to the pathology of dementia, but largely an expression of emotion or unmet need that the person with dementia cannot otherwise express (such as pain, frustration, loneliness, confusion or fear).[7] This is a viewpoint often expressed by families and carers of people living with dementia with whom Dementia Australia liaises, and there is usually the added caveat that health and aged care services are not equipped to interpret behaviours and engage the most appropriate response.

For example, a person with dementia living in residential aged care, who previously seemed to enjoy mealtimes may suddenly become distressed and scream during meals. This new response may be due to changes in the brain caused by the dementia or could be due to an overstimulating

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[1] The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2017). *Economic Cost of Dementia in Australia 2016-2056.*

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

[3] Best Practice Advocacy Centre, New Zealand. (2008). Antipsychotics in Dementia: Best Practice Guide. http://www.bpac.org.nz/a4d/resources/docs/bpac_A4D_best_practice_guide.pdf

[4] Brodaty, H, Draper, BM, Low, L. (2003). Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. *Medical Journal of Australia*, 178, 231-234.

[5] Brodaty, H, Draper, BM, Low, L. (2003). Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. *Medical Journal of Australia*, 178, 231-234.

[6] Brodaty, H, Draper, BM, Low, L. (2003). Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. *Medical Journal of Australia*, 178, 231-234.

[7] Algase, D., et al. (1996). Need-driven dementia-compromised behaviour: AN alternative view of disruptive behaviour. *American Journal of Alzheimer's Disease & Other Dementias*, *11*(6), 10-19.

environment or undiagnosed pain that makes sitting on the chair uncomfortable. Screaming may be the only way the individual is able to communicate discomfort. Understanding what has caused the change in behaviour can help prevent or modify the behaviour, but a common service response may be to shift the location of meals to the resident's room or explore pharmacological interventions.

Consumers and aged care professionals report that right now there is significant difficulty in accessing appropriate care and support for people with any expression of BPSD, let alone the most severe tiers of behaviour. For individuals living in the community, for example, the only avenue for families and carers unable to manage very severe BPSD may be to call emergency or psychiatric services. Individuals with BPSD are sometimes turned away from respite services because their care needs are too high, while in residential care, some individuals are physically or chemically restrained without the consent of the person or their family carer. A NSW study conducted in three residential aged care facilities found that, for 87% of residents who received antipsychotics, appropriate consent procedures were not followed and care was in violation of guardianship regulations.[8] Individuals with the most severe behaviours may also spend months in acute care wards because no other services are willing or able to care for them.

The challenges faced by consumers are perhaps best described in their own words. Below is a selection of quotes from consultations undertaken by Dementia Australia.

> *"People with BPSD who are entering care services are not provided with appropriate care. Challenging behaviours associated with progressive dementia are especially seen as too difficult to cope with in the aged care setting or even in dementia-specific settings."*

> *"My husband was tied to a chair in the nursing home most of the day. I complained and I was told he wanders into other people's rooms. He got aggressive when four people changed his pad so he was subdued with a tranquiliser. He was treated like a dog."*

> *"The care manager of the facility we visited said we will take him on a trial run but if he is aggressive we can't keep him. The care manager made it clear she didn't want him because he was much fitter and younger than other residents. She called after 2 days and said he can't stay. I was given no advice on where to go."*

In determining the role and need for SDCUs, therefore, it is vital to consider the management of BPSD more broadly across the health and ageing sectors. The attention on SDCUs should not be to the detriment of a broader focus on ensuring that people living with dementia, their families and carers have access to quality dementia care across the health and ageing sectors. Understanding and addressing existing gaps in appropriate service delivery are critical in building a sector in which dementia is expected to be core business.

If the ultimate goal of the SDCU program is to improve the systemic response of the aged care sector to the care and management of people with very severe BPSD – and in turn improve the quality of life for these individuals – this cannot be achieved without building the capacity of all services to deliver quality support across the spectrum of service delivery. As such, Dementia Australia recommends a cautionary approach to SDCUs, with thorough piloting and evaluation before a more systemic roll-out, combined with an ongoing focus on the delivery of care for people with dementia in mainstream health and aged care services.

