National Disability Strategy

Stage 2 Consultation

October 2020

The
Public Advocate
Influencing change to empower lives

Summary

As Queensland's Public Advocate, I work on behalf of adults with impaired decision-making capacity to:

- Promote and protect their rights, including protecting them from neglect, exploitation and abuse.
- Encourage the development of programs to help them reach their greatest degree of autonomy
- Promote, monitor and review and provision of services and facilities for them.

The National Disability Strategy has the potential to make a real difference to lives of people with impaired decision-making capacity. These Australians share, like all us, needs and rights to be included in their community, to have opportunities to contribute and be connected to their community in a meaningful way.

There have been major changes to the lives of people with impaired decision-making capacity over the life of the current National Disability Strategy (2010-2020). However we still have a long way to go to realise the vision and goals of the strategy and fulfil Australia's obligations under the UN Convention on the Rights of Persons with Disabilities.

This submission focusses on what I believe to be the fundamental components that are necessary to have in place before we can reasonably expect to move forward and realise change in the six outcomes areas included in the strategy (economic security, inclusive and accessible communities, rights protection, justice and legislation, personal and community support, learning and skills and health and wellbeing).

The fundamental components include;

- **a comprehensive advocacy strategy** - that empowers people with disability and gives them a voice in all aspects of their lives;
- **a safeguarding framework** - to protect people with disability who are particularly vulnerable to violence, abuse, neglect and exploitation;
- **coordination and collaboration between key government service systems** – key government systems at all levels commit to working together to deliver customer-centered, integrated services, including when responding to national emergencies; and
- **strong governance** - that requires governments to take action, charts responsibilities, collects data and measures and reports on performance under the strategy.

I have also recommended that the new strategy include an additional focus area, being accommodation. Safe, accessible, stable and affordable accommodation is fundamental for people with disability to live safe and health lives and be productive members of the community. Evidence heard at the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability earlier this year has told us that accommodation choices for people with disability are still limited and this lack of choice leads to, in some cases, people with disability remaining in accommodation where they are at significant risk of abuse, violence or exploitation. The Commission concluded, and leading disability experts agree, that Australians with disability require real choice and control in relation to housing, supported by increases in available housing stock. If we cannot guarantee people with disability access to safe and secure housing including choice about with where and whom they live, it is difficult to envision how we can achieve success in any of the other outcome areas in the strategy.

The strategy will also need to acknowledge the diversity of Australians with disability and the numerous additional challenges they face in fulfilling their potential as equal members of the community. While people with disability are considerably marginalised in Australia, people with disability who also identify as Aboriginal or Torres Strait Islander (First Nations), being from a culturally and linguistically diverse background (CaLD) or lesbian, gay, bisexual, transgender, queer or questioning, intersex and asexual or allied (LGBTQIA) face barriers to accessing systems, services and programs that are unique and should be acknowledged and addressed at a national level.

Introduction

Thank you for the opportunity to provide feedback during the Stage 2 Consultation associated with the development of a new National Disability Strategy.

The strategy provides a fundamental mechanism to drive community inclusion in Australia and to empower people with disability to access their rights and live their best lives. The National Disability Strategy also functions as the principal document addressing Australia's obligations under the United Nations' *Convention on the Rights of Persons with Disabilities*.[1]

As the Public Advocate for Queensland, I undertake systemic advocacy to promote and protect the rights and interests of Queensland adults with impaired decision-making capacity.[2]

There are a range of conditions that may impact a person's decision-making capacity. These include intellectual disability, acquired brain injury, mental illness, neurological disorders (such as dementia) or problematic alcohol and drug use. While not all people with these conditions will experience impaired decision-making capacity, it is likely that many may, at some point in their lives. For some, impaired decision-making capacity may be episodic or temporary, requiring intensive supports at specific times in their lives, while others may require lifelong support with decision-making and communicating choices and decisions.

People with impaired decision-making capacity are a broad and diverse group. They can be all ages, cultures, and demographics. As with all people, they have the right to be included in our community, have opportunities to contribute, and be connected with our community in a meaningful way.

The National Disability Strategy provides the base from which all governments in Australia can commit to a unified approach over the next 10 years to achieving the goal of creating a truly inclusive Australian society. To achieve this the strategy needs to promote actions that recognise, embed and protect the fundamental rights of people with disability in all focus areas, and provide them with real opportunities to participate in community and work, and achieve their potential.

National Disability Strategy

While the need for a National Disability Strategy is supported, the outcomes of the current strategy (2010-2020) have been limited. Over the last decade, some Australians with disability have experienced significant positive change in their lives. However, this has largely been a product of the introduction of the National Disability Insurance Scheme (NDIS). It is acknowledged that this scheme is related to the strategy, however, little progress has occurred for people with disability in other areas of strategy implementation.

Hearings of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) have highlighted a very real lack of progress in any of the areas of policy action listed in the National Disability Strategy.

People with disability are still not receiving equitable and inclusive access to education or health services, housing choice, availability and security remains an issue, and the risk of neglect, violence, abuse and exploitation is ever present for the most vulnerable. Observations by the Royal Commission Chair, The Hon Ronald Sackville AO QC during the course of the seven public hearings held by the Royal Commission to date illustrate these issues clearly.

Closing comments – Public Hearing 2: Inclusive Education in Queensland – preliminary Inquiry:

> As I said in my opening, some of the information and submissions received by the Commission paint the stark picture that, in some schools across Australia, students with a disability are not only not receiving an equitable education but are also subject to violence, abuse, neglect, and exploitation in

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[1] 'Discussion Paper – Review of the National Disability Advocacy Framework' (Department of Social Services, June 2015), p 3.

[2] *Guardianship and Administration Act 2000* (Qld) s209.

> the most hideous forms. No doubt some of that is due to ignorance and prejudice. And so I finish with an extract, with respect, from the evidence of Ms Swancutt:
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> > We can't possibly be happy with what we are currently doing because history has reminded us time and again that the segregation and othering of diverse groups of our own human kind results in the most horrific outcomes which linger for many decades and transcend generations. We have known better for an awfully long time. We must act with urgency and do better.[3]

Closing comments – Public Hearing 4: Health Care and Services for people with cognitive disability:

> I said that the consequences of neglect and abuse by or within the health system for people with cognitive disability are as disturbing as they are profound. I also said that the extent and consequences of neglect and abuse should shock the conscience of all Australians. We have heard a great deal of evidence that amply bears out that assessment. The evidence has frequently been distressing, sometimes even heart-breaking.[4]
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> We have heard graphic evidence of the consequences, sometimes catastrophic, of lack of understanding and entrenched bias in the delivery of health services. The impetus for reforms will be very much driven by a recognition within the Australian community that a grave injustice has been inflicted on a very large number of vulnerable people.[5]

Closing comments – Public Hearing 3: the experience of living in a group home for people with disability:

> We have heard much evidence of the routine abuse and dehumanisation of people with disability in institutions and in some group homes. As we heard in the evidence from Yooralla, the interchanges that took place, the abuse and dehumanisation we have been told about cannot be given the comforting designation of "historic". The accounts we have heard reflect what has happened in Australia in the 21st century and, indeed, despite many official reports and many legislative reforms, as Kevin Stone of VALID and the panel of advocates yesterday so forcefully told us, the abuse and dehumanisation continue even today.[6]

Closing comments – Public Hearing 5: Experiences of people with disability during the ongoing COVID-19 Pandemic:

> But the pandemic, as we've heard, has exacted another terrible toll that has largely been hidden from the general Australian community, and that toll is no less real. We have heard people with disability experiencing the sudden loss of essential support services, an absence of clear and consistent information in accessible form essential to their health and wellbeing; an inability to access health care, personal protective equipment and even the basic necessities of life such as food and medication; we've heard of isolation from the community, from friends and family and from social networks; exposure to a heightened risk of domestic violence; stress and anxiety associated with exposure to the virus; inadequate measures for the protection of people with disability, and uncertainty about how to survive in the face of disruptions to care and essential services, sometimes leading to worsening mental health.[7]

Accepting the evidence of the Royal Commission, it is reasonable to acknowledge, that despite best intentions at the time of the inaugural National Disability Strategy, it has fallen a long way short in achieving positive change in any of the six original outcome areas.

