Office of the Public Advocate (Queensland)
Systems Advocacy

Submission to the Senate Community Affairs References Committee

For the inquiry into the *Care and Management of Younger and Older Australians living with Dementia and Behavioural and Psychiatric Symptoms of Dementia (BPSD)*

May 2013

Queensland Government

Interest of the Public Advocate

The Public Advocate was established by the *Guardianship and Administration Act 2000* to undertake systems advocacy on behalf of adults with impaired decision-making capacity in Queensland. The primary role of the Public Advocate is to promote and protect the rights, autonomy and participation of Queensland adults with impaired decision-making capacity (the adults) in all aspects of community life.

More specifically, the functions of the Public Advocate are:

- Promoting and protecting the rights of the adults with impaired capacity;
- Promoting the protection of the adults from neglect, exploitation or abuse;
- Encouraging the development of programs to help the adults reach their greatest practicable degree of autonomy;
- Promoting the provision of services and facilities for the adults; and
- Monitoring and reviewing the delivery of services and facilities to the adults.[1]

In 2013, there are approximately 114,000 Queensland adults with impaired decision-making capacity. This vulnerable cohort includes young adults and older Queenslanders with a disability, dementia or mental illness. The most common categories of disability experienced by Queensland adults with impaired decision-making capacity were psychiatric disability (54%), intellectual disability (26%) and dementia (14%).[2]

The majority of Queensland adults with impaired decision-making capacity are aged over 50 years. Twenty-two percent (22%) are aged 80 years or older, which is primarily attributable to the increased prevalence of age-related conditions, such as dementia, that can specifically impair a person's decision-making capacity.[3]

Queensland adults with impaired decision-making capacity are among the most disadvantaged people in the community. An unacceptably high level of disadvantage is experienced across a range of social and economic indicators. This disadvantage significantly reduces quality of life and increases the risk of abuse, neglect and exploitation.

Despite accessing multiple service systems, across multiple sectors (government, non-government and private organisations), people with impaired decision-making capacity have a high level of unmet need. The current combination of specialist interventions and mainstream services is failing to meet the support needs of people with impaired decision-making capacity.

As a result, there is a critical and immediate need for all levels of government, across all sectors, to invest in a sustainable social system that ensures access to social, economic, civic and specialist resources for people with impaired decision-making capacity, their families and support networks. This is a primary way to promote inclusion, protect rights and interests, and reduce risks of abuse, neglect and exploitation.

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[1] *Guardianship and Administration Act 2000*, Section 209.

[2] Office of the Public Advocate (Qld) 2013, *The Potential Population for Systems Advocacy*, Office of the Public Advocate, Brisbane.

[3] Office of the Public Advocate (Qld) 2013, *The Potential Population for Systems Advocacy*, Office of the Public Advocate, Brisbane.

Executive Summary

Dementia is a significant health issue in Australia with nearly one million Australians predicted to experience dementia and the behavioural and psychiatric symptoms of dementia (BPSD) by 2050. Dementia is forecast to become the leading cause of disability in Australia so this inquiry into the care and management of dementia and BPSD is of critical importance.

People experiencing dementia have needs that extend across a number of service systems including aged care, disability, health and housing. The manner in which Australia's human services system is structured and administered is fragmented. While intended to be responsive to the needs of vulnerable Australians, it too often results in inequitable access to supports, exclusion from systems, and the channelling of people with similar needs into different systems according to arbitrarily defined service boundaries.

To appropriately and effectively respond to the needs of Australians living with dementia and BPSD, systems reform must be focussed on inclusion and outcomes. It must also be the shared responsibility of multiple government agencies. This will require a coordinated and integrated approach. The government portfolio charged with primary responsibility for addressing the needs of Australians experiencing dementia and BPSD must be identified and provide leadership to ensure a coordinated and equitable approach.

Future models for the care and management of people living with dementia or BPSD must be innovative, flexible, multi-faceted and able to be tailored to individual needs in order to achieve positive individualised outcomes. They should provide people experiencing dementia and BPSD with opportunities to maximise their participation and inclusion in the community and enable them to remain living in the community for as long as possible.

Australians who experience younger onset dementia experience additional challenges to those who experience its onset later in life. They can experience difficulties in securing a diagnosis, have family and work responsibilities, have significant financial commitments and often 'fall through the cracks' of existing service systems. People with younger onset dementia are often excluded from service systems due to the inflexible nature of service models, eligibility criteria and policies.