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[8] Rendina, N., Brodaty, H., Draper, B., Peisah, C., & Brugue, E. (2009). Substitute consent for nursing home residents prescribed psychotropic medication. *International Journal of Geriatric Psychiatry, 24*(3), 226-231.

QUESTIONS RAISED BY CONSULTATION PAPER

Q1) Are there are other system reforms that would impact on, or be impacted by, the establishment of Australian Government-funded SDCUs?

It is important to consider the depth and breadth of the current and ongoing aged care reforms that will undoubtedly have an impact on residential and home care settings as well as the systems that are in place to oversee their accessibility and operation. Of primary consideration are:

- Recommendations made by David Tune's Aged Care Legislated Review, including the recommendation that residential aged care places be allocated directly to consumers in line with similar changes across home care.
- Recommendations made by the Carnell and Paterson Review of National Aged Care Quality and Regulatory Processes, which includes recommendations such as additional limitations on the use of restrictive practices across residential care, as well as many other recommendations that can significantly improve on the current state of aged care quality and regulatory processes.
- Ongoing Senate Inquiries into the quality of residential aged care which will undoubtedly also make many recommendations that will influence the current aged care system.
- Ongoing efforts to overhaul the Aged Care Funding Instrument (ACFI), with a review finding that the tool was "no longer fit for purpose" and its structure was "not clinically plausible". Findings that the ACFI "no longer satisfactorily discriminates between residents based on their care needs" are indicative of the foundational imbalance between consumer need and the ability of aged care services to meet that need appropriately. The ongoing Resource Utilisation and Classification Study will also have some crucial findings that can greatly affect the current environment in which residential aged care operates.
- The move to a Single Quality Framework across aged care, which will significantly impact how residential and home care providers define the quality of their services.
- Ongoing work by the Aged Care Workforce Taskforce, which will also have implications on the training and education of staff that work across aged care.

The common thread of all of these system reforms is that more effective, tailored services and supports within current home care and residential aged care settings is required. Although the creation of SDCUs will go some way to improving the access to appropriate services for people with very severe BPSD, the new units should not be seen as a 'catch all' for dementia-related behaviour management. Their development must occur in tandem with a stronger focus on quality dementia services across home and residential care settings.

Q2) What other risks and issues need to be considered in introducing SDCUs into the existing service systems for people with very severe (tier 6) BPSD?

It will be vital to address the risk factors associated with all of the key elements summarised in the discussion paper – avoiding duplication, testing the model, building appropriate pathways in and out of the service, building flexibility, meeting the needs of specific populations and addressing concerns of institutionalisation.

As mentioned above, however, there are several contributing factors that result in poor or inappropriate management of BPSD in the current service environment. The need for ongoing workforce training and education (especially in pain and delirium management), the lack of incentive for aged care providers to focus on wellbeing and re-ablement and the capacity of providers to deliver quality dementia care must be addressed in order for the SDCUs to operate effectively. Without this holistic approach there is a risk that SDCUs will result, at best, in the creation of a temporary failsafe.

As noted in the consultation paper, there is a risk that mainstream residential aged care providers will assume that SDCUs will provide care for the majority of residents with BPSD, and consequently reduce their focus on identifying and addressing causes of dementia-related behaviours or become less willing to accept residents with BPSD. This is a significant concern for Dementia Australia and consumers.

> *If separate facilities are set up it will be all too easy for nursing homes to send away patients that they regard as being high maintenance, rather than trying to deal with their frustrations productively.*

There is also a risk that a lack of focus on BPSD in mainstream residential and home care services will effectively feed the demand for SDCU places by facilitating an escalation of behaviours that could have been addressed through earlier interventions.

> ***Case Study 1:*** *A 79-year-old man who had previously no history of BPSD or falls at home was placed in permanent residential aged care home. When he arrived he had difficulty navigating his way around the facility due to lack of access to outside areas, signage and cues. He became confused and disorientated, and also distressed because he could not locate his wife. The facility managed his intrusive wandering and distress through the regular administration of antipsychotics. Subsequently, the man had serious falls and was hospitalised. When he returned to the residential facility his lifestyle was transformed from mobile and alert to passive, sedate and immobile. His family was reluctant to request modifications or reductions in the medications as they did not want to risk being refused care at the residential facility and having to find a place in another facility.*

It is also imperative that the profiles of people with dementia in mental health, psychogeriatric or neuro-cognitive services are identified, understood and addressed; otherwise there is a risk that services for people living with dementia will continue to be fragmented, that demand and supply will not be adequately understood, and that competing service pathways will be retained.

