Submission to Department of Health's Specialist Dementia Care Units Consultation Paper

January 2018

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

It has been noted that people with younger onset dementia will be eligible for SDCU support should they be unable to access the required supports in more age appropriate settings. With this is mind, ADA Australia suggests that it may be beneficial to consider how SDCUs would interact with the NDIS.

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?

ADA Australia would like to reinforce concerns raised in previous SDCU consultations regarding the potential for mainstream residential aged care providers to reduce their focus on developing dementia-related skills following the introduction of SDCUs. ADA Australia also agrees that there is a risk that residential aged care facilities will become less willing to accept residents with BPSD if there is an alternative solution available.

In ADA Australia's experience, many residential aged care services are already picking and choosing who they accept into their service. For example, ADA Australia was recently involved in a case where a residential aged care service refused to accept a client with Korsakoff Dementia because the client **could potentially develop** aggressive behaviours as their dementia progressed.

ADA Australia has also identified a number of risks associated with the temporary nature of the SDCUs.

There are risks associated with transferring people with BPSD in and out of facilities. It is widely acknowledged that consistency of environment, schedule and carers is an essential factor in providing care to people with dementia. There is also evidence to suggest the transition process can intensify complex behaviours.

There is also the risk that people with BPSD will enter a cycle of continuously moving between mainstream residential care and SDCUs. This risk will increase where the underlying environmental and staffing deficits of the mainstream residential care services remain unaddressed. Further to this, there may be some BPSD that are associated with changes taking place in the brain rather than environmental, health or medication factors that are easily addressed. These types of behaviours may not improve with a temporary visit to a SDCU.

ADA Australia considers it essential that mainstream residential care services be supported to establish long term strategies for responding to people with BPSD on site.

ADA Australia also fears there is a very high possibility that mainstream residential care facilities will not accept residents returning from SDCUs. ADA Australia has already been involved in several cases where residential care facilities have refused to accept the return of residents with behaviours associated with complex mental health following a stay in hospital.

Further to this, if SDCU clients are expected to pay full residential care fees throughout their 6-12-month placement in a SDCU, it is unlikely that they will also be able to afford the fees required to maintain a place at their mainstream residential care facility. In these circumstances, it is highly likely that residents will lose their place at their original mainstream service, as few residential care facilities will be in the position to maintain an unfunded bed whilst they await the return of a client with complex behaviours.

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

ADA Australia suggests that an outreach model, building on the current work of the SBRT's and providing more intensive support on site may be more appropriate.

This type of outreach model could:

- Focus on enhancing the ability of mainstream residential care services to respond to complex BPSD.
- Eliminate concerns associated with transitioning people with complex BPSD between services.
- Provide a more accessible service for people residing in rural and remote locations and people from culturally and linguistically diverse and Aboriginal and Torres Strait Islander backgrounds.

ADA Australia recommends that consideration also be given to more flexible models of distributing SDCU places. A national priority system such as that currently used for Home Care Packages would allow the SDCU funding to be directed where it is most needed. It would also provide valuable insight into the extent of unmet need. This type of flexibility would be more achievable with an outreach model.

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?

ADA Australia has concerns that 8-12 beds per PHN region will not be enough to meet the demands of larger, highly populated metropolitan areas. As noted in Question 3, ADA Australia recommends consideration be given to a more flexible national priority system that directs funding where it most needed. This type of system would also assist in identifying unmet need.

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

ADA Australia is supportive of the proposed SDCU service principles.

ADA Australia recommends that the SCDU's also be subject to the Charter of Care Recipient's Rights and Responsibilities – Residential Care.

ADA Australia consider it essential that SDCU residents and their families/representatives have access to the National Aged Care Advocacy Program at all stages of their journey. Advocacy supports assist in ensuring that service principles are put into practice.

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

Yes. ADA Australia agrees that benefits listed in section 4.3 of the consultation paper are reflective of what SDCU's should be aiming achieve.

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?

Given the complex nature of SDCU clients, ADA Australia agrees that the assessment for SDCUs should sit outside of the My Aged Care system.

ADA Australia considers the SBRT's to be the most appropriate body to carry out the assessment role. SBRT's are experienced in dementia behaviours and may already be in contact with many of the SDCU eligible clients. SBRT's will hopefully be able to offer a seamless referral to higher lever supports and should already be appropriately equipped to refer people to alternative supports if they don't meet the eligibility criteria for SDCU's or if interim supports are required where waitlist for SDCU services exist.