Future models of care must promote and enhance early diagnosis of dementia and BPSD. The benefits to obtaining an early diagnosis are significant and recognised. More robust connections between the medical professionals who diagnose dementia and BPSD and those who provide early intervention and support services must be developed. There is also a need for targeted and easily accessible information to assist people to navigate service systems, identify potential supports and services, and tailor arrangements that are responsive and individualised.

A range of practical strategies, support options and funding models should be made available, with the flexibility to tailor these in a way that meets more immediate needs and allows for adaptation to address a person's changing needs over time. The natural supports of a person should be recognised and supported in a way that complements the provision of specialist services. This can assist in slowing the progression of the syndrome (where possible) and mitigate the need to move into supported accommodation or residential aged care.

There should be a strong human rights focus to any reform with consideration for the development of best practice guidelines that incorporate core principles such as early diagnosis and intervention, the promotion of autonomy and independence, the application of a multi-faceted approach, the valuable role of carers, social inclusion and participation, and a support approach based on need and outcomes.

I support initiatives that encourage people to plan for and organise their future personal, health, financial and legal affairs as soon as they are diagnosed with dementia and BPSD so that medical evidence can be obtained to support their capacity and therefore the legitimacy of any authoritative instruments they may choose to prepare.

While these instruments are developed in recognition of the likelihood that decision-making capacity will become impaired at a future point, their existence should not preclude the involvement of the person in any decisions regarding their care and support. Every endeavour must be made to provide information in appropriate formats to enable the person to participate in decision-making to the greatest extent possible and their views should always be considered in any decision-making processes, even once they are deemed to lack capacity.

I am concerned that there may be an increase in the use of anti-psychotic medication to manage some behavioural symptoms of dementia. Sadly, the use of restraints such as these may be an option of convenience rather than being the option that is in the best interests of the person. I support efforts to reduce the use of physical and chemical restraint as it is an infringement of a person's human rights.

Consideration should also be given to the extent to which support for people with dementia and BPSD may be available through the National Disability Insurance Scheme.

I reiterate my support for this inquiry and look forward to further opportunities to contribute to reform in this important field of human services in the interests of ensuring improved outcomes for people living with dementia and BPSD.

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Jodie Cook

Public Advocate (Queensland)

Position of the Public Advocate

I commend the Committee for its work in reviewing the care and management of Australians living with dementia and the behavioural and psychiatric symptoms of dementia (BPSD). With the number of Australians living with dementia and BPSD estimated to reach nearly one million people by 2050, dementia is forecast to becoming the leading cause of disability in Australia.[4] There is therefore a critical need to review and refine the models of care, and ensure they are adequately resourced to facilitate well supported living and improved outcomes for Australians impacted by dementia and BPSD.

The delivery of human services

People experiencing dementia and BPSD have needs that extend across a number of current service systems, including aged care, housing, health and disability. The broader human services system, which is intended to be responsive to the needs of these vulnerable Australians, is fragmented and lacks cohesion. People are either excluded by systems or channelled into different service systems in accordance with arbitrarily defined target groups or the service parameters of those systems.

The type, quality and quantity of supports that people receive through these different systems are varied and often inequitable. Further to this, supports are too often provided according to rigid models of service delivery that do not give sufficient consideration for the outcomes being sought by the person nor how to create an effective network of support and services to assist the person to achieve their goals.

A system that appropriately, effectively and equitably responds to people living with dementia and BPSD is the shared responsibility of multiple government agencies and requires a coordinated and integrated approach. There is a need for a more inclusive and outcomes-focussed approach to the delivery of services to ensure the efficient and effective provision of appropriate support to people experiencing dementia and BPSD.

Irrespective of whether a more holistic, needs-based approach is pursued, further clarity is urgently required regarding the federal government portfolio that will take primary responsibility for addressing the needs of people living with dementia and BPSD. Detail regarding the systems of response that will be available for younger Australians versus older Australians should also be provided. Attention should be given to ensuring that available supports are equitable and easily accessible regardless of age of onset.

The process by which support is obtained should be streamlined to ensure that people are able to access what they need in a timely manner. Further to this, there should be clear information regarding both how to access the necessary supports and the system from which this support will be provided.

