

Research and Advocacy News

July 2013

The Office of the Public Advocate undertakes systems advocacy on behalf of all vulnerable Queenslanders who have impaired decision-making capacity.

Our systems advocacy function operates within a statutory framework outlined in Section 209 of the *Guardianship and Administration Act 2000*.

We deliver statutory systems advocacy through an evidence-based approach. Our key purpose is to promote improved life opportunities and outcomes for all people with impaired decision-making capacity across all aspects of life.

Our Research and Advocacy news will provide updates about our projects and report on outcomes as they become available.

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New research and advocacy projects

Continuing the deinstitutionalisation of people with disability in Queensland

On 17 June 2013, the Public Advocate released a position statement on Continuing the deinstitutionalisation of people with disability in Queensland.

Up until the 1980s in Australia, it was common practice for people with disability to reside in large institutions, situated on the outskirts of cities with other children and adults with disability. While there was a gradual reversal of this trend, with many people with disability relocated into community-based living, the Public Advocate remains concerned about the numbers of people with disability in Queensland who remain living in institutional-type settings.

The Position Statement outlines the Public Advocate's concerns and commitment to monitoring this issue, and to working collaboratively with Government and other key stakeholders to ensure that there are increased opportunities for people with disability to lead more autonomous lives.

The Position Statement can be accessed on the public advocate's website www.publicadvocate.qld.gov.au under the heading "current research and advocacy projects".

People with disability in long-stay health care facilities

This new project will build on the Position Statement referenced above, but focuses specifically on people with intellectual disability or cognitive impairment residing in

long-stay health care facilities like psychiatric hospitals and rehabilitation services.

In 2001 it was reported that 110 people with multiple disabilities (that is an intellectual disability and physical and/or psychiatric disabilities) were living in health department psychiatric hospitals and a further 112 people with multiple disabilities, that included intellectual disabilities were living in two wards attached to general hospitals in Brisbane and Rockhampton.¹

The Public Advocate has sought information from key government agencies about the number of people with intellectual disability or cognitive impairment who continue to reside in long-stay health care facilities. She is also seeking information on the extent to which key agencies are working together to assess the immediate and future needs of individuals in these facilities; and plan, on an individual basis, for improved access to appropriate community-based accommodation and/ or support arrangements.

Institutional environments provide little opportunity for self-determination and limited choice in relation to things that most people take for granted such as when to eat, who to live with, and where to go on outings and visit friends and or family. It is not surprising therefore that many studies in western and developing countries have measured positive outcomes for people with disability as a result of moving into the community. These outcomes include substantial improvements in daily living skills, more contact with family, improvements in communication and social skills, greater social interaction, increased recreational and leisure activities, and greater use of community facilities.²³

Not all studies however show consistent and universally favourable outcomes for people moving from institutional settings into

¹ Lisa Bostock, Brendan Gleeson, Alisa McPherson and Lillian Pang, *Deinstitutionalisation and Housing Futures: Final Report*, Australian Housing and Urban Research Institute, 2001, 27.

² Lesley Chenoweth, *Closing the Doors: insights and reflections on deinstitutionalisation* (2000) 17(2) Law in Context, 84.

³ Louise Young, Adrian Ashman and Paul Grevell, *Closure of the Challinor Centre II: An extended report on 95 individuals after 12 months of community living*, Journal of Intellectual and Developmental Disability, 26(1), 52.

community-based living. Good outcomes for people are often dependent upon the nature of opportunities and support services provided in each community setting.

The Public Advocate is committed to ensuring that any relocation of people with disability from institutional settings into the community is well planned, and that appropriate supports are provided according to the needs, goals and circumstances of each individual.

Call for submissions

The Public Advocate has also called for submissions on this issue. Views are sought on the immediate and future support needs of individuals with intellectual disability or cognitive impairment currently residing in health care facilities and the issues that should be taken into account in relation to:

- Whether the support needs of individuals are being met;
- The immediate and future support needs of individuals;
- Whether the support needs of individuals could be better met in community-based living and the factors that should be considered in making this determination;
- The issues that should be taken into account to support successful transition from institutional to community-based living, where appropriate.

More information about the submission process is available on the public advocate's website www.publicadvocate.qld.gov.au under the heading current research and advocacy projects.

Due date for submissions - 2 August 2013

A Report on the first stage of the project will be produced later in 2013 and the Public Advocate will continue to work collaboratively with key government agencies and other key stakeholders.

Aboriginal and Torres Strait Islander People in the Guardianship System

In 2011 the Office of the Public Advocate funded a joint research project undertaken by Griffith, Central Queensland and James Cook Universities. The project highlighted many knowledge gaps including that there was limited information regarding how many Aboriginal and Torres Strait Islander people have contact with the guardianship system in Queensland. Since that time improvements in the way data is collected in some agencies has provided an opportunity to obtain more information to complement existing research on guardianship for Indigenous Queenslanders.

