Caring for older people with behavioural & psychological symptoms of dementia (BPSD)

Much has been said about the Government’s cessation of the Dementia and Severe Behaviours Supplement (DSBS) in residential care.

Although its timing outside the Budget context was unprecedented, the decision was not entirely surprising given the budget for the DSBS was being exceeded ten-fold. What was surprising was the limited consultation before the decision, which quickly followed the other eyebrow raising Budget decision signalling the removal of the Payroll Tax Supplement.

Putting aside the manner of the decision, it is now time to take up the Government’s commitment to work with aged care providers and consumers in the support of people with severe BPSD, including to design a replacement program ‘within the existing funding envelope’.

We are reminded that the redesign should be in the context of dementia care being ‘core business’ in aged care, though there is some vagueness about what is meant by ‘within the existing funding envelope’.

The purpose of this Update is to present background and context to help inform an alternative strategy for caring for people with, or at risk of developing, severe BPSD resulting in behaviours prejudicial to their and others welfare.

Was the policy basis of the DSBS flawed or just the costings? Did the policy make sense when considered in the wider context of dementia care services?

Dementia as Core Business

Dementia care is core business for residential aged care providers.

Of the 167,600 people permanently residing in aged care homes on 30 June 2013, 134,884 (80%) had a diagnosis of dementia or mental illness, or a combination of both (AIHW). Of these, 91,000 (60%) were claiming the maximum High level behaviour supplement under the Aged Care Funding Instrument (ACFI).

The more frequently a resident’s symptoms of dementia are expressed through wandering, verbal or physical behaviours, or the greater the impact of cognitive skill deficits or depression, the higher the level of supplement received by providers. As such, ACFI is the major source of funding
specifically to care for residents with more challenging behaviours related to dementia and mental illness. With the payment at the High level currently set at $31.03 per day/person ($11,326 per annum), this will amount to just over $1.0 billion in 2014-15.

The ACFI behaviour supplement has an equivalent in home care - the *Dementia and Cognition Supplement* – which was introduced in October 2013. This is a 10% loading applied to each package level, with supplements ranging from $782 to $4,756 per annum, considerably less than the maximum supplement in residential care. This supplement is being claimed by some 5,000 home care recipients to date, or about 10% of the home care population.

A source of dementia care support for residential and home care services, family carers and health professionals in acute and primary care settings is the *Dementia Behaviour Management Advisory Service* (DBMAS). DBMAS operates an out-reach service in each jurisdiction providing interventions where behaviour impacts on care, including assessment, short term care management, clinical supervision and mentoring. It has a budget of about $11m per annum (indexed).

There are also a number of specialist *high dependency units* in most States operating at the interface between the aged care and mental health sectors, targeting people with more severe behaviours. These units are jointly funded by the Commonwealth and State Governments using various combination of funding sources, including ACFI funding, State mental health funding, visiting clinical specialists from State mental health agencies and support from DBMAS. There is no consistency in these units across Australia and information on their capacity (ie number of beds) and total funding is difficult to obtain.

There are also a number of *dementia-specific Commonwealth programs* directed to supporting dementia care more generally, involving expenditure of about $25m in 2014-15. These programs focus on:

- translating research into practice and upskilling GPs and nurses;
- training resources for GPs and practice nurses to support more timely diagnosis and interventions;
- support services for people with dementia, their families, carers and health professionals such as a help line, education and training, information and awareness raising;
- support for people from special needs groups to access dementia care;
- education and training services targeting family carers to increase their competence and confidence; and
- care coordination for people with early onset dementia and their carers to assist with accessing appropriate care as their dementia progresses.

**The Dementia and Severe Behaviours Supplement (DSBS)**

The DSBS was announced as part of the 2012 Living Longer Living Better (LLLB) package to help aged care services provide specialist care for residents with the most severe behaviours, which the Government correlates with Tiers 6 and 7 of the Brodaty triangle (discussed further below).

It is acknowledged by the Department of Social Services (DSS) that the ACFI does not capture severe and complex behavioural and psychological symptoms which can be associated with dementia and other conditions.1 This is not surprising as the ACFI was not developed in the expectation that aged care services would be providing care to people with extreme behaviour problems.2

The DSBS was estimated to cost $41m over four years (2012 prices) and that about 1% of residents would qualify (some 2,000 residents by 2013 when the DSBS was due to be introduced). Of the $41m budgeted for the DSBS, $35.6 m was sourced by reducing indexation for the High level behaviour supplement by 1%, meaning that new funding to meet the additional specialist care
needs of the target group was $5.4 m over four years (2012 prices).