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[3] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Public Hearing 2: Inclusive Education in Queensland – preliminary inquiry, Hearing Transcript 7 November 2019*, p-334, https://disability.royalcommission.gov.au/publications/transcript-7-november-2019.

[4] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Public Hearing 4: Health Care and Services for people with cognitive disability, Hearing Transcript 28 February 2020*, p-884, https://disability.royalcommission.gov.au/publications/transcript-day-9-health-care-sydney.

[5] Ibid, p-886.

[6] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Public Hearing 3: The experience of living in a group home for people with disability, Hearing Transcript 6 December 2019*, p-443, https://disability.royalcommission.gov.au/publications/transcript-6-december-2019.

[7] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Public Hearing 5: Experiences of people with disability during the ongoing COVID-19 pandemic, Hearing Transcript 21 August 2020*, p-410, https://disability.royalcommission.gov.au/publications/transcript-day-4-public-hearing-5-sydney.

The fundamentals

If the new National Disability Strategy is to achieve its objectives for people with disability over the next 10 years, we need a different approach. Serious consideration should be given to establishing some foundational elements that are necessary to have in place before we can reasonably expect to achieve real change for people with disability in the six outcome areas of the strategy.

During the more than four years that I have been the Public Advocate in Queensland, I have identified that the wide range of issues for people with disability that I have dealt with can be reduced to four key categories of systemic issues:

- the need for people with disability to have advocacy support to have their voices heard, especially when engaging with difficult-to-navigate or unresponsive systems;
- the need for a system of safeguards to protect particularly people with disability who are vulnerable to abuse, exploitation and neglect;
- the need for government systems to take a coordinated and cooperative approach to the delivery of services to people with disability that cross levels of government and service systems, to provide consistent frameworks, policies and programs that deliver holistic, 'joined up' services for people with complex needs;
- the need for appropriate governance and accountability to accompany strategies and plans which provide incentives and encouragement for action, accountability, measurement of outcomes and reporting.

On the basis of this systemic experience, I suggest that the new National Disability Strategy should include four additional foundational elements that need to be established before we can focus on achieving positive change for people with disability in the specific outcome areas. These are:

- **comprehensive advocacy strategy** - that empowers people with disability and gives them a voice in all aspects of their lives;
- **safeguarding framework** - to protect people with disability who are particularly vulnerable to violence, abuse, neglect and exploitation;
- **coordination and collaboration between key government service systems** – key government systems at all levels commit to working together to deliver customer-centered, integrated services, including when responding to national emergencies; and
- **strong governance** - that requires governments to take action, chart responsibilities, collect data and measure and report on performance under the strategy.

Advocacy

If people with disability are not heard, they have no power over their own lives. We cannot hope to progress the objects of any strategy without people with disability having access to advocacy supports. While the process for development of the new National Disability Strategy has actively sought the views of people with disability, they need a voice beyond this process. The development of the strategy is just the beginning. The new National Disability Strategy must recognise that the provision of advocacy services that are available and accessible to people with disability is fundamental to the successful implementation of the strategy and must be a foundational component of the strategy.

The Department of Social Services has defined disability advocacy as 'advocacy supporting people with disability to:

- stand up for their rights and choices;
- take part in their community;
- find employment and training;
- feel valued and respected;
- achieve their goals;
- have their say'.[8]

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[8] 'Discussion Paper – Review of the National Disability Advocacy Framework' (Department of Social Services, June 2015), p 2.

Too often, disability advocacy is viewed as exclusively for the purpose of supporting people to access disability service systems. It is acknowledged that issues relating to eligibility, labyrinthine administrative processes or errors in assessments about levels of support required, are routine challenges for people with disability engaging with the disability service system. While advocacy to assist people to access disability supports is of critical importance to people with disability, it is only one aspect of the range of systems and issues that people with disability require advocacy support to navigate. Their advocacy needs are as diverse as the range of government and private services that any member of the Australian community may want to access, from health to travel and entertainment. And as with any other member of the community their ability to negotiate those systems may be impacted by numerous compounding personal, environmental and social factors.

Due to the very nature of advocacy services, it is critical that they are independent of the services and systems that people are engaging with. Independent advocacy can operate as a check and balance to help ensure systems and services remain accountable for their actions and decisions. It is also necessary for people with disability wanting to raise or escalate issues with their service providers – support workers are in a position of conflict in seeking to advocate for a client with their service provider.

Having access to independent advocacy also potentially reduces risk for people with disability. Given the nature of personal support services, which are often delivered in private homes or small group accommodation, the concerns raised by a person with disability receiving services in those circumstances may go 'unheard', be 'trivialised', or may not be given the necessary ongoing attention to ensure that it is properly addressed. Some people will be too afraid of reprisal from their service provider to raise issues, unless they have independent advocacy support and know that the advocate will have some oversight of their situation on an ongoing basis.

The National Disability Advocacy Framework was developed in 2008 by State and Territory Disability Ministers under the auspices of the National Disability Agreement. It sought to develop a nationally consistent framework for advocacy that covers individual and system wide advocacy, common definitions and desired outcomes and data issues.[9] The long-term goal of the application of this framework throughout Australia is to ensure that:

> People with disability have access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling full community participation.[10]

Both the National Disability Advocacy Framework and the National Disability Advocacy Program, which provides funding (on a shared basis with state and territory governments) to advocacy organisations to achieve this vision, were reviewed in 2015 and 2016.

The report of that review outlined the vision of the Department of Social Services for a reformed National Disability Advocacy Program as one that:

- Provides accessible, timely, appropriate and independent advocacy support to people disability irrespective of their age, disability type, cultural background, or place of residence.
- Includes a data collection system that contributes to the evidence base and provides information on systemic issues to policy makers.
- Integrates with and complements the services provided within the NDIS, by states and territories and by mainstream organisations.
- Includes a consistent and equitable funding model.[11]

To date, however, it appears that the outcomes from both reviews are yet to be considered by the Australian Government and the current framework and program remain in operation.

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[9] Department of Social Services, *National Disability Advocacy Framework*, August 2021, p.1, https://www.dss.gov.au/sites/default/files/documents/11_2014/attachment_a.2_-_national_disability_advocacy_framework.pdf

[10] Ibid, p.3.

[11] Department of Social Services, *Review of the National Disability Advocacy Program – Consultation Report*, July 2017, p.4, https://engage.dss.gov.au/wp-content/uploads/2017/07/consultation_report_-_review_of_the_national_disability_advocacy_program.pdf.

At public hearings of the Royal Commission, we have heard that advocacy remains a critical need for people with disability, and existing services are currently not meeting demand.

The Royal Commission held hearings in December 2019 examining the experience of people with disability living in a group home. Several expert witnesses gave evidence about the lack of available advocacy services, which limited the ability of people with disability to make their own choices about matters such as where they live, with whom they live and how they can escape an unsafe situation.[12]

In its report on these hearings, the Royal Commission noted that 'the importance of independent advocacy and self-advocacy for people with disability has been a constant theme at all hearings held by the Royal Commission to date, as well as in submissions and responses to Issues Papers'.[13]

At its Public Hearing 4: Health Care and Services for people with cognitive disability, the Royal Commission Chair noted:

> this hearing has also demonstrated the crucial role that can be played by disability advocacy organisations and individual advocates at both a systemic and individual level. The evidence from the representatives of the Commonwealth and the State of New South Wales, from whom we heard yesterday, demonstrates the significance of the work of the New South Wales Council for Intellectual Disability and other advocacy organisations which seek to advance the wellbeing of people with cognitive disability.[14]

With these observations in mind, it is critical that the new National Disability Strategy incorporate an advocacy framework and program as a key foundational element. This would demonstrate the commitment of governments at all levels across Australia to the fundamental right of people with disability to be supported to have their voice heard in all aspects of their lives and engagements with services and industry. Only when this occurs can we claim to be a genuinely inclusive society.