Future models of care and management

There is general recognition of the importance and significant benefit of the early diagnosis of dementia and BPSD. It is therefore important that future models of care promote and enhance early and accurate diagnosis. An Australian Institute of Health and Welfare review identified the need for stronger connections between the health professionals who diagnose dementia and early intervention and support services, and made a number of associated recommendations for practice improvement.[5]

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[4] Department of Health and Ageing 2012, *Living Longer. Living Better.*, Commonwealth of Australia, Canberra.

[5] Runge, C., Gilham, J. and Peut, A. 2009, *Transitions in Care for People with Dementia*, Australian Institute of Health and Welfare, Canberra.

The best possible outcomes for people with dementia and BPSD will only be achieved through a flexible, innovative, individualised, needs-based and multi-faceted approach to the provision of support services. There needs to be a range of appropriate and accessible support and service options so that individuals, their families and carers can generate care arrangements that are tailored to the specific needs of the person. This must be recognised in the design and implementation of reforms for people experiencing dementia and BPSD.

Adaptive equipment and assistive technologies are an importance inclusion in any individualised, needs-based support model. Use of adaptive equipment and assistive technologies can assist a person experiencing dementia and BPSD to remain living in their home for longer and reduce the need for early entry into supported accommodation or hospital. Other benefits include the promotion of autonomy and independence, risk management around the home, improved quality of life, assistance with memory and recall, reduced burden for family members and carers, and the maintenance of employment (particularly for those experiencing younger onset dementia).[6]

Assistive technologies include any ‘device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed'.[7] It can assist with problems relating to vision, speaking, hearing, memory and cognition, interacting and socialising, moving within the home, accessing the community and other daily living activities.[8]

The ethical considerations relating to the use of adaptive equipment and assistive technologies include the potential for the equipment or technology to replace human contact or restrict a person’s freedom of movement (rather than enhancing it). The visual presence of equipment and technologies may remind a person about their memory or cognitive impairment and could cause them distress. It is therefore important to involve the person experiencing dementia and BPSD in the decision-making process about whether to use particular equipment and/or technologies and obtain their consent. A person should not be forced into using equipment or technology that they do not feel comfortable using or that is not appropriate for their needs.[9]

Fundamental to the development of future models of formal care is the need to ensure that they are underpinned by appropriately targeted care principles and best practice guidelines. In the United Kingdom, a set of eight core principles are applied to the support provided to people living with dementia. The principles support early diagnosis and intervention, effective communication, a multi-disciplinary approach to care, independence and the valued role of carers.[10]

People living with dementia and BPSD are often supported through formal health and social support workers either in their home or other care settings. The provision of high quality care by these workers is an essential component of an effective care model. High quality care can help maintain quality of life, retain autonomy and independence and reduce demand for more tertiary and expensive supports. A poor standard of care can have serious repercussions for people living with dementia and BPSD and their family and carers, including the denial of opportunities for good quality of life, repeated hospital admissions, early admission into supported accommodation or residential aged care and poor health and mental health outcomes for family members and carers.[11]

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[6] Alzeihmer’s Society 2013, *Assistive Technology - Devices to Help with Everyday Living*, viewed 1 May 2013, http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=109.

[7] Royal Commission on Long Term Care 1999, *With Respect to Old Age: Long Term Care- Rights and responsibilities*, The Stationery Office, London.

[8] Alzeihmer’s Society 2013, *Assistive Technology - Devices to Help with Everyday Living*, viewed 1 May 2013, http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=109.

[9] Alzeihmer’s Society 2013, *Assistive Technology - Devices to Help with Everyday Living*, viewed 1 May 2013, http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=109.

[10] Skills for Care and Skills for Health 2011, *Common Core Principles for Supporting People with Dementia: A Guide to Train the Social Care and Health Workforce*, Skills for Care and Skills for Health, Leeds and Bristol.

[11] Alzeihmer’s Society 2013, *Formal Care of People with Dementia*, viewed 1 May 2013, http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=402.

Living in the community

Future models of care should provide people living with dementia and BPSD with opportunities to maximise their participation and inclusion in the community and to remain living in the community for as long as possible. There should also be a clear focus on maintaining and strengthening family connections wherever possible.

This will require the provision of appropriate specialist and support services to both the person living with dementia and BPSD and their family and carers. I trust that this inquiry will draw on available evidence and the experience of those who are living with dementia and BPSD, as well as those who work at the direct service delivery level, to identify the most appropriate and effective ways to support individuals and their families and carers.