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?

ADA Australia has been involved in a number of cases, particularly in the Gold Coast region, where resident's security of tenure has been at risk due to behavioural concerns. In many of these cases, resident's behaviours have been associated with a complex mental health diagnosis rather than dementia. In these instances, it has been very difficult to locate support services to assist in addressing the influencing factors within the residential aged care setting. Whilst some of the behaviours displayed by these residents were similar to those experienced by people with dementia, their mental health diagnosis meant they could not access services such as the Severe Behaviour Response Team.

ADA Australia notes that people can have co-morbid conditions, and different conditions can be elevated at different times. For example, mental illnesses are usually fluctuating from no impact on a person, to being the major health concern for a person, even if dementia is the primary diagnosis. The risk with the SDCU model, is that the most challenging and complex consumers may be excluded because they do not fit into a binary model of primary diagnosis of dementia (or non-primary diagnosis of dementia).

ADA Australia would also like to highlight that in rural, remote and regional areas, there are few medical experts who are able to differentiate between the possible underlying behavioural causes which may be similar in their expression, but caused by different conditions – including delirium, dementia and mental illnesses.

ADA Australia recommends that provisions be put in place to ensure that people with a mental health diagnosis are not excluded from accessing supports through 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?

As noted in Question 3, ADA Australia suggests an outreach model, building on the current work of the SBRT's and providing more intensive support on site may be more appropriate.

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

ADA Australia recommends that transitional periods be tailored to the unique needs of the individual and not restricted by set timeframes. Rushing the transition process before the individual is ready may compromise the progress achieved through the SDCU's. All transitions should be managed by specialist transition planners.

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

ADA Australia is not necessarily concerned about the application of security of tenure provisions within SDCU's. Rather, ADA Australia fears that the longer, 6-12-month nature of the SDCU placements will make it difficult for residential care facilities to maintain security tenure/security of place for residents temporarily accessing the SDCU. The risks associated is that the resident's bed may not be available when they return from SDCU or the mainstream facility will not accept their return. This may lead to the person BPSD being bounced from one facility to the next or permanently placed in a SDCU.

As mentioned in Question 2. ADA Australia has already been involved in several cases where residential care facilities have refused to accept the return of residents experiencing behaviours associated with dementia and complex mental health, following short term hospital visits. ADA Australia advocates have been very active in supporting clients in these types of cases to exercise their rights under security of tenure provisions.

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

Intergenerational trauma associated with the child removal policies of the past will prevent many Aboriginal and Torres Strait Islander Elders and their families from accessing care in an institutional setting such as a SDCU.

ADA Australia suggests that a flexible outreach model, building on the current work of the SBRT's and providing more intensive support on site and in community may be more appropriate for both people from culturally and linguistically diverse and Aboriginal and/or Torres Strait Islander backgrounds.

ADA Australia suggests that any specialist dementia service providing supports to Aboriginal and/or Torres Strait Islander people should be required to demonstrate an understanding of the history that has significantly impacted on the social and emotional wellbeing of Aboriginal and/or Torres Strait Islander people. An understanding of the intergenerational trauma associated with the stolen generation will be essential, particularly for Elders with dementia who may revert their focus to past experiences.

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?

ADA Australia suggests that a flexible outreach model, building on the current work of the SBRT's and providing more intensive support on site may be a more appropriate model for people in rural remote locations. This approach may also build on the models used by Flexible Aged Care Services or Multi-Purpose Services

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

ADA Australia notes that page 44 of the consultation paper suggests that the funding available to SDCU's will be in the range of $150 -300 (per day/per bed) above the ordinary residential aged care funding.

ADA Australia suggests that with this type of additional funding and increased support from the SBRT, mainstream residential care services may be able to better support people with BPSD on site.

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

ADA Australia has concerns about the suggestion that people temporarily residing in SDCU will be subject to current residential aged care fees and payments.

If SDCU clients are expected to pay full residential care fees throughout their 6-12-month placement in a SDCU, it is unlikely that they will also be able to afford the fees required to maintain a bed at their mainstream residential care facility. In these circumstances it is highly likely that residents will lose their place at their mainstream service, as few residential care facilities will maintain an unfunded bed whilst they await the return of a client with complex behaviours.