Clearly, for this commitment to be meaningful, all levels of government across Australia must take responsibility to contribute to the adequate resourcing of the disability advocacy sector.

A national safeguarding framework for people with disability who may be vulnerable

In 2019, the NDIS Quality and Safeguards Commission engaged the Australian Institute of Health and Welfare to develop a summary report of mortality issues and trends relating to people with disability based on nationally available data.[15] The report is Australia's first national report on mortality rates for this population. As such, it provides an extremely valuable resource from which to monitor the deaths and, in particular, the potentially avoidable deaths, of Australians with disability who are accessing disability support services.

The report notes that users of disability support services, in comparison with the general population, are 4.7 times more likely to die before the age of 65 and 3.6 times more likely to die a potentially avoidable death. These statistics, in combination with tragedies such as the death earlier this year of Ms Ann-Marie Smith, an NDIS participant from Adelaide who was severely neglected by her disability service, highlight the need for a national safeguarding framework for Australians with disability who may be particularly vulnerable.

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[12] Royal Commission into Violence, Neglect, Abuse and Exploitation of People with Disability. *Report on Public Hearing 3: the experience of living in a group home for people with disability*, Melbourne Convention and Exhibition Centre 2-6 December 2019, https://disability.royalcommission.gov.au/system/files/2020-04/Transcript%20Day%205%20-%20Homes%20and%20living%2C%20Melbourne.pdf.

[13] Ibid, p.85.

[14] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Public Hearing 4: Health Care and Services for people with cognitive disability, Hearing Transcript 28 February 2020*, p-886, https://disability.royalcommission.gov.au/publications/transcript-day-9-health-care-sydney.

[15] Australian Institute of Health Welfare, *Mortality patterns among people using disability support services: 1 July 2013 to 30 June 2018, September 2020, https://www.aihw.gov.au/getmedia/de0fc029-4574-4e7b-899c-9818fa482966/aihw-dis-76-summary.pdf.aspx?inline=true.*

A definition of vulnerable in this context was suggested by the South Australian Task Force that led one of the reviews into Ms Smith's death:

> Vulnerable individuals are those with complex support needs (including communication difficulties), cognitive challenges, poverty, domestic violence or poor connection to family/friends/services.[16]

This definition includes people with disability and complex health conditions, people with disability who are reliant on others care providers for the necessities of daily life, and people with disability who do not have an established network of family/carer/supporters to oversee their care and advocate on their behalf.

While it is important to avoid being overprotective and recognise that not all people with disability are vulnerable and in need of protection, it is critically important that Australia has a national system of monitoring and oversight that will identify risks to vulnerable participants, and act on them before the person suffers harm.

This type of framework could be implemented by services systems such as the NDIS and should incorporate a range of practical initiatives to monitor the health and wellbeing of vulnerable people with disability.

Key features would include:
- Establishing a system to identify vulnerable people with disability who are highly dependent on others for care or have minimal support networks outside of their disability support workers who require safeguarding.
- Developing a system of 'red flags' in the NDIS Quality and Safeguards monitoring system to identify indicators of risk to vulnerable NDIS participants at an early stage that would trigger and intervention (this could be based on the Australian Institute of Health and Welfare research referred to above).
- Appointment of a specialist, independent NIDS supports coordinator for each vulnerable person with disability, who will maintain a relationship with the person and ensure all of the disability and health supports necessary to maintain the person's health and well-being are in place.
- A system of monitoring the person's access to health services that would include a requirement that each vulnerable NDIS participant have an annual health assessment and an annual health plan, including preventative treatments such as vaccinations and cancer screening. The annual health plan be noted in the person's NDIS plan and be implemented by the supports coordinator, including booking medical appointments etc and ensuring the person is supported to attend these appointments.
- The person's access to health services could be monitored through the Medicare system and a red flag triggered if an identified vulnerable person with disability did not attend a Medicare-funded appointment in over 12 months.
- Consideration of a national community visitor program for vulnerable people with disability that will provide for regular home visits, even where the person is living in their own home.
- Funding for an independent advocate for vulnerable people with disability. The advocate will provide advocacy support for the person for them to express their views and preferences and maximise their ability to exercise their autonomy, while operating as an accountability process by having 'eyes on the person'.

Had systems like those suggested been in place, the neglect of Ms Smith may have been detected before it became fatal.

Once trialled for NDIS participants, the safeguarding framework could be adapted for people with disability who may be vulnerable and receiving support services from other agencies or organisations.

It is important that a safeguarding framework strike the correct balance between appropriate oversight and monitoring of the quality of services delivered, while respecting the rights of

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[16] Government of South Australia Safeguarding Task Force, *Interim Report,* 15 June 2020, p 6.

individuals to independence and autonomy. This can be a difficult balance between ensuring people with disability who may be vulnerable can live safe from neglect, abuse and exploitation, while avoiding excessive intrusion into their lives driven by a desire to protect them from risk and harm.

It is also imperative that the safeguarding framework be developed using a nationally consistent approach. A national framework has numerous benefits, including being invaluable in times of crisis, like the COVID-19 pandemic. Had this type of safeguarding framework been in place prior to the pandemic, the identification of people with disability most at risk would have been possible, allowing plans to be developed to ensure that vulnerable people with disability were able to continue to access the services and supports they needed during the pandemic.

It is only when people with a disability can live a life free from fear of neglect, exploitation and abuse that they can move beyond the basics, in terms of achieving the community inclusivity and participation goals outlined in the National Disability Strategy.

Integrated service systems

It is critical that governments commit to working together to achieve the goals of the National Disability Strategy.

It is noted in the discussion paper that the strategy is committed to the articulation of the roles and responsibilities of various levels of government in disability policy and service delivery. However, achieving outcomes for people with disability often relies on government services working together to provide integrated responses and services.

A relevant example of this problem of system integration is the Australian health system. Our national health system features the Australian Government-funded primary health networks, which include our general practitioners, state-funded hospital and health services, allied health services funded variously by different levels of government, and community-based health services, including child health and mental health, also funded by various levels of government.

Navigating such a complex system is difficult and is more challenging for people with disability.

A report prepared by my predecessor in 2016, which investigated the deaths of 73 people with disability in care, found that many preventable deaths of people with disability were the result of the failure of systems and services communicating and working together. The report noted that ‘systemic issues such as a lack of appropriate support (including support to access health care and appropriate responses by health care agencies) and ineffective coordination between disability and health services can have a serious effect on people with disability. For some, this includes risk of premature death’.[17]

Recommendations made in this report included improving the quality of health care and disability supports provided to Queenslanders with disability living in care. This includes improved primary care and intervention practices with regular general heath and annual comprehensive health checks, the identification of the signs of serious illness early, improved access to health care and support including medical specialists for complex conditions, enhanced coordination of health care and disability services, and end-of-life care and decision-making[18].

A good example of the effectiveness of government service agencies working together to achieve better outcomes for the community is the operation of the Queensland Health-led COVID-19 Working Groups for people in residential aged care and people with a disability. I am a member of both working groups. Prior to the pandemic, Queensland had a significant problem with hundreds of people with disability residing long-term in hospital and health facilities (despite being medically

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[17] Office of the Public Advocate (Qld), *Upholding the right to life and health: A review of the deaths in care of people with disability in Queensland*, 2016, p.xi, https://www.justice.qld.gov.au/__data/assets/pdf_file/0008/460088/final-systemic-advocacy-report-deaths-in-care-of-people-with-disability-in-Queensland-February-2016.pdf.

[18] Ibid.

ready for discharge). Despite implementing a Joint Action Plan over a number of years, the progress to transition this group of people from hospital to supported community living had been slow. At the beginning of the pandemic, State and Australian Government agencies found a new impetus to address this issue. Working closely with the National Disability Insurance Agency, in the first two months of the pandemic, Queensland Health successfully transitioned 392 long-stay patients with disability from public health facilities to community living. Work is continuing on the discharge of a further 197 patients.[19]

This discharge program highlights what can be achieved when systems work together on critical issues and prioritise outcomes.