In effect, $35.6 m was skimmed off what would normally have been paid on behalf of 91,000 High level behaviour residents so that it could be redirected to about 2,000 residents with the most severe behavioural and psychological symptoms of dementia. The redirection of funding in this way was considered appropriate because residents with the highest care requirement would be eligible for the DSBS, thereby receiving both the High level behaviour payment ($31.03 per person/day) and the DSBS ($16 per person/day). In the meantime, those with a High level assessment not eligible for the DSBS would receive marginally less funding.

Service providers were asked to consider using the additional DSBS funding to:

- engage a designated behaviour management program coordinator responsible for identifying staff training needs, ensuring access to appropriate materials and resources, and coordinating access to specialist clinicians with expertise in managing severe behaviours (including DBMAS services);
- conduct an environmental audit and to address issues identified;
- regularly review the behaviour management program (including the use of restraint and antipsychotic medications, care outcomes and issues around seclusion); and
- conduct a fortnightly review of each care plan.

**Claiming Behaviour for the DSBS**

As we know, claimants for the DSBS far exceeded the estimated 2,000, reaching 29,927 by 30 June 2014 (at a cost of $110m in 2013-14 compared with a budget of $11.7m).

What do we know about claiming behaviour?

- Just under half of services (49% or 1,370 services) claimed the DSBS for less than 5% of their residents (35% had nil claimants).
- 5.7% (155 services) claimed for more than 50%, including 0.1% who claimed for more than 90%.
- The rest of the services (46%) were evenly spread across a claim rate of between 10% and 50%.

The number of claimants per claiming service averaged 16; services with fewer than 50 residents averaged eight claimants and the rest averaged 18 claimants.

Assuming an annual DSBS payment of $5,840 per person, services with less than 50 residents would have received on average an additional $46,720 per annum, whereas those larger than 50 would have received $105,120 on average. The 48 services with less than 20 residents that averaged four claimants would have received $23,360 in a year. While every dollar counts, these revenues compare with an estimated cost for a full-time dedicated behaviour program coordinator of between $120,000 and $150,000 in salary and oncosts alone.

A provider with a large number of claimants, or the capacity to deploy a coordinator across a number of services, or access a part-time coordinator, would be best placed to maximize the effectiveness of the funding.

**The Brodaty Triangle**

The Brodaty Triangle, which was referenced by the Expert Reference Group advising on the design of the DSBS, sets out a seven-tiered model of service delivery for the care of people with dementia and behavioural and psychological symptoms of dementia (BPSD).

Brodaty estimates that 10% of people with dementia present with severe BPSD including very
severe disturbances such as depression, aggression and marked agitation (Tier 5), and that the vast majority of these people would likely be in aged care homes.

The AIHW reported that an estimated 298,000 Australians had dementia in 2011 (400,000 by 2020), which suggests that just over 30,000 people with severe BPSD may be living in aged care homes. Brodaty reports that trials have demonstrated that this category of resident can be effectively cared for within a specialist case-management model using multi-disciplinary teams comprising specialists such as psychiatrists, geriatricians, specialist doctors prescribing medications and psychologists.

Brodaty also estimates that less than 1% of people with dementia exhibit very severe behaviours (Tier 6) ie. less than 3,000 in 2011. (Note that the Commonwealth Government correlates the target group for the DSBS with Tiers 6 & 7, which it estimated to comprise about 2,000 residents).

Brodaty advises that people in this category would benefit from short term placement in more intensive specialist units under the care of multi-disciplinary specialist mental health services that would not be available in aged care homes. After a period of intensive care, people may be able to return to mainstream care services with a capacity to provide step-down care.

Brodaty also reports that cases of people exhibiting violent behaviours (extreme BPSD or Tier 7) are rare, and require intensive care in a high-security specialist unit with a large ratio of male staff to patients.

Although the Brodaty triangle is a useful categorisation of the spectrum of BPSD disorders, it is reasonable to assume that the estimates of the number of people in each category represent broad orders of magnitude, yet nonetheless the best available and useful for policy purposes. Importantly, the authors of the triangle highlight that people can move between the tiers and that education for all staff working in aged care has the potential to reduce the prevalence and severity of BPSD and the subsequent demand for more specialised and expensive services ie early intervention and prevention strategies.

The Brodaty triangle also demonstrates the overlap between Commonwealth and State responsibilities in caring for older people with severe BPSD, cutting across Commonwealth aged care programs and State mental health services. Brodaty’s paper concludes by calling for a joint Commonwealth/State approach to caring for older people with BPSD.