Finally, there is also a pressing need to build the capacity of acute health services to respond more effectively to the needs of patients living with dementia. The recent changes to the quality standards for health care in relation to cognitive impairment will be a critical impetus to this work.

Q3) Are there alternatives to the establishment of SDCUs that would better address the current system issues, which should be considered by Government?

As noted earlier, there are a number of ongoing reviews and reforms across areas that have a significant impact on BPSD management. These include:

- Building the core skills of staff in residential and home care to identify and manage BPSD through the introduction of mandatory education standards;
- Developing more specific standards around the physical environment;
- Incentivising providers to deliver care that is based on wellness and wellbeing rather than high care needs; and
- Assessing the resident mix in existing psychogeriatric/neuro-cognitive units to develop more effective pathways between acute care, mental health and aged care.

> *Staff members require training to understand dementia, not just the physical care of residents. They need to understand the complexity of the disease and the wide range of symptoms that people can experience. I think that*

> *they should be given actual experiences of what it is like to live in the dementia world, through that 3D experience and through other creative exercises. They need to be introduced to the validation techniques that can be used effectively in communicating with people with dementia. They also need professional development in possible activities they could use with residents. I find it fascinating that all staff members are required to do Fire Training annually. It is now mandatory, in response to the Quaker's Hill fire, I imagine, yet Dementia training is not mandatory. It would be difficult to sue regarding a lack of duty of care with the latter!*

Alternative approaches, therefore, may include: a stronger, sustained focus on building the capacity of existing services to deliver quality dementia care; an investment in education and training around BPSD management; and a closer analysis of psychogeriatric/neuro-cognitive units and their potential role in supporting the cohort of individuals for whom SDCUs are intended.

Q4) Do you consider 1,450 to be a reasonable estimate of the national demand for SDCU-like beds for people with very severe BPSD? If not what other factors and/or methodologies should be considered?

Dementia Australia acknowledges that the number of SDCU places has not been calculated on a population based target, and that places will vary at the level of primary health network. However, the following observations should be noted:

- Dementia Australia estimates of people living with dementia are that there are almost 425,000 in 2018. One percent of that cohort is 4,250 people with very severe BPSD. There is a significant risk, therefore, that the demand for SDCUs will already outstrip availability at their establishment.
- A review of mental health and psychogeriatric settings should be undertaken to determine how many people with dementia and/or BPSD are residing in those settings to ensure that real demand is being calculated effectively.
- It is also our view that the estimates of younger people with dementia have been underestimated, as:
    - levels of BPSD can be elevated in younger people;[9]
    - there are fewer appropriate care settings for them and the NDIS is unlikely to address their needs; and
    - behaviour management is not typically part of NDIS care planning.

Q5) Are the proposed SDCU service principles appropriate? If not, how should they be amended?

The service principles proposed in the SDCU discussion paper are comprehensive and arguably they could – and should – be applied to the aged care system as a whole.

Careful alignment of the principles with their operationalisation will be vital, with particular consideration of:

- definition of the level and type of expertise underpin "appropriately skilled and trained staff";
- the impact of state and territory mental health legislation on adopting "least restrictive practices";

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[9] Data from AIHW illustrates that care needs of younger people in residential care are on average higher than older residents. The proportion of permanent residents under 65 assessed who required high-level care in the behaviour domain of the ACFI at 30 June 2013 was 88% - this compares with 81% for all people 65+ assessed (AIHW (2013). Residential aged care and aged care packages in the community, 2012–13).

- the mechanisms through which collaborations and partnerships with other heath networks are facilitated, including close examination of the pathways into and out of SDCUs.

Q6) Are the above benefits what SDCUs should be aiming to deliver? If not, why?

Arguably, the benefits listed in the discussion paper are reflective of a cohesive, effective health and ageing system more generally, and they should not be restricted to SDCUs.

In addition to those listed, a further benefit may be the establishment of a national community of practice to support SDCU staff share their learnings and develop informed evidence bases.

Q7) What are the pros and cons of the SBRT performing the SDCU assessment service role? What other body (or bodies) might appropriately carry out this role?