The new National Disability Strategy presents a unique opportunity, but also a perfect platform to promote the need for government service systems to work together to develop more integrated service systems. There is no group in the community that suffers more from unresponsive, disconnected service systems, than people with disability. A commitment by governments of all levels under the National Disability Strategy to service systems working together on a more routine basis to improve service responsiveness and quality and address system failures and gaps could potentially change, and save, the lives of Australians with disability.

There could be a key role for Disability Advisory Councils (see suggested governance framework for the strategy below) in identifying system integration and coordination issues. The Councils would report these issues to the Disability Reform Council (or its equivalent with the introduction of the National Cabinet and its associated Councils or Committees), which could prioritise the issues and initiate projects to improve service integration. State, Territory and Australian Government departments and service agencies would be responsible for implementing the service integration projects and would be required to report annual on outcomes. Annual performance measures related to those projects could be allocated to the responsible agency.

Governance and measuring performance

While the position paper prepared for the National Disability Strategy review notes that a commitment is being made to strengthen the accountability of all levels of governance in relation to the strategy, there is little detail about the proposed governance structures for measuring strategy implementation and outcomes.

Given that accountability was identified as a key issue during the consultation phase, it is recommended that the strategy include a detailed governance structure that clearly maps what agencies and/or levels of government are responsible for implementation of the various parts of the strategy. It is critical to the new strategy being an effective document for driving real social change in Australia, that its governance structure outlines clearly what actions agencies and governments will take to implement their responsibilities under the strategy. Considering the issues with accountability under current strategy, the new strategy needs to include incentives for agencies and governments to deliver on their commitments in a measurable and meaningful way and the consequences of inaction (if any).

While it is anticipated that the Disability Reform Council or its equivalent will hold overall responsibility for the plan, it is imperative that other reporting and other governance frameworks at the state and territory level are also tapped into to provide the Council or its equivalent with information about strategy implementation and issues. Embedding information and data collection at the state and territory level will ensure that the strategy maintains its relevance across its 10 year lifespan.

Accordingly, it is recommended that the governance structure for the new strategy incorporate input from Disability Advisory Councils or their equivalent in states and territories on, at least, an annual basis. The Disability Advisory Council in Queensland acts as a ‘key channel for independent

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[19] Letter from Ms Bronwyn Nardi, Assistant Deputy Director-General, Prevention Division, Queensland Health to Ms Mary Burgess, Public Advocate, 18 August 2020.

advice to the Minister on a range of disability and related matters that affect the broader community. The Council is representative of the community and includes people with disability, family members, carers, as well as members from community organisations and disability service providers'.[20] At present the role of this Council does not appear to extend to providing the Minister with advice regarding implementation of the National Disability Strategy.

It is not enough to have a new National Disability Strategy that says all of the right things but does not measure its performance or outcomes. The new strategy requires clear performance measures for each of its outcome areas as well as the suggested new foundational elements (see above). These measures need to represent real and positive change in the lives of people with disability.

There should be annual reporting to Parliament on the implementation and performance of the National Disability Strategy by all levels of government. This could occur during National Disability Action Week. This reporting should include comprehensive data about performance measures and outcomes and should also include the individual stories of people with disability to demonstrate how the implementation of the strategy has impacted their lives for the better and made Australia a more inclusive society.

National Disability Strategy Outcome Areas

I support the continuation of the outcome areas included in the current National Disability Strategy 2010-2020. As noted, the hearings from the Royal Commission have illustrated clearly that the existing outcome areas remain current and should be retained as areas to progress for Australians with disability over the next decade.

I recommend that one additional outcome area be added to those already included in the strategy — accommodation. This outcome area remains of vital importance to people with disability. Safe, accessible, stable and affordable accommodation is fundamental for people with disability to live safe and healthy lives and be productive members of the community. If we cannot guarantee people with disability access to safe and secure housing, it is difficult to envision how we, as a nation, can achieve success in any of the other outcome areas in the strategy.

The United Nations' Convention on the Rights of Persons with Disabilities, Article 19 – Living independently and being included in the community, states that:

> State Parties to this Convention recognise the equal rights of all people with disabilities to live in the community, with choices equal to others…
>
> (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement.[21]

The Royal Commission's Public hearing 3: the experience of living in a group home for people with disability, highlighted that Australians with disability have extremely limited opportunities to choose where they live and with whom they live. This lack of choice leads to, in some cases, people with disability remaining in accommodation where they are at significant risk of abuse, violence or exploitation.

The report prepared at the conclusion of Public hearing 3 provided numerous examples of people with disability experiencing a lack of housing choice, leading to the conclusion by the Commission, and echoed by leading disability experts that Australians with disability require real choice and control in relation to housing, supported by increases in available housing stock.

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[20] Department of Communities, Disability Services and Seniors (Qld), *Queensland Disability Advisory Council*, 2 July 2020, https://www.communities.qld.gov.au/industry-partners/stakeholder-engagement/queensland-disability-advisory-council

[21] Convention on the Rights of Persons with Disabilities opened for signature 30 March 2007 [2008] ATS 12 (entered into force 3 May 2008) ('Convention on the Rights of Persons with Disabilities') art 19.

> An overwhelming theme emerging from Public hearing 3 was choice and control, including very significantly, choice about where or with whom a person with disability lives, empowering them to have control.[22]

Dr. Ilan Wiese, a senior lecturer in urban geography at the School of Geography, University of Melbourne spoke of a need for improved planning;

> What I would like to see from the Royal Commission is a…. very strong push, for governments to come up with plans to address unmet need, and to provide a supply of housing that is affordable for people with disability that gives them choice about where they live, that is suitable for people in terms of design, the management of their homes, that is well located, that is not segregated.[23]

From Dr. Winkler and Dr. Taleporos from The Summer Foundation, there were calls for a number of recommendations from the Royal Commission including:

> That the Australian Government develop a National Housing Strategy including a specific strategy for people with disability. The strategy should include a commitment that all new government-funded housing meets minimum accessibility standards. [24]

Drs Winkler and Taleporos also noted that their recommendations to the Commission were aligned with a number of principles including:

- housing promoting community inclusion and connection;
- the provision of choice and control; the need for separation of housing and provision of support services; and
- regulation that promotes life in the community (as opposed to an institution, like a residential aged care facility).[25]

A person with disability giving direct evidence to the Royal Commission (known as AAI), completed her evidence with the following:

> If you are not given the same opportunities and the same choices as people who do not have a disability, then your life becomes difficult.[26]

The issue of the provision of firstly, suitable housing and then, sufficient housing for people with disability to exercise choice and control, is not new. It was raised extensively by my office during the consultation phase associated with the development of the National Disability Strategy in 2009.

I have attached a copy of the relevant section of that submission for reference, as it includes detailed information regarding three critical areas:

- Accommodation and support for adults with intellectual disability;
- Accommodation and support for adults with mental illness/psychiatric disability;
- Chronic homelessness and impaired decision-making capacity.

While some of the statistics referred to in that submission may now be outdated and references to the expected impact of the NDIS have not been as projected, it is my view, reinforced by the evidence given to the Royal Commission, that most of the issues identified in that document remain unresolved today.

Failure to address the availability of suitable accommodation also creates a 'domino effect' for each of the other outcome areas included in the strategy. A lack of stable accommodation leads to greater difficulty in finding permanent employment and consequent economic security, which then limits opportunities for community participation and inclusion that then may lead to a breach

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[22] Royal Commission into Violence, Neglect, Abuse and Exploitation of People with Disability. *Report on Public Hearing 3: the experience of living in a group home for people with disability*, Melbourne Convention and Exhibition Centre 2-6 December 2019, p.67, https://disability.royalcommission.gov.au/publications/public-hearing-report-public-hearing-3-experience-living-group-home-people-disability

[23] Ibid, p.68

[24] Ibid, p.30.