The Murnane Report

The Murnane report was commissioned by Government in 2008 in response to concerns that people with more severe and complex psychogeriatric disorders were posing injury risks to themselves, their carers and other residents.

The report concluded that an optimal system for older people who are ambulant and who have moderate to severe behavioural disorders resulting from dementia or cognitive impairment would include specialist high dependency units with ongoing support from psychiatrists and mental health teams. The units would use, in the main, longer term transition care models designed to step down clients to less intensive care options (primarily residential aged care). It considered that the transition care model would work most effectively if located within a physical or virtual aged care ‘campus’.

To be successful, this model of care needs to be complemented by mainstream aged care services that have:

- the capacity not only to facilitate step-down care, but also the capacity to manage behaviours so as to prevent their escalation to higher dependency units. This includes sympathetic environmental design and appropriately skilled staff to manage people with aggressive
behaviours; and

- access to timely expert medical and psychiatric diagnosis and care to ensure appropriate behavioural management strategies and pharmacological regimens are in place.

Noting that effective care delivery for people with BPSD operates at the interface between mental health and aged care, the report observes that collaboration across Commonwealth and State and Territory Governments has been under done, and that a national approach would require the attention of the Council of Australian Governments (COAG).

In the absence of this issue being adopted by COAG as one of national significance requiring coordinated action by all Australian governments, the report recommends:

- the development of principles of effective care and support including protocols for effective collaboration across the residential aged care and State mental health systems;
- development of evidence-based practice guidelines;
- fostering collaborative networks across the primary, acute, mental health and aged care sectors;
- promoting leadership such as encouraging leading residential providers to establish high dependency units within their portfolio of aged care services, including with the support of place allocations under the ACAR;
- giving higher priority to training in relation to behaviour management, including management of difficult behaviours; and
- encouraging better GP training and GP access.

**Where does this leave us?**

If the DSBS was intended to target people with Tier 6 and 7 BPSD (very severe and extreme BPSD), its relationship with the existing high dependency unit model which has developed for this target group is unclear.

With the benefit of hindsight, it is not obvious that Commonwealth’s policy formulation gave due attention to the role that high dependency units could play. Perhaps the DSBS was seen as an easier and more practical option in the circumstances than the pitfalls and potential delays of negotiating with the States/Territories to develop a national approach.

In particular, the DSBS’s design does not align with the nature and intensity of the interventions required for the effective care of people with very severe and extreme BPSD. Brodaty makes it clear that effective care of this group requires treatment in high dependency or psychogeriatric units. These units require more and better trained staff than in aged care homes, including ongoing support from multi-disciplinary specialist mental health services for older people. However, as noted earlier, the DSBS was intended to support providers in engaging a designated behaviour management program coordinator responsible for staff training, a sympathetic environmental design, appropriate materials and resources, and for coordinating access to specialist clinicians, including DBMAS.

Moreover, the DSBS policy made no provision for improving access to specialist clinicians. An appropriately resourced and readily accessible DBMAS could provide this service, yet the difficulty in accessing DBMAS on a timely basis and the lack of consistency in DBMAS services across jurisdictions is well recognised, but was not addressed. (As it happens, DBMAS funding was increased in the LLLB package - $41.3m over 5 years - but the additional funds were directed to expanding the service into acute and primary care settings.)

So where does this leave us?

In practice, it seems that the DSBS was a policy response which is more appropriately applied to people with Tier 5 BPSD – people with severe BPSD. Under the Brodaty triangle, this group can be
effectively cared for in aged care services within a case-management model in which tailored programs are implemented by a specialist multidisciplinary team, such as that which can be provided through DBMAS, with the support of a skilled behaviour management coordinator and appropriately trained staff within the aged care service.

Brodaty estimates that 10% of people with dementia (about 30,000) fall into Tier 5 and most are in residential aged care. It is perhaps not a coincidence that this figure is similar to the 29,927 DSBS claimants at 30 June 2014.

Where to from here?

The best available advice and evidence indicates that a strategy for addressing the care needs of people with BPSD should include:

- a network of high dependency units jointly funded by the Commonwealth and States operating at the interface between the aged care and mental health sectors to treat people with very severe behaviours; and
- capacity building in mainstream aged care to facilitate step-up/step-down arrangements with the high dependency units and to better manage people prone to exhibit severe behaviours, including early intervention to prevent escalation to very severe behaviours. As noted earlier, it is estimated that some 30,000 existing residents of aged care homes may fall within this category. Capacity building in the sector would entail both upskilling of staff and sympathetic design to support the implementation of behaviour management strategies and ready access to the support of out-reach specialist services either attached to the high dependency units or DBMAS.