If the model of care for SDCUs is underpinned by sound operating processes and clear pathways, a range of providers may be equipped to undertake the assessment role.

Benefits of the assessment role being carried out by the SBRT include:

- An assessment and care continuum that is reinforced through the structures of a single provider;
- Potentially streamlined assessment service and data management;
- Ability to assess performance of provider across the full continuum of BPSD service delivery.

Possible disadvantages include:

- An ‘insider’ understanding of supply and demand that leads to assessments based on availability of places rather than need;
- The risk of closed consultations and assessment processes that do not facilitate the inclusion of outside/independent opinions;
- A concentration of staff skilled in BPSD management in one element of the service sector;
- A public perception of provider monopoly;
- The risk of existing service bottlenecks being maintained or exacerbated.

Q8) Might the requirement for evidence of a primary dementia diagnosis (as described above) impact on timely access to SDCU services for some people with BPSD?

If it is the intention that the SDCU will be able to respond to very severe BPSD needs across community, residential and acute care sectors, evidence of a primary dementia diagnosis should not be a requirement. Not everyone has a formal diagnosis of dementia and if there are significant behaviours of unmet need it can be difficult to conduct the necessary assessments to obtain a diagnosis. Given very severe BPSD usually requires an immediate response to ensure the safety and wellbeing of the individual and those around them, evidence of a formal diagnosis may constitute a barrier to those who most require support.

In particular, vulnerable population groups, such as those from diverse backgrounds, often face additional barriers to obtaining a primary diagnosis, but we know they are over represented in the dementia population group.

Q9) Are the proposed assessment arrangements appropriate? If not, why not?

Q10) What other factors should the SDCU assessment service consider in deciding whether to recommend a person for a SDCU placement?

The proposed elements of preliminary screening, needs based assessment and placement assessment are consistent with other assessment mechanisms in the health and ageing sectors.

As mentioned above, however, it is the application of the process that is the vital factor in determining whether the process is appropriate.

In relation to the preliminary screening:

- The requirement of a primary dementia diagnosis may be difficult in some cases (see Q. 8, above);
- A clear pathway of access to assessment from acute care and mental health settings must be in evidence;
- Assessment must take into consideration acute health to ensure all symptoms – clinical and behavioural – are treated appropriately;
- Pathways inclusive and exclusive of GPs should be in evidence in case the GP disagrees with an approach or opts to stay uninvolved;
- Consistent training and skills in assessment need to be embedded across the workforce.

In relation to needs based assessment:

- The ability to assess whether an individual is likely to be able to transition back into mainstream care within 6-12 months will be very difficult to assess until their responsiveness to particular strategies is determined;
- A clear framework for assessing risk will need to be clearly communicated to individuals, families and carers, and the broader community;
- Potential issues around consent must be built into the assessment pathway, including mechanisms for timely resolution and minimising the impact on the individual, families and carers;
- There should be evidence of an ongoing focus on training and support for staff within alternative care settings, should a person not be recommended for SDCU placement.

In relation to placement assessment:

- Standardised practices around 'take back' arrangements would need to be clear and transparent;
- The processes for managing transition into and out of SDCUs would need to be clear for individuals, families and providers;
- The way in which 'good fit' is defined and alternatives approaches for those deemed not to be a 'good fit' need to be clear;
- The way in which special needs will be addressed within a SDCU need to be clearly defined;
- The processes for managing a waitlist (local, centralised etc.) need to be clearly articulated and transparent.

The timeliness of these assessment stages is also vital and time-based performance indicators should be considered as part of the design and implementation of the SDCUs.

Q11) Is an 8–12 bed unit (within a larger residential aged care facility) the appropriate care setting for SDCUs? Are there circumstances in which larger or smaller units would be more appropriate?

Feedback from people living with dementia, their families and carers suggests that smaller units tend to provide more 'home like' conditions, but that above all else, the important components in providing quality dementia care is:

- the ratio of staff to residents;

- the layout of the physical environment;
- the available of diverse lifestyle supports; and
- the capability and capacity of staff to provide quality dementia care.

These elements should be reflected in SDCUs as well as broader residential care services, regardless of size/number of units. The management, appearance and nature of public perception of SDCUs, especially if they are co-located or located within existing residential aged care services, will also be critical.