[25] Ibid, p.29.

[26] Ibid, p.17.

of a person's human rights, if individuals with disability are forced (due to a lack of choice) into accommodation that is not safe, secure or suited to their needs.

The importance of accommodation cannot be understated. It is critical that accommodation is adopted as an additional outcome area for the new National Disability Strategy and that the new strategy have a strong focus on addressing the critical accommodation shortages for people with disability while ensuring they retain choice and control over where, and with whom, they live.

As well as the inclusion of accommodation as an additional outcome area for the strategy, I would like to respectfully suggest that the revised strategy also acknowledge the diversity of Australians with disability and the numerous additional challenges they face in fulfilling their potential as 'equal members of the community'.[27]

While people with disability are considerably marginalised in Australia, people with disability who also identify as Aboriginal or Torres Strait Islander (First Nations), being from a culturally and linguistically diverse background (CaLD) or lesbian, gay, bisexual, transgender, queer or questioning, intersex and asexual or allied (LGBTQIA) face barriers to accessing systems, services and programs that are unique and should be acknowledged and addressed at a national level.

A study undertaken in 2018 by Lannard and Lam from the University of LaTrobe in Melbourne,[28] highlighted the everyday experiences of lesbian, gay, bisexual, transgender and intersex people living with disability. It found that higher rates of discrimination and reduced levels of service access are prevalent among LGBTI people with disability compared with people with disability and LGBTI people without disability. Restrictions on freedom of sexual expression, reduced social support and connection with both LGBTI and disability communities was also experienced, exacerbated by many disability services and workers being unwilling to address the sexual and gender identify rights and freedoms of LGBTI people with disability.[29]

Conclusion

Thank you for the opportunity to contribute to the second phase of the consultation for the new National Disability Strategy. I fully support the vision and outcome areas proposed in the strategy, which move further towards ensuring that the fundamental rights of people with disability are protected and that they can live full and productive lives as valued members of our communities.

However, as I have outlined in this submission, I consider there are a number of critical additional elements that need to be included in the strategy, and addressed before we can hope to make progress towards the goals of the strategy.

Ensuring that people with disability have access to appropriate levels of independent advocacy, the provision of a safeguarding framework for vulnerable people with disability, governments committing to delivering integrated services for people with disability, and a strong governance structure are all essential to the new National Disability Strategy achieving its vision and goals.

I have also recommended that the strategy include an additional outcome area — accommodation, in recognition of the vital role it plays in providing security and stability in people's lives. Stable accommodation in a community setting for people with a disability is fundamental to our goal of an inclusive society.

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[27] Department of Social Services, *Review of the National Disability Advocacy Program – Consultation Report*, July 2017, p.6, https://engage.dss.gov.au/wp-content/uploads/2017/07/consultation_report_-_review_of_the_national_disability_advocacy_program.pdf

[28] Leonard, W. and Mann, R. *The everyday experience of lesbian, gay, bisexual, transgender and intersex (LGBTI) people living with disability*, No.111 GLHV@ARCSHS, 2018, La Trobe University: Melbourne, http://www.rainbowhealthvic.org.au/media/pages/research-resources/the-everyday-experiences-of-lesbian-gay-bisexual-transgender-and-intersex-lgbti-people-living-with-disability/1242611313-1564625168/the-everyday-experiences-of-lesbian-gay-bisexual-transgender-and-intersex-lgbti-people-living-with-disability.pdf

[29] Ibid, p.4

Evidence before the Royal Commission has sadly demonstrated how far we still have to go to ensure that people with disability can look forward to a safe and supported life, free from discrimination, abuse and neglect. It is critical that the new National Disability Strategy responds to the findings of the Royal Commission.

I look forward to, any additional opportunities to provide feedback as development of strategy progresses and, most importantly, the final strategy providing clear and accountable goals for all levels of government.

Yours sincerely

MCBurgess

Mary Burgess

Public Advocate (Queensland)

Submission by the Public Advocate – Queensland
in relation to
The *National Disability Strategy* Discussion Paper
1 December 2008

Section 1 Introduction

1.1 Background to the submission

On 17 October 2008, the Minister for Families, Housing, Community Services and Indigenous Affairs, Jenny Macklin, and Parliamentary Secretary for Disabilities and Children's Services, Bill Shorten, launched a discussion paper for the National Disability Strategy. The discussion paper is intended to generate public comment about the barriers to full inclusion experienced by people with a disability, promote social inclusion, and ensure the principles of the *United Nations Convention on the Rights of Persons with Disabilities* (UN Convention) are integrated into policies and programs affecting people with a disability, their families and carers.[30]

1.2 Interest of the Public Advocate

The Office of the Public Advocate – Queensland (the Office) was created under the *Guardianship and Administration Act 2000* (Qld) to provide systemic advocacy for adult Queenslanders with impaired decision-making capacity. Broadly, the role of the Public Advocate is to protect and promote the rights and interests of individuals with impaired decision-making capacity. Specifically, the functions of the Public Advocate, as set out under section 209 of the *Guardianship and Administration Act 2000* (Qld), are:

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

An adult is considered the have the capacity to make decisions when they are capable of;

- understanding the nature and effect of decisions about the matter; and
- freely and voluntarily making decisions about the matter; and
- communicating the decision is some way.

Adults whose capacity to make decisions is impaired may include people with intellectual disability, mental illness/psychiatric disability, acquired brain injury and dementia.

The Public Advocate affirms the need for Commonwealth and State governments to develop structures, strategies and systems that support full social inclusion of people with a disability, particularly those with impaired decision-making capacity, and that result in the full implementation of the UN Convention.

The Public Advocate commends this initiative as a step in that process, and makes these comments to promote and protect the rights and interests of these adults.

1.3 Content and scope of the submission

The Public Advocate's submission is focussed on identifying barriers to inclusion and, where possible, suggesting strategies to remove these barriers and improve support within the context of the UN Convention. Where possible, the suggestions are based on available evidence or research. In other instances, ideas and examples are put forward as possibilities for consideration. However, research is required in some relevant areas in order to establish international best practice. The government is urged to commission necessary research.
The issues discussed in this submission explore a number of areas, and offer some suggestions, where policy and program development, service delivery and allocation of funding have the

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[30] Refer to http://www.fahcsia.gov.au/internet/billshorten.nsf/content/nds_17oct08.htm at 11 November 2008.

potential to make a significant contribution to social inclusion of adults with disability/impaired decision-making capacity.

The Office's comments relate specifically to barriers experienced by adults with impaired decision-making capacity, who comprise a significant portion of the population of people with disability. Because of limited data collection, and the fluctuating nature of some cognitive impairments, it is difficult to state precisely how many Queenslanders, or Australians, live with a decision-making disability. However, adults with impaired decision-making capacity include people who experience the impact of:

- **a mental illness**: mental health problems are often episodic and fluctuating in nature. Overall, 20% of the population will experience a mental disorder during their lifetime. Around 3% will have a severe mental illness at any one time;
- **an intellectual disability**: people who have an intellectual disability comprise 2% of the total population. This figure includes people with mild, moderate or severe intellectual disability;
- **an acquired brain injury**: In 2003, the incidence of people with acquired brain injury in Queensland was approximately 110,000 people[31];
- **dementia**: Currently 1% of the Australian population has dementia. In 2005, there were approximately 37,800 Queenslanders with dementia. By 2050, there will be as many Queenslanders with dementia (171,000) as there were in the whole of Australia in 2000.[32]

It can be reasonably extrapolated that many of the barriers raised and strategies suggested will be relevant for individuals with physical and sensory disabilities as well. While comments are expected to be relevant for the general Australian context, many of the observations made in this submission are a result of the Office's involvement in Queensland.

The discussion that follows in this submission is not a comprehensive consideration of all the issues that could be explored in relation to the barriers to social inclusion, community participation and personal development that people with disability/impaired decision-making capacity encounter. Rather, this submission focuses on a range of salient issues that constitute significant barriers for this cohort.