The Government has asked that a redesigned replacement program should be funded from ‘within the existing funding envelope’. If the existing funding envelope is taken to be the DSBS allocation ($11.7m indexed), it alone will not cut it. With no cure on the horizon, a national strategy that will meet the care needs of the increasing number of older people with BPSD has to be more comprehensive, and must be developed as a matter of urgency.

On the other hand, if we take the Government’s statements at face value, it would be naïve to expect Governments at this stage of the economic and budgetary cycle to prioritise significant extra funding for dementia care (noting also the commitment to increase funding for dementia research).

In the circumstances, it is essential that whatever spending the Government commits in the short term is part of a clearly enunciated medium term strategy to improve services for people with BPSD. Any temptation for an ad hoc response should be resisted.

Against this background, the following strategy presents itself:

(i) Consistent with the rationale for making dementia a national health priority, the Commonwealth should develop and transparently prosecute the case for having the care of older people with severe BPSD prioritised as one of national significance requiring the coordinated action of State/Territory funded mental health services and Commonwealth funded aged care.

The objective would be to agree arrangements for the progressive expansion of a network of high dependency units by aged care providers willing to specialise in the care of people with very severe behaviours.

Commonwealth funding should flow from the allocation of places under the ACAR and access to ACFI; State/Territory governments would contribute mental health funds and expertise. The Commonwealth could provide the capital through the accommodation supplement or as an up-front capital grant, with people with very severe behaviours being recognised as a special needs group.
As these services would tend to be small, they should be block-funded to cater for any fluctuations in occupancy.

(ii) Increasing the capacity of aged care to deliver best practice behaviour management services for people with severe BPSD and step-down care for those with very severe BPSD.

A start to increasing this capacity could be made by directing the current DSBS funding envelope to those services that can demonstrate the capability and willingness to offer step-down services and to manage the behaviours of residents with severe behaviours, including appropriate environmental design, appropriately skilled staff and a designated behaviour management program coordinator.

The strategy would also acknowledge that funding to increase the coverage of these services would be a priority in future budgets.

A feature of the DSBS was that some of the funding was spread quite thinly across services, which suggests that the critical mass required to fund a material improvement in services for people with severe BPSD is less likely to be achieved. A redesigned program should have regard to the marginal cost of increasing capacity in the way suggested. The basis for setting the current DSBS price needs to be transparently reviewed.

(iii) Complementing (ii) above, there would need to be an expansion of DBMAS services (or equivalent) to provide ready access to specialist out-reach services, and a review to ensure a consistent and appropriate capability across the jurisdictions.

(iv) As noted earlier, there are also a number of separate Commonwealth programs intended to support dementia care more generally. Many of these align with the recommendations in the Murnane report, but have been introduced progressively over the years. It is time for a comprehensive review to identify gaps and overlaps and to assess their collective effectiveness, particularly with regard to workforce development and the dissemination of applied research into better practice.

It is improbable that such a review would be a source of savings, but it may identify opportunities to make more effective use of existing funding.

(v) Because of the need to increase the supply of staff skilled in dementia care, it is important that current workforce development and training arrangements are geared to respond. The scope of the Minister’s review of existing workforce development strategies should therefore explicitly prioritise an assessment of the capacity of the current training arrangements to deliver the workforce skilled in dementia care that will be required.

References & End Notes

1. Eligibility Guidelines: Dementia and Severe Behaviours Supplement August 2003. The comment taken from this publication should not be interpreted as DSS agreeing to an increase in funding under ACFI, an alternative being a redistribution of available funds to recognise the additional costs of caring for this group of residents. This would be consistent with the ACFI being a resource allocation tool which aims to distribute available funding so that it more closely aligns with the relative care needs of residents.

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


5. This element of the strategy is included while being mindful of the Commonwealth/State issues involved, noting that a focus of the current Reform of the Federation White Paper is the clarification of Commonwealth/State responsibilities in relation to health. The fact remains, however, that access to specialist mental health practitioners is essential for people with very severe BPSD.

Disclosure Statement: The author of Aged Care Update, Nick Mersiades, is a member of the Aged Care Financing Authority. The opinions in this Update should not be read as being an expression of the views of the Aged Care Financing Authority.