It is imperative that models of care focus on people experiencing dementia and BPSD as well as those caring for them, particularly those who provide informal care in a home or community setting. The development of adaptive strategies that specifically target the needs of both carers and people living with dementia and BPSD are critical to enabling people to remain living in their homes for as long as possible. Adaptive strategies must have a dual focus of addressing immediate and practical needs as well as future needs with a view to slowing the progression of the syndrome (where possible) and mitigating the need to move into supported accommodation or residential aged care.

While the provision of respite may not be seen to be as critical as other supports, it is a key strategy to enabling people to remain living in their home and community for as long as practically possible. Caring for a person living with dementia and BPSD, particularly as the syndrome progresses, is an around-the-clock role that can lead to physical fatigue, emotional exhaustion and social isolation. Respite can help carers remain in their caring role for longer, therefore reducing the need for additional and more costly supports.

Respite support provides care-givers with a break from their responsibilities and may enable an opportunity to relax, time to take care of errands and household demands, or time to socialise and connect with others.

For the person experiencing dementia and BPSD, respite support can provide an opportunity to interact with other people in similar circumstances, participate in activities that are appropriate to their needs and abilities, and adapt to having other people provide them with care and support. It can also provide them with a break from the high level of activity that is often present in households that can cause anxiety and distress for a person with dementia and BPSD.

Supporting people with impaired decision-making capacity

People with dementia and BPSD whose decision-making capacity is impaired have the same rights as people who have the capacity to make decisions. It is therefore essential that future models of care accommodate and protect people with impaired decision-making capacity. The needs of people with impaired decision-making capacity must be considered and addressed at both policy and operational levels. Access to, and navigation within, the aged care and other systems must allow for supported and/or substitute decision-making and include protections from potential abuse, neglect or exploitation.

It should be noted that Australians with impaired decision-making capacity may have a court appointed guardian to make personal and health care decisions on their behalf and/or an administrator to act on their behalf in relation to financial matters. Guardians and administrators are appointed to ensure the interests of the adult with impaired decision-making capacity are protected and their needs are met.

It should also be noted that an individual's personal circumstances can change over time which may result in the revocation of a guardianship or administration order or the appointment of an alternative guardian or administrator. Models and providers of care must recognise the existence of court-appointed guardians and administrators and be responsive to any changes in guardianship or administration orders.

People living with dementia and BPSD can experience difficulty making personal and financial decisions and may therefore require support to make decisions and/or manage their affairs. Ideally, informal support could be provided by known and trusted family members, friends or carers.

In most cases it is more desirable for a person with impaired decision-making capacity to receive support to make their own decisions, rather than have a guardian (for personal or health matters) or administrator (for financial matters) appointed as a substitute decision-maker. However the need for a substitute decision-maker may arise in circumstances where support is not available to a person, or where an enduring power of attorney, advance health care directive, and/or other authoritative instrument is not in place.

I strongly support initiatives that encourage people to plan for their future as soon as they are diagnosed with dementia and BPSD. Planning should include the organisation and preparation of their personal, health, financial and legal affairs and preparing authoritative instruments to ensure their views and directions are known to relevant parties in the future.

The use of advance health care directives has potential to be further explored and utilised for people living with dementia and BPSD, or indeed the wider Australian population, given the undeniable evidence about Australia's ageing population, and the increasing likelihood that at some point in time, a person may develop dementia and subsequently experience impaired decision-making.

A diagnosis of dementia and BPSD does not automatically imply that a person does not have capacity to make decisions or manage their affairs. It might, however, prompt a person to consider making enduring instruments while they retain capacity so that they are able to obtain medical evidence to support their capacity and thus the legitimacy of any authoritative instruments they may prepare.

Younger Onset Dementia

The Australian Institute of Health and Welfare estimates that there are 24,000 Australians living with younger onset dementia.[12] Approximately 16,000 of these people are currently under the age of 65 years.[13] Australians with younger onset dementia face additional challenges to those who experience its onset later in life. They can experience difficulties in securing a diagnosis, have family and work responsibilities, have significant financial commitments and face exclusion from existing service systems.