Q12) Should there be a maximum limit on the duration of an individual's residence within a SDCU? If not, why not? If so, how long?

If the SDCUs are truly person-centred in their operation, defined tenure will be difficult to stipulate and enforce. A mandated maximum length of stay presumes that every person with dementia who is assessed as eligible for SDCU support will a) improve to a point where they can return to mainstream aged care; or b) be able to transition into some form of palliative care.

Consumer feedback to Dementia Australia is that this is not always able to be guaranteed.

> *No! Never! There simply can't be! The behaviours keep changing. At one stage my husband was walking anything from 40-60 hours at a stretch. He was exhausted and the geriatrician refused to prescribe sleeping tablets – she kept reassuring me that Noel would eventually settle …!*
>
> *At another stage it would take 4 staff members to change him and at other times even that failed, but that all passed. One friend's husband was in Ward 17 (Psycho-Geriatric unit) for 5 months, while the husband of another lady I know was there for 8 months. Noel was only there 3 weeks! I thought that was a lifetime and am still damaged by the experience! All behaviours, no matter how severe, do pass, it is the nature of the disease! However, it is different for everyone. Some pass through the stages more quickly than others. Hence there can be NO TIME LIMIT!*
>
> *I'm horrified that this is something that could be even considered or discussed. Does anyone ask "Should there be a limit on how long people can stay in Intensive Care Units?" or "How long they can be kept in an induced coma?" or "How long a patient suffering from cancer can be offered new treatments?"*
>
> *It is appalling that that question is in the mind of anyone - but so often people with dementia are treated as second-class citizens! This is yet another example.*

If a 12-month maximum length of stay is a key component of the financial and operational model of SDCUs, these elements will require a renewed consideration of viability and efficacy.

Q13) What is a reasonable period for transitional support from a SDCU to the new accommodation provider?

Determining a standard period for transitional support to the new service provider after an episode of SDCU care will very much depend on the individual. In all cases, as part of the transition arrangements, it is likely to be necessary to provide training to direct care staff (or informal carers where appropriate) in:

- A palliative approach to care
- Meaningful engagement

- Communication
- Pain management
- Identification and management of delirium

It is also likely to be critical that consideration of the physical and clinical environment is given at the point of transition to ensure the person with dementia is not simply referred back to exactly the same environment and other circumstances that exacerbated the symptoms of BPSD in the first place.

In the view of people impacted by dementia and many providers, the ability of the aged care sector to facilitate this level of systemic practice change is already constrained, so significant shifts in the culture of aged care, spanning regulation, operations and workforce, would need to be considered in conjunction with the development of the SDCU model.

Q14) Might existing security of tenure arrangements pose a significant issue for the 'transitional' operation of SDCUs? If so, how?

Q15) What strategies could be used to facilitate SDCU 'throughput' within existing security of tenure provisions?

Security of tenure arrangements will be a complex element of the management of SDCUs. Although current providers of home care and residential aged care will have more insight into this issue, it is clear to Dementia Australia that having transparent pathways into and out of a SDCU service, including guidance on the impact of these pathways on the mainstream service providers from whom the individual has transitioned or will transition back to, is imperative.

Q16) What mechanisms should be used to support partnerships between SDCUs and acute services?

The approach to clinical governance and partnerships outlined within the discussion paper should be underpinned by:

- Linkages to the cognitive impairment standards developed by the Australian Commission on Safety and Quality in Healthcare;
- A requirement of the SDCU assessors and providers to demonstrate linkages with hospital and acute services within specific primary health networks;
- Access to common/shared education and training across the SDCU and acute care environments; and
- Identification of the pathways between acute care and psychogeriatric/neuro-cognitive settings and ensuring that the strengths and weaknesses of these pathways are addressed through the SDCU initiative.

Q17) Should there be any additional requirements for SDCU providers caring for people from Aboriginal and Torres Strait Islander, CALD or other diverse backgrounds?

The discussion paper notes that all SDCU providers will be expected to provide person-centred and culturally appropriate care, and providers will be expected to tailor the physical design of units to the cultural background of the expected local resident population.