1.4 The term disability/impaired decision-making capacity.

The term disability/impaired decision-making capacity is used throughout this submission to refer to people with disability whose capacity to make decisions is impaired.

Section 2 The barriers to access, inclusion and participation

There are a diverse range of barriers that inhibit the opportunities for adults with disability/impaired decision-making capacity to explore their potential, to develop as individuals and to engage with and participate in community in a genuine way.

Some of these barriers relate to the forms of accommodation that many adults with disability/impaired decision-making capacity experience. Often the person has no choice in relation to their form of accommodation, and often they are forced to endure unsatisfactory arrangements. Lack of access to adequate levels of support is a significant barrier for many, while the way those support services are provided to those who do receive support services can create barriers for others. Inequity in relation to access to physical and dental health care services poses significant health care issues for many amongst this cohort. Engagement with the criminal justice and corrective services systems can involve encountering a range of barriers that are inappropriate and counter-productive to addressing the person's disability support needs. The lack of access to individual social advocacy can pose significant barriers in terms of protection from abuse, neglect and exploitation and promotion of rights. Planning for the future can be a significant factor in the long term well-being and interests of people with disability/impaired decision-making capacity, and the lack of focus and support for this constitutes a major barrier. The lack of genuine opportunities in regard to employment and education are significant issues.

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[31] Brain Injury Association Queensland, Australian Statistics on Acquired Brain Injury (2006) http://www.biaq.com.au at 30 March 2007.

[32] Access Economics, 'Dementia estimates and Projections: Australian States and Territories' (Report by Access Economics for Alzheimer's Australia, 2005).

Education is a significant contributor to personal development and facilitating employment opportunities, while employment itself is one of the fundamentals of what might be considered a 'good life', not only in terms of income but also in relation to one's sense of self-worth and being perceived as a valued community member.

Underlying this range of practical barriers are attitudinal barriers - a range of perspectives, beliefs, approaches and ideologies - that influence the way individuals in the community, communities as a group, and those involved in policy development and service provision, respond to people with disability/impaired decision-making capacity.

2.1 Barriers arising from approaches to accommodation and support

UN Convention on the Rights of Persons with Disabilities
Article 19 – Living independently and being included in the community
State Parties to this Convention recognise the equal rights of all people with disabilities to live in the community, with choices equal to others…
(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live on a particular living arrangement.
(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.
(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs

Adults with impaired decision-making capacity, including adults with intellectual disability, mental illness/psychiatric disability, acquired brain injury or dementia, live in a diverse range of accommodation circumstances. Many require support in relation to the activities of daily living, social skills, community access and participation, social and recreational activities, vocational and employment options and exploring their interests. Some receive this support, many do not. Unmet need for disability support is widely acknowledged.

This submission does not discuss the broad range of situations in relation to the accommodation and support for this cohort, nor the multitude of barriers to social inclusion and community participation experienced by them. Rather, there is a focus on three specific areas:

- Accommodation and support for adults with intellectual disability;
- Accommodation and support for adults with mental illness/psychiatric disability;
- Chronic homelessness and impaired decision-making capacity.

2.2.1 Accommodation and Support for people with intellectual disability

Many people with intellectual disability/impaired decision-making capacity require support in relation to the activities of daily living, the development of social skills, community access, and social and recreational activities. The level of support they require will depend on the nature and level of their disability/impairment.

Many people in this cohort, usually those with higher levels of disability/impaired decision-making capacity and higher level support needs, receive funded support services, often provided in the context of an accommodation setting, so that they live in some form of supported accommodation. This includes large residential centres, residential campuses, intentional/village communities, cluster housing and community residential units (group homes), where the support can be provided by government or government-funded community service agencies. Group homes are the dominant form of supported accommodation in Australia, and in several other westernised countries. Typically between three to six people live together in a domestic sized house in the community, and share support from paid workers.

In relation to the size of the accommodation setting and the number of people who live together to share support, extensive research indicates that smaller, dispersed community housing tends to provide more opportunities and improved outcomes over larger residential or cluster settings. The research indicates that practices and routines carried out in supported accommodation settings are a significant factor in the outcomes for the residents, and the size of the setting, to a large extent, determines the daily routines in a particular residence. The larger the number of people congregated together, the more there is a need for greater regimentation of these routines, and subsequent lessening of the opportunities for choice and personal preferences.

A recent review of national and international research carried out for the Victorian Department of Human Services identified and described the key elements of community-based accommodation and support that provides the best personal outcomes for people with disability.[33] In the final report, the researchers Parmenter and Arnold concluded that a move from congregate facilities to smaller community-based settings is accompanied by different ways of planning and providing support, especially through processes that ensure that the lives of people are enriched with emphasis upon individual needs, preferences and choices.

Clearly, the group home model constitutes a better alternative to larger residential settings. The research in relation to the group homes has identified a number of positive characteristics in comparison to larger settings, including: domestic experience; community location; development of relationships between residents; and monitoring of health and wellbeing. However, the research cites a range of negative characteristics, including that fact that group homes have bureaucratically determined resident groupings, inflexible staff shift patterns, sometimes have rigid routines and practices, and there is a paucity of evidence of effective facilitation of community inclusion and engagements.[34]

While group home living is a significant improvement over the situation 40 years ago, where large institutions were the norm, it has not delivered on the gains hoped for when the model was being developed. This is due to problems with the model itself, some of which are mentioned above, as well as weaknesses in its implementation.[35] A range of factors, including: the failure to measure outcomes; a focus on inputs such as staffing levels; quality standards and workplace health and safety requirements, combine to make it difficult to provide support which mirrors the domestic experience of others in the community.[36]

Consideration of these factors indicates that group home living is a compromise in terms of meeting the individual needs of residents and facilitating their community inclusion. It is reasonable to argue that very few people living in group homes would choose to live in such a setting if they had a realistic choice. It is a compromise brought about by necessity, as they do not have enough support through funding for paid support, even augmented by their family and informal support networks, to live in their own home. Group homes are still environments that congregate and segregate people based on their commonality of having intellectual disability/impaired decision-making capacity. Such environments isolate people from the community, inhibit their social inclusion and limit their opportunities for personal development. The concept of community living for people with intellectual disability is a much richer concept than a mere physical presence in a community setting, which by itself does not guarantee community integration and inclusion. As support workers often work alone, there remains significant risk of abuse and neglect.

Yet there appears to be a perspective abroad that the group home model is the best that can be expected, that this is ‘the end of the road’ in terms of providing smaller supported accommodation settings. If full social inclusion of people with disability/impaired decision-making capacity is to be genuinely pursued, this perspective needs to be challenged. In part, this is the perennial issue of

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[33] Parmenter, T. and Arnold, S., Centre for Developmental disability Studies, *Disability Accommodation and Support Framework Report*, 2008

[34] Bleasdale, M (2007) *Supporting the Housing of People with Complex Needs*, final report, AHURI, Melbourne; Bridge, C, et al (2002) *Housing and care for younger and older adults with disabilities*, final report, AHURI, Sydney; MacArthur, J. (2003) *Support of daily living for adults with an intellectual disability*, Donald Beasley Institute, Wellington; Felce, D. (2000) Quality of Life for People with Learning Disabilities in Supported Housing in the Community, http://www.ripa.org.uk/aboutus/archive/files/reports/QualityOfLife.pdf.

[35] Mansell, J (2006) ‘Deinstitutionalisation and Community living: progress, problems and priorities’, *Journal of Intellectual and Developmental Disability*; Felce, D. (2000) Quality of Life for People with Learning Disabilities in Supported Housing in the Community, http://www.ripa.org.uk/aboutus/archive/files/reports/QualityOfLife.pdf.