At a recent national summit on younger onset dementia, the National President of Alzheimer's Australia highlighted the particular challenges faced by people experiencing younger onset dementia, *'They don't typically qualify for aged care and find it difficult to fit into disability services because they have to cope with a completely different set of professional and family-related issues. They also experience difficulties in accessing respite care, getting a diagnosis and dealing with stigma and isolation within the broader community'*.[14]

At the summit, there were six areas identified for immediate action:

- Increased awareness to reduce stigma and improved opportunities for social participation;
- More timely and accurate diagnosis and improved access to specialist services;

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[12] Australian Institute of Health and Welfare 2012, *Dementia in Australia*, Cat. No. AGE 70, Australian Institute of Health and Welfare, Canberra.
[13] Department of Health and Ageing 2012, *Living Longer. Living Better*., Commonwealth of Australia, Canberra.
[14] Alzeihmer's Australia 2013, *Summit Highlights Needs of People with Younger Onset Dementia*, viewed 15 April 2013, http://www.fightdementia.org.au/services/younger-onset-dementia-a-new-horizon---national-summit.aspx.

- A central focus on the person experiencing younger onset dementia and their family within the National Disability Insurance Scheme (NDIS);
- The redesign of services to provide more flexible responses;
- Improved employment opportunities and income security; and
- Greater investment in research into the cause, cure and care of younger onset dementia.[15]

Unfortunately, people who experience difficulties in accessing support services or ‘fall through the cracks’ are victims of the inequitable and fragmented human services system that exists in Australia. People are currently channelled into different service systems primarily on the basis of their diagnosis, with many of these systems lacking the sophistication to determine and provide an appropriate mix of services to adequately respond to the needs of the person.

The type, quantity and quality of support services available to a person can differ from system to system. This is the result of inflexible and narrowly defined service models that do not prioritise the desired outcomes of the person or focus on building an effective mix of supports to help them achieve their goals.

The shortfalls of these systems often lead to services being provided in an *ad hoc* manner that does not address the causal factors underpinning the person’s circumstances. Furthermore, the current approach centres more on the ‘type’ of impairment experienced by the person than the ‘nature’ of their impairment. This approach will continue to exacerbate the exclusion and disadvantage experienced by vulnerable Australians.

In addition, people such as those who experience younger onset dementia are often excluded from service systems due to the rigid nature of service models, eligibility criteria, policies and procedures. A more inclusive and outcomes-focussed approach to the delivery of human services would generate increased opportunities for improvement and integration within and across systems, thus enabling more appropriate support to be provided to vulnerable Australians.

I commend the government for expanding the National Dementia Support Program to improve the access and coordination of services, and investing in the National Younger Onset Dementia Key Worker Program. Notwithstanding this significant investment, the delivery of human services remains fragmented and inequitable and this ‘bandaid’ investment will not change the current system. Significant change will only occur when Government recognises and makes an earnest commitment to designing integrated models and approaches for the delivery of human services, rather than designing systems and responses around narrowly and often arbitrarily defined cohorts.

I support initiatives that will lead to timely and accurate diagnoses for people experiencing younger onset dementia and improve access to specialist services. The early provision of medical treatment and other supports will lead to better outcomes for the individual, maintain their quality of life and increase their opportunities for economic and social participation.

The supports provided to people living with younger onset dementia must be flexible and recognise that practical support may be required for everyday living, while other support may be required to assist the person plan for the future. This will uphold the dignity and autonomy of the person, enable them to remain in their home for longer, and empower them to maintain control over their future care and personal affairs.

I support the priority areas of increased awareness and increased funding for research into younger onset dementia. Initiatives to build community awareness should be developed with meaningful and targeted objectives. Research into the causes, cure and care of people with younger onset dementia should be undertaken to better understand the syndrome, pursue potential cures and advance positive and meaningful outcomes for those impacted.

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[15] Alzeihmer’s Australia 2013, *National Consumer Summit March 2013, Younger Onset Dementia: A New Horizon?*, viewed 15 April 2013, http://www.fightdementia.org.au/common/files/NAT/A_New_Horizon(3).pdf.

Young Australians in residential aged care (YPIRAC)

I wholeheartedly support reforms that seek to move young people living in aged care to more suitable living and support arrangements, and that enhance the specialist services to younger people with dementia or other impairments who remain in aged care. Central to any reform in this area should be a focus on minimising the number of young people entering residential aged care.