All SDCU providers caring for people from Aboriginal and Torres Strait Islander, CALD or other diverse backgrounds should have demonstrated experience of providing quality care for these communities or be able to demonstrate how they are able to access additional resources in order to deliver appropriate care.

Furthermore, all staff should have experience working with clients from different cultural groups and have undertaken cultural competency training or similar. Bi-lingual workers may also be required. As a consumer told Dementia Australia:

> *"Speaking to patients in their first language is vital. Any form of dementia is frightening for all involved. The person with the disease is disorientated, confused and most lose expressive language skills. However, in my experience, they retain receptive language skills but usually in their first language."*

It is well known that people with dementia often revert to their first language. Poor communication can be trigger for behaviours with people venting their frustration that they are unable to understand and/or are unable to be understood by others. The ability to address this will be critical for providers of SDCUs.

Q18) Would it be feasible to establish SDCUs in rural and remote locations? How can SDCUs (or alternative initiatives) best support people with very severe BPSD living in rural and remote areas?

There is a potential risk in placing an SDCU in some rural and remote locations since there is likely a need for numerous other specialised services which would also be in short supply in these settings. Whilst this may seem to further disadvantage these communities, the greater risk may be in failure of the model here if it is not well supported or complemented by other services and systems.

Additionally, given the large distances taken in by some of the PHNs, moving a person with very severe BPSD from their remote location to the nearest SDCU would inevitably take them out of their community and away from their family and other support networks. This move could exacerbate existing behaviours and act as a trigger for new ones. Further, it would require that carers and families spend hours travelling to spend time with their relative. This scenario could result in very difficult situations for many.

The 'hub and spoke' arrangements or a 'wrap around' approach as outlined in the consultation paper may be a more effective and efficient approach to delivering specialised support to people with very severe BPSD living in rural and remote areas, although the ability to access appropriate supports may still represent a challenge.

Q19) What specific costs would contribute to the 'top up' amount?

Q20) To what extent might these costs vary across SDCUs, for example in response to geographic location or local mix of people with BPSD?

Q21) Which 'top up' funding option do you prefer? Why?

The individuals with dementia, families and carers that Dementia Australia consulted with in preparation for this submission did not have clear views on 'top up' funding other than to express concern that SDCU capital funding streams were not being considered as part of the program design. There was concern that either, a) providers would be unwilling or uninterested in investing in this high-care service model or that b) SDCUs would ultimately end up being 're-badged' existing dementia units, with a slightly higher staffing ratio but no real attempt to address common triggers for BPSD.

Dementia Australia would also caution against modelling a 'top-up' amount for SDCUs without considering the broader context of reforms to the Aged Care Funding Instrument and the way in which it, in its current form, dis-incentivises providers to focus on wellbeing over clinical and functional need.

Elements that would need to be considered within the context of a 'top up' amount include:

- Additional aids and equipment required to support individuals with very severe BPSD;
- Additional staff, including occupational therapists, diversional therapists and other specialist services that could support someone with very severe BPSD;
- Mandatory training and education for staff;
- Clear arrangements for managing the already-complex funding arrangements between commonwealth versus state-run services.

It is likely that costs will vary according to the location of the SDCU or the mix of residents within the unit and that any funding model would need to have some flexibility to address such issues as, for instance, embedding telehealth or video-health capacities for services that lack access to specialist expertise.

Right now we also know that individuals who require psychogeriatric care are often unable to access care that addresses both their aged care and mental health needs because of structural and cost barriers between the state-funded mental health system and the Commonwealth funded aged care system.[10] While some states do provide specialised SDCU-like care through aged care facilities that are funded through the Aged Care Act and topped up with funding from the State Government to provide high levels of mental health support, the success of this model is variable.[11]

Q22) Are there other funding mechanisms that should be considered?

Q23) Is block funding, occupancy-based funding or a combination of both most appropriate for SDCUs? Why?

Q24) Are the proposed uses of 'top up' funding appropriate or should there be other costs included or excluded?

The sustainability of SDCUs and the funding that enables them should be considered within the broader context of funding for dementia across the health and ageing sectors.