[36] Ferguson, P. & O’Brien, P (2007) ‘From giving service to being of service’, in O’Brien, P. & Sullivan, M. Allies in Emancipation: Shifting from providing service to being of support, Thompson Dunmore Press, Auckland; DiRita, P., Parmenter. T. & Stancliffe, R. (2008) ‘Utility, economic rationalism and the circumscription of agency’ *Journal of Intellectual Disability Research*.

unmet need due to the need for increased resources. However, consideration about how resources are used warrants critical scrutiny. The suggestions provided below under Section 2.2.1.1, and the issues discussed under 2.3: *Funding and Service Options*, are relevant.

2.2.1.1 Strategies to address accommodation and support issues for adults with intellectual disability

A well-developed approach to addressing the barriers experienced by people with disability in relation to accommodation and support would require a full submission in its own right. The following ideas are some suggestions that would form part of a larger piece of work:

- Continue to devolve larger residential settings toward smaller accommodation options;
- Where it is necessary for people to live with others in order to share support, focus on establishing the smallest groupings possible.
    - nb: It is acknowledged that many non-disabled people, especially younger people, share housing with friends. In this regard, it might be argued that sharing housing is an experience for many people in community, and that in this way, people with disability sharing housing mirrors general community options. However, it needs to be taken into account that the experiences of disabled and non-disabled people diverge in that:
        - Non-disabled people who share accommodation with others generally choose to do so, whereas disabled people generally have no choice in the matter;
        - non-disabled people who choose to share accommodation generally choose who they share with, whereas people with disability generally don't;
        - non-disabled people usually move on after some time of sharing accommodation to live in their own home, whereas people with disability generally remain in a group home situation for life;
        - very often, people with disability have needs that would be better served by living in their own home rather than in a share situation, but their opportunities to do so are limited.
- Establish, to the greatest degree possible, situations where people live in their own home and are not forced to live with others to share support if they choose not to.
- Focus on the needs of the individual, and develop person-centred support responses.
- Provide support to families and informal support networks to develop and implement their vision and aspirations for their family member.
- Develop and deliver training to support workers and carers in community access/belonging.
- Ensure that individual people with disability are adequately funded so that the support services they receive are not just about assistance with the activities of daily living, but provide capacity for support to access and engage with community and pursue personal interests and goals, including educational and vocational goals.
- Provide support to small community-based organisations to develop and maintain infrastructure and resources to assist such organisations to maintain flexible and person-centred responses (e.g. support and resources for management committees).
- Provide as much control as possible to the person with the disability/impaired decision/making capacity, their families and substitute decision-makers in regard to how support funding is spent.

2.2.2 Accommodation and support for people with mental illness/psychiatric disability

Many people with mental illness or psychiatric disability require assistance with accommodation and support in order to facilitate recovery, and consequently, maximise the potential for social inclusion and community participation.

For many people who are recovering from a mental health episode or who experience a psychiatric disability, it is often not enough merely to provide accommodation and expect that person to sustain the tenancy – the provision of appropriate support services in coordination with that accommodation can be a significant influence in supporting their mental health recovery and sustaining their tenancy, contributing a better quality of life and increased positive community participation and contribution.

The term 'recovery' is used in the mental health context to refer to a '… journey toward a new and valued sense of identity, role and purpose outside the parameters of mental illness; and living well despite any limitation resulting from the illness.'[37] The recovery approach which has been embraced by the government and the mental health sector, is compatible with community models of service provision and promotes the need for community support. The approach looks outward and assists people to find and use community services, support and opportunities.[38] The provision of accommodation and support services within a recovery framework maximises the potential for recovery for a person with mental illness or psychiatric disability, and promotes social inclusion and community participation.

Stable accommodation is an essential foundation of treatment and recovery for a person with mental illness or psychiatric disability. As argued in the Burdekin Report, housing is 'an important part of a therapeutic system of rehabilitation and enablement that will help recovery.[39] Further, the Mental Health Council of Australia (MHCA) advocates the need for:

> …community supported recovery services [that] work alongside people with a mental illness. These programs … assist people with housing, activities of daily living, social skills, community access, social and recreational activities, counselling and advocacy, financial skills and management, vocational and employment support as well as general and specialist information sharing.[40]

The concept of 'stable housing' is contrary to the negative experiences of many people with mental illness who experience unstable housing, including homelessness and the insecurity experienced within short-term supported accommodation, such as transition housing models in community-based programs and hostels and boarding houses. In his research in this area, Bleasdale points to 'the connection between increased recovery of people with mental illness and the stability of their accommodation'.[41] Bleasdale also found that unstable and unsuitable accommodation can cause and be an ongoing stimulus for mental illness, and that once the need for accommodation had been addressed, the person with mental illness was better placed to focus on becoming well. This accords with the experiences of many people with mental illness as related anecdotally by them, their families and friends and by government agencies involved in their support.

In Queensland, there are examples of programs that provide accommodation for people with mental illness in coordination with clinical and non-clinical support services that clearly indicate the success of this approach. For example:

- Project 300 (P300) assists some people with psychiatric disability, who would otherwise become long stay residents in mental health facilities due to the lack of community support services, to move into community living. It involves the provision of support packages, including mental health clinical services, non-clinical disability support services and public housing. Services responses are individualised.
- The Housing and Support Program (HASP) assists people with a psychiatric disability to transition from Queensland Health facilities to community living through the provision of social housing, and support from clinical and non-clinical services. Based on a similar approach to P300, HASP differs in that it targets people in both acute and long stay mental health facilities.

A recent research project conducted by the Department of Housing, in partnership with Queensland Health, Disability Services Queensland and the Office of the Public Advocate, considered housing and support issues for people with mental illness or psychiatric disability, The

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[37] Queensland Health, (2005) *Sharing Responsibility for Recovery*, Queensland Government.

[38] New Zealand Mental Health Commission, 2001, *Recovery Competencies for New Zealand Mental Health Workers*, New Zealand.

[39] Human Rights and Equal Opportunity Commission (HREOC) (1993), Human Rights and Mental Illness, Report of the National Inquiry into the Human rights of People with Mental Illness, HREOC, Australian government Publishing Service, Canberra.

[40] Mental Health Council of Australia (MHCA) (2006), *Smart Services: Innovative Models of Mental Health Care in Australia and overseas*, MHCA, Canberra.

[41] Bleasdale, M. (2007), *Positioning Paper: Supporting the housing of people with complex needs*, Australian Housing and Urban research Institute, AHURI.

Final Report identified ten principles for effective housing and associated support a range of implications for policy change, which are detailed under Section 2.2.2.1 of this submission.[42]

2.2.2.1 Strategies to address accommodation and support issues for people with mental illness/psychiatric disability

A recent research project by the Department of Housing, in partnership with Queensland Health. Disability Services Queensland and the Office of the Public Advocate, in relation to housing and support issues for people with mental illness or psychiatric disability, proposed ten principles for effective housing and associated support, and identified policy directions for providing housing and associated support services in a way that sustains tenancies for, and support recovery of, people with mental illness or psychiatric disability.[43]

The principles are:
- Recovery approach
- Person-centred services
- Primacy of the person's housing needs and preferences
- Choice for independent living
- Responsiveness to population needs
- Separation of housing and support
- Interagency coordination
- Individual and systemic advocacy
- Long-term perspective of housing and support needs
- Preventing homelessness

The proposed principles, and the suggestions for policy change, are set out in **Appendix 1**.

2.2.3 Chronic homelessness and impaired decision-making capacity

The current Commonwealth Government has identified homelessness as an important social priority for Australia, committing $150 million during its first term for extra housing for homeless people and commissioning Green and White Papers to examine strategies for tackling homelessness over the next decade.

These initiatives will provide an opportunity to address what is a significant issue that until recently has not been given due attention – that many chronically homeless people have impaired decision-making capacity. Based on reports from service providers in the homeless sector, there are a significant portion of homeless people who live with some form of mental illness or cognitive impairment (such as acquired brain injury, intellectual disability or dementia), and whose capacity to make decisions is impaired. Their disability may be misdiagnosed, inaccurately assessed or remain unidentified, and their lack of capacity to make decisions is not recognised. Transient lifestyles and fleeting, intermittent contact with services, together with lack of awareness about impaired decision-making capacity amongst service staff and professionals, contribute to their vulnerability.