Young Australians with high care needs have the right to access appropriate services and support, both now and in the future, as their needs change. I support enhancements to the current system that afford young people with high care needs improved access to appropriate services and support, greater social inclusion and protection from abuse, neglect and exploitation.

I am pleased that the *YPIRAC^2: The Next Steps* report recognised that a coordinated systemic approach to the issue of young people in residential aged care is required to address the deficiencies of the current system and facilitate improved outcomes for young people with high care needs. The report acknowledged that an appropriate service response to this cohort is *'beyond the capacity of any one service system'*[16] and requires a collaborative partnership between health, disability, housing and aged care.

Greater integration between these human service areas will lead to an improved understanding of young people in residential aged care across government and improved recognition of this important issue in policy development and review and program design. As mentioned previously, an outcomes-focussed approach to addressing the nature of a person's impairment is required to achieve significant change.

The Younger Onset Dementia Association Inc. reports that approximately one person in every thousand people with dementia is below the age of 65 years. The Association also advises that younger people tend to be affected by more rare forms of dementia that are associated with challenging behaviour and a faster progression of the syndrome.[17] Appropriate support to manage challenging behaviours may not be available through residential aged care facilities. Arguably, the needs of people who live with dementia and BPSD and exhibit challenging behaviour may be better met through alternative supported accommodation arrangements. Alternatively, appropriate supports may be provided within their existing place of residence e.g. the family home.

The lack of recently published public information on the YPIRAC initiative suggests that there has not been any significant recent action to advance this area of reform and further transition young people with high care needs out of residential aged care. This important issue should be prioritised by federal and state governments. It is a violation of the inherent dignity of young people with high care needs to deny them appropriate accommodation and care support.

The *YPIRAC^2: The Next Steps* report suggests that a national implementation governance group be established to enable a systemic approach to transitioning young people out of residential aged care. The report also called for a significant increase in funding to support the YPIRAC initiative to minimise the number of young people entering aged care, move young people from aged care into more suitable living and support arrangements and improve the support provided to young people who remain in aged care. The Young People in Nursing Homes Alliance reports that *'taking a proactive approach to delivering the services and supports this group requires in a timely manner, does deliver significant cost savings to the service system'*.[18]

I respectfully encourage the Committee to consider recommendations that would include funding for a range of models that focus both on preventative strategies that seek to maintain skills and functional ability and support people to remain with family and in community, as well as providing for a range of therapeutic, support and accommodation models that consider the need of both younger and older Australians living with dementia and BPSD.

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[16] The Young People in Nursing Homes National Alliance 2001, *YPIRAC^2: The Next Steps*, Commonwealth of Australia, Canberra, p10.

[17] Younger Onset Dementia Association Inc. 2013, *Younger Onset Dementia Association Inc.*, viewed 26 April 2013, http://www.youngeronset.net/.

[18] The Young People in Nursing Homes National Alliance 2001, *YPIRAC^2: The Next Steps*, Commonwealth of Australia, Canberra, p31.

Use of restraint, including chemical restraint

Alternatives to restraint

Dementia can commonly result in behavioural changes such as aggression and wandering that can pose a risk of harm to the person and others. Restraint, including physical restraint, mechanical restraint and chemical restraint should be a last resort and the least restrictive of options applied in response to behaviours that may cause harm.

The use of appropriate care and support models that are person-centred and responsive to the individual (including consideration for their age) should reduce the need for the use of restraints in the care of people with dementia and BPSD. A person with dementia exhibiting behaviours that may cause harm to themselves or others should have access to a comprehensive assessment that includes an identification of individual triggers that may lead to harmful behaviour and recommendations for positive and less restrictive strategies to prevent and/or manage their behaviour.

There is extensive literature on alternative and less restrictive ways to mange some of the behavioural symptoms of dementia. For example, strategies such as ensuring easy access to safe outdoor areas such as gardens or safe indoor areas in which to wander, increased stimulating activities during the day and access to 'activity areas' or alternatively access to quiet areas (where the individual prefers quietness rather than stimulation) have been found to be effective.[19] [20]

Potentially harmful effects of chemical restraints

Anecdotal evidence within Queensland, as well as data from a number of international jurisdictions, suggests that the use of anti-psychotic medications to address the behavioural symptoms of dementia is increasingly prevalent.[21]

As early as 2005, Canadian and United States national health authorities issued warnings regarding the risks associated with the use of anti-psychotic medications for adults experiencing dementia and BPSD.[22] [23] Since that time, a number of studies have been undertaken in Canada, the United States of America and the United Kingdom that have indicated the increased risk of death associated with the use of antipsychotic medication in elderly patients, including those with dementia and BPSD.[24]

The high risk associated with the use of antipsychotic medication for elderly patients, including those with dementia and BPSD, highlights the need to mandate the use of positive and less restrictive strategies to prevent or manage behaviours that may cause harm to the person or others, prior to resorting to chemical restraint.