While Dementia Australia is unable to comment on the viability of block funding, occupancy funding or other funding mechanisms, we are concerned that the $72 million proposed to be invested in SDCUs comes at the expense of quality dementia services across the aged care sector more broadly. Although we acknowledge that some BPSD cannot be ameliorated by mainstream interventions, a sustained investment in quality dementia care in these settings is vital if we are to be confident that SDCUs are a final option for extreme behaviours. As one family carer commented:

> *the SDCU model only addresses the problem of BPSD at the pointy end, rather than focusing on early intervention or prevention. Perhaps some of the resources intended for SDCU could be redirected to a more preventative approach.*

It should be added that, key to any funding approach should be enforcing a minimum standard of training and skill competency which would also assist the current efforts of DBMAS, SBRT and others to build capacity within the aged care workforce. Integral aspects of competency based workforce training should include a particular focus on concentrated pain assessments and management of delirium.

Q25) With no specific capital funding for SDCUs proposed – is there a minimum funding period to justify an operator investing to establish a SDCU?

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[10] Department of Health and Ageing (2008). Report to the Minister for Ageing on Residential Care and People with Psychogeriatric Disorders.

[11] Department of Health and Ageing (2008). Report to the Minister for Ageing on Residential Care and People with Psychogeriatric Disorders.

Q26) Do the proposed provider funding arrangements pose any financial sustainability risks?

Based on consultations with consumers and providers, Dementia Australia believes that capital funding for SDCUs is required if best practice in dementia building and environmental design is to be expected of operators.

That the institutional environment of residential care is a trigger for significant behaviours is perhaps understated and downplayed in the consultation paper as is the assumption that residential aged care services are best placed to embed SDCUs within them. It is likely that investment in infrastructure will be required to some degree and that providers will seek assurance that their investment will be justified by a minimum period of funding.

It is also in the interests of people living with dementia, especially those affected by BPSD, to have service continuity to ensure security of tenure and sustained, stable care and support.

Q27) Should any special resident fees and payments arrangements apply to people receiving care in a SDCU?

Any special fee arrangements should take into consideration equity of access for people with dementia. An individual’s symptoms, regardless of their severity, should not impact their ability to receive appropriate, quality dementia care.

Q28) Are the proposed provider selection criteria appropriate? Do you consider some selection criteria mandatory?

Mandatory elements should include:

- A clear and transparent competitive selection round;
- A requirement that applicants are providers or residential aged care or possibly of psychogeriatric/neuro-cognitive care;
- Demonstrated expertise in supporting people living with dementia across all stages of BPSD, not just very severe behaviours;
- Demonstrated experience in best practice dementia design; and
- Mandatory and ongoing training and education in appropriate management of BPSD and dementia more broadly.

Q29) Which factors should be prioritised in determining the regional rollout schedule and why?

Because of the complexity of the SDCU model in terms of regulation, funding, operation and sustainability – not to mention the impact on people living with dementia, their families and carers – Dementia Australia urges caution in the rollout schedule.

A staged approach with some discrete pilots, perhaps in a regional and metropolitan location, should be accompanied by robust research and evaluation to ensure the full impact of the SDCUs can be measured, evidenced, further tailored and improved upon.

Q30) What factors should be considered in evaluating the SDCU program?

The Sax Institute report[12] of an Evidence Check rapid review of the literature to inform the implementation of the decision to establish SDCUs found a lack of evaluation of similar programs in Australia and internationally. It is therefore critical that that a rigorous process and impact

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[12] Masso M., Duncan C., Grootematt P., Phillipson L., Samsa P., Fildes D., Gordon R. (2017). *Specialist dementia care units: An Evidence Check rapid review* brokered by the Sax Institute for the Commonwealth Department of Health.

evaluation is conducted on this program to determine if this is an effective and efficient way of supporting people with very severe BPSD. This should include and is not limited to:

- A clear definition of what success and failure should/could look like;
- Quality of life and care outcomes;
- Family and carer satisfaction;
- Staff metrics (including turnover, satisfaction, training etc.);
- Unit based outcomes on length of stay, adverse events, etc.; and
- The impact of training and education on staff and residents.

Furthermore, a comprehensive economic analysis of the issue that the SDCU program is attempting to address needs to be conducted prior to the implementation of the units, to provide further evidence about whether or not the initiative has achieved its objectives. Although some economic impacts on the current system are addressed in the consultation paper, there is no systematic and consistent presentation of these to have the full picture.