The basic needs of many of these chronically homeless adults are not being met despite their frequent interactions with a variety of service delivery systems including the mental health, criminal justice, emergency services, health and homelessness sectors. Much of the contact these individuals have with services and systems is uncoordinated and reactive, and many fall between the gaps of the mental health, disability support, housing, homelessness and other related systems. The current systems and services intended to address homelessness are not responding to the range and complexity of issues experienced by chronically homeless adults with impaired decision-making capacity.

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[42] University of New South Wales Consortium, (June 2008), Housing and Associated support for People with Mental Illness or Psychiatric Disability, Final Report for the Queensland Department of Housing.

[43] University of New South Wales Consortium, (June 2008), Housing and Associated support for People with Mental Illness or Psychiatric Disability, Final Report for the Queensland Department of Housing.

There is general societal exclusion of, and bias against, this group of people. Widespread prejudices and cultural misconceptions about chronic homelessness impact significantly on society's approach to addressing their needs.

A review of the literature reveals that little research has been undertaken in the area of chronic homelessness and impaired decision-making capacity. The Queensland Office of the Public Advocate, Micah Projects Incorporated, Mission Australia and HART 4000 have entered into a research partnership with the School of Human Services at Griffith University to investigate the nature and prevalence of impaired capacity in homeless people in several regions in Queensland. It is anticipated that the research will be completed in March 2009. The results are expected to have implications for the development of policy and programs by government.

Commonwealth Green Paper on Homelessness

On 22 May 2008, the Commonwealth Government released a Green Paper, *Which Way Home? A New Approach to Homelessness* (the Green Paper). The Green Paper promoted pubic discussion on homelessness, highlighted the challenges faced by people who are homeless, and suggested ways forward. The Minister for Housing invited public discussion on homelessness and written contributions to inform the development of the White Paper that would set out the Commonwealth Government's national plan of action in this area to 2020.

The Office provided a written submission to the Green Paper, in which the Public Advocate commented on the nature and vulnerability of chronically homeless people with impaired decision-making capacity. The submission made a range of recommendations for systems changes to protect this group of vulnerable adults, which are detailed under Section 2.2.3.1.

2.2.3.1 Strategies Chronic Homelessness and Impaired Decision-Making Capacity

In its submission to the Commonwealth Government Green Paper on homelessness, *Which Way Home? A New Approach to Homelessness* (the Green Paper), the Public Advocate expressed concerns that, while mental illness was discussed a number of times in the Green Paper, and the broader issue of impaired decision-making capacity was not addressed. While responding to the needs of people with a mental illness is essential, consideration must be given to individuals who live with other forms of cognitive impairment affecting their ability to end their homelessness and remain housed. Other causes of homelessness such as domestic violence and increasing house prices are significant contributors to homelessness and must be remedied. However, the Public Advocate urged the Commonwealth Government to give focused attention to the needs of vulnerable adults with impaired decision-making capacity who are chronically entrenched in homelessness.

In the submission, the Public advocate made a range of recommendations for systems changes to protect chronically homeless people with impaired decision-making capacity. The implementation of these recommendations would provide opportunities to reduce barriers to social inclusion for this vulnerable cohort. The recommendations called for:

- the development and implementation of a coordinated and flexible system for responding to homelessness (including early intervention and prevention, crisis response, and ongoing support);
- the provision of ongoing and continuing support for this group once they are housed;
- the establishment of chronic homelessness and impaired decision-making capacity as a major research priority;
- the establishment of targets for reducing homelessness to ensure that chronic homelessness is reduced at the same rate as the overall homeless population;
- addressing the cultural prejudice and stigma towards chronically homeless people;
- adequate resourcing and support for the overall system and its frontline services;
- the retention of the Supported Accommodation Assistance Program (SAAP) system as part of the response to homelessness, but with some reform;
- the evaluation of mainstream homelessness services to ensure that they are adequately equipped to meet the needs of this cohort, and to minimise the risk of exclusion and devaluation.
- The development and implementation of legislation in relation to homelessness to provide a foundation for the development of policy development and program implementation.

APPENDIX 1: Principles for effective housing and support for people with mental illness/ psychiatric disability

nb: The information in this table is a summary of the recommendations from a research project conducted by the Queensland Department of Housing, in partnership with Queensland Health, Disability Services Queensland and the Office of the Public Advocate.[44]

Principle	Suggestions for policy change
Recovery Approach	Review current mainstream and mental health specialist services to determine how to better apply the principles for effective housing and associated support - to modify services and propose additional ones to meet the implications of the principles
Person-centred Services	Review mainstream and specialists services to ensure they have a focus on housing and support that facilitates consumer outcomes, including: sustainable housing; quality of life; community participation; family connectedness; independent living; and economic security - to modify service delivery processes to meet the implications of person-centred service planning, funding and delivery.
Primacy of the Person's Housing Needs and Preferences	Review public and priority housing allocation criteria, with the aim of reflecting the principal of choice in housing for people with mental illness, in particular with regard to fulfilling long-term preferences for location and type of housing - to modify allocation criteria and processes to respond to people's needs and preferences for sustainable housing and support.
Choice for Independent Living	Review individual and system housing and support policies to incorporate the goal of independent living in the planning, funding and delivery of housing and support to individuals over their life course. This also has implications for the supply, planning and funding of housing and support types so that people can fulfil their choices as they change during their life - to modify housing and support processes and propose new housing and support options to offer sustainable housing and support as required.
Responsiveness to Population Needs	In relation to people in particular population groups, including: Indigenous; culturally and linguistically diverse communities; women; parents; and young people: • seek the participation of people and communities to identify needs and to comment on policy opportunities; • ensure that mainstream services are equipped to respond flexibly to particular needs associated with diversity; and • ensure that specialist services are established and adequately resourced to respond to particular to the population needs.
Separation of Housing and Support	Conducting a review of the structure, funding and delivery of support services check whether the principle of separating housing and support has been considered so as to minimise risks of conflict of interest and vulnerability of people receiving support. Where: • housing and support remains the responsibility of one organisation, the mechanisms within the organisation to address the risks should also be reviewed; • the functions are separated, mechanisms to effectively coordinate the functions should be reviewed.
Interagency Coordination	Review the formal mechanisms and informal processes to facilitate coordination the government and non-government organisations that are responsible for housing and support and have contact with people with mental health and psychiatric disability. The mechanisms and processes should be reviewed against the aims of effective coordination between the four types of housing and support, to improve outcomes for the person and to implement the principles for effectiveness.

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[44] University of New South Wales Consortium (June 2008), Housing and Associated Support for People with Mental Illness or Psychiatric Disability, Final Report for the Queensland Department of Housing.

Individual and systemic Advocacy	Review and improve the mechanisms that provide opportunities for people with mental illness and psychiatric disability to express their opinions about problems and solutions for housing and support. This needs to be accompanied by resources to support those mechanisms Provide more resources to increase the capacity of the advocacy sector to improve access for people with mental illness to individual advocates and to represent the interests of people with mental illness in systemic change in the housing, support and mainstream service sectors. Current advocacy agencies do not have the capacity to do more with the current resources; Implement a community development approach to elicit participation and community responsiveness, and engage with marginalised groups with mental illness and psychiatric disability Continue to work with the non-government sector to develop and implement community awareness and education strategies highlighting diverse and positive images of people with mental illness or psychiatric disability living and participating in the community.
Long-term Perspective of Housing and support Needs	Review policy processes that prioritise opportunities to allocate permanent housing with support rather than transition models for people with mental illness, given that the sustainability of housing and recovery relies on a long-term perspective; Focus on sustainable tenancies through the choices of housing and provision of support to sustain the tenancy.
Preventing Homelessness	Review housing allocation policy and practice to prioritise access to permanent, dispersed housing for people with mental illness and psychiatric disability with the view to prevent homelessness. In addition, the affordable housing stock managed by the social housing sector needs to be increased, including methods to engage private housing sector through long term leases.