There is also a need for further research and/or investigation into the prevalence of use, and the potentially adverse effects, of these medications for this cohort in Australia. As recently generated in British Columbia, consideration should be given to developing best practice guidelines that support clinical assessment and care decisions for people experiencing dementia and BPSD.[25]

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[19] Qureshi, H. 2009, *Restraint in Care Homes for Older People: a Review of Selected Literature*, Social Care Institute for Excellence, London.

[20] Joanna Briggs Institute 2002, *Physical Restraint – Pt 2: Minimisation in Acute and Residential Care Facilities*, quoted in Australian Government 2012, *Decision Making Tool: Supporting a Restraint Free Environment in Residential Aged Care*, Department of Health and Ageing, Canberra.

[21] Jeste D.V., Blazer D. et al 2007, *ACNP White Paper: update on use of antipsychotic drugs in elderly persons with dementia*, Neuropsychopharmacology, 33: 957-70, Department of Psychiatry and Neurosciences, University of California, San Diego.

[22] U.S. Food and Drug Administration 2005, *FDA issues public health advisory for antipsychotic drugs used for treatment of behavioural disorders in elderly patients*, FDA talk paper T05-13, MD: U.S. Food and Drug Administration, Rockville.

[23] Health Canada 2005*, Health Canada advises consumers about important safety information on atypical antipsychotic drugs and dementia*, Advisory 2005-63, Health Canada, Ottawa.

[24] Gill S.S., Bronskill S.E. et al 2007, *Antipsychotic drug use and mortality in older adults with dementia*, Ann Intern Med; 146: 775-86, Queen's University, Ontario.

[25] British Columbia Ministry of Health 2012, *Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care: A Person-Centred Interdisciplinary Approach*, viewed 30 April 2013, http://www.health.gov.bc.ca/library/publications/year/2012/bpsd-guideline.pdf.

Impact on human rights and the importance of consent or lawful authority

The use of restraint is a significant infringement on a person's human rights, in particular the right to liberty and security of the person, the right not to be deprived of their liberty or to be subject to cruel, inhuman or degrading treatment or punishment. It is also potentially unlawful and may give rise to criminal or civil liability. Therefore it is imperative that both the ethical and legal issues are comprehensively explored and addressed before using restraint. It is important that a person's family and carers, their guardians and attorneys are engaged in decision making and give consent where it is appropriate.

The lawful authority for the use of restraint in aged care settings may in many cases be ambiguous at best. In recognition of the potential to overuse restrictive practices and the uncertainty in relation to the lawful authority for their use in relation to people with intellectual or cognitive disability, the positive behaviour support regime in Queensland, which is given authority by the *Disability Services Act 2006* and the *Guardianship and Administration Act 2000*, was introduced in 2008.

This regime provides some level of protection for people who are subject to restraint or prescribed anti-psychotic medication to respond to challenging behaviour and who are receive services that are funded or provided through the Department of Communities, Chid Safety and Disability Services. A significant and positive aspect of this regime is its requirement for service providers to generate preventative strategies that seek to reduce or eliminate a person's need for challenging behaviour, and thus the need for restraints.

However, there is debate regarding whether the prescription of anti-psychotic medication for people living with dementia and BPSD should be considered chemical restraint within the context of these legislative provisions. This is currently the subject of ongoing discussion.

Furthermore, this legislation only extends to disability services provided or funded by the Queensland Government's Department of Communities, Child Safety and Disability Services, which limits the extent of its protections for this cohort given that many people with dementia and BPSD are supported through other systems in Queensland, e.g. aged care and/or health.

National Disability Insurance Scheme

Younger Onset Dementia

The *National Disability Insurance Scheme Act 2013* specifies several eligibility criteria, one of which is the nature of a person's impairment. If a person experiencing younger onset dementia and BPSD secured a diagnosis of a cognitive impairment, they may be able to secure funding for specialist services and other supports through the NDIS. This would also be dependent on the person satisfying all of the eligibility criteria and rules of the scheme.

In response to the current fragmented system that often excludes people diagnosed with younger onset dementia and BPSD, people may participate in 'doctor shopping' to secure a cognitive impairment diagnosis and the opportunity to access NDIS funding.

Alternatively, medical professionals could falsely report a person's diagnosis as a cognitive impairment to assist their client to access funding for support. I respectfully recommend that the Committee seek to engage with the NDIS to explore the inclusion of people experiencing younger onset dementia and BPSD in the NDIS in the interests of mitigating the risks of doctor shopping and fraudulent diagnoses, as well as equitable and appropriate support services.

People over 65 years with dementia

According to the National Disability Insurance Scheme Rules Consultation Paper, a NDIS participant over the age of 65 years has the ability to choose whether they would like to be supported by the aged care system or remain supported by the NDIS.[26] The provision of this choice to NDIS participants may have a significant financial impact on the disability and aged care systems, particularly given the significant number of people that will potentially be afforded this choice.

In accordance with this, it is important that the Department of Health and Ageing and the Department of Families, Housing, Community Services and Indigenous Affairs finalise the funding arrangements for older Australians who turn 65 after having been supported by the NDIS.

Presumably, a person receiving NDIS support would not experience any change in the supports they receive once they turn 65 years (should their support needs remain the same), however the funding of these services would shift from the NDIS to the aged care system (to maintain the financial viability of the NDIS). Should a person's needs change and become better supported through the aged care system, then the person should be connected with the aged care system.

Concluding Comments

I commend the Committee for reviewing the care and management of Australians living with dementia and BPSD. Dementia is a major national health issue and a significant issue for health, aged care and social policy more broadly.

I trust that this inquiry will lead to an improved understanding across government of the care and management of dementia and BPSD and to advancements in the support and social inclusion of people living with dementia and BPSD.

I wholeheartedly support enhancements to the current system that afford people living with dementia and BPSD improved access to appropriate services and support, greater social inclusion and the ability to live independently and meaningfully in their community for as long as practicable.

Notwithstanding this, the delivery of human services, inclusive of those provided to people experiencing dementia and BPSD, lacks cohesion and can be inequitable. Meaningful change will only occur when the approach to, and provision of, human services has an outcomes-focussed approach.

The provision of appropriate specialist and support services to people, their families and carers in the right way and at the right time should underpin the future models of care and management for people experiencing dementia and BPSD. This will maximise opportunities for social inclusion, social participation and maximise the ability of people to remain connected to, and living in, the community for as long as possible.

Given the critical issue of people obtaining an early diagnosis of dementia and BPSD, I look forward to the House Standing Committee on Health and Ageing's report on the *Inquiry into Dementia: Early Diagnosis and Intervention*. Early diagnosis is a precursor to ensuring appropriate and important early intervention and prevention strategies are pursued with a view to improving the quality of life and maintaining the independence of people with dementia and BPSD for as long as possible, maximising their opportunities for social and economic participation (particularly for those with younger onset dementia), and enabling appropriate planning for health, personal and financial matters.

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[26] Commonwealth of Australia 2013, *National Disability Insurance Scheme Rules Consultation Paper*, viewed 26 April 2013, http://www.ndis.gov.au/wp-content/uploads/2013/02/consultation_paper.pdf.

I support initiatives that seek to reduce the use of physical and chemical restraint as it is a considerable infringement on a person's basic human rights. It is a concern that there may be an increase in the use of anti-psychotic medications to manage some behavioural symptoms of dementia. This method of restraint may have adverse effects on a person and may not be the least restrictive behaviour management option. Sadly, it may sometimes be an option of convenience, as opposed to being in the best interest of the person.

I am pleased to lend my support to the Committee as it progresses this important inquiry in the interests of ensuring that future models of care meet the needs of the people they are designed to support. I would be pleased to make myself available to the Committee should there be an opportunity to expand on the points made in this submission.

JMCook.

Jodie Cook

Public Advocate (Queensland)

Office of the Public Advocate (Queensland)

Website	**www.publicadvocate.qld.gov.au**
Email	**public.advocate@justice.qld.gov.au**
Write to	**GPO Box 149, BRISBANE QLD 4001**
Telephone	**(07) 3224 7424**
Fax	**(07) 3224 7364**