The Office of the Public Advocate will work with key agencies in the guardianship system to ascertain the proportion of Indigenous and non-Indigenous Queenslanders in the guardianship system.

It is anticipated that the data gained through this project will give the Office a more accurate picture of the extent to which Indigenous people access guardianship and administration services and an evidence base to explore any identified issues.

A Fact Sheet will be published that will summarise the representation and profile of Indigenous Queenslanders in the guardianship system. Updates, reports and related resources, as they become available, will be published on the Office of the Public Advocate's website at www.publicadvocate.qld.gov.au.

Research Insights

Safe at Home –safety strategies used by people with intellectual disability

Feeling safe and strategies to keep yourself safe are important to us all. Where a person has a significant reliance on support staff and

support services, or lives in a group home with other people, different strategies might be used and different challenges faced.

The Office of the Public Advocate partnered with Griffith University and the Office of the Adult Guardian to explore the ways in which people with intellectual disability keep themselves safe in the places where they live.

This was a participatory study with group and individual interviews of 20 people with intellectual disability. People with intellectual disability provided advice on the research design, interview guides and the easy-read booklet that was used to facilitate interviews.

The results of the study have been incorporated into an article in the *Scandinavian Journal of Disability Research*, written by Sally Robinson,⁴ and summarised in a Research Insights fact sheet available on the Public Advocate's website www.publicadvocate.qld.gov.au.

This study employed an innovative methodology and also explored new territory. Research in this area often focuses on the prevalence of violence and abuse against people with intellectual disability, the experience of abuse and neglect or strategies to keep people with disability safe. There is less research that directly asks people with intellectual disability how they recognise danger and how they keep themselves safe. This formed the basis of the University's research.

Summary of findings

Strategies to keep safe

Participants in the study used a number of common strategies to keep safe.

Physical strategies: included locking doors (particularly when alone at home), fire safety plans, and careful use of electronic appliances. Avoiding potentially dangerous situations to avoid confrontation was also common, for example not leaving the house

at night, or locking their door and remaining inside if a neighbourhood argument started. Some men also talked about being prepared to take physical action if necessary and keeping an item for self-defence by their bed at night.

Relational strategies: included being with family, having a say about who provided their support, and having a good relationship with the people they live with. Other important strategies included knowing who their friends are, only having people in their room that they can trust, and being able to rely on neighbours.

Help-seeking strategies: included understanding how to make an effective complaint, knowing how to contact emergency services on the phone, and telling someone if something happens that makes them feel unsafe. Many participants however had a negative experience of making complaints.

What makes it hard to stay safe

Participant's responses to the question about what makes it hard to stay safe fell into three clear areas.

Lack of choice and control: over their lives, particularly for those who shared their homes with others, made it difficult to feel safe. The personal safety of many people was undermined by a lack of personal power to negotiate care, move house, or to make changes if they felt uncomfortable. Being able to lock the door to keep unwanted people out of their home was important to those who lived alone.

Problems with paid staff: was a particular issue for people who were highly dependent upon staff for significant levels of assistance such as personal care. Several participants talked about how difficult it was to negotiate issues regarding poor professional practice with staff and many had negative outcomes after making a complaint. Several participants raised experiences of workers bringing friends into their homes, which they felt uncomfortable about, but felt unable to take action.

Inter-relational problems: including being bullied and intimidated by co-residents were commonly raised. One person had been affected by domestic violence. Several participants said that when they relayed their

⁴ Sally Robinson, *Safe at home? Factors influencing the safety strategies used by people with intellectual disability*, *Scandinavian Journal of Disability Research* (2013)

concerns about inter-relational problems to support workers and friends, these were downplayed.

Fear: of the possibilities and realities of harm was a concern for most people. Women especially were concerned about theft, and several people were concerned about prowlers at night, particularly those people with physical disabilities who relied on support staff to get them out of bed.

Insights for policy and practice

From listening to the participants of this study, researchers concluded that safety issues that related to problems in the general community were better resolved than those related to disability service provision. Participants felt they could draw on the same resources as the broader community – neighbours, the police, the Fire Brigade. More difficult however was negotiating care with disability support services. It was difficult for many participants with intellectual disability to put their safety strategies into action, not due to capacity, but to circumstance.

As Sally Robinson comments, the lived experience of people with intellectual disability and the challenges they face in keeping themselves safe should be taken into account in the context of the changes occurring in policy and practice in Australia, including the rapid move towards individualised funding and support.

Policy and law reform

Submissions made by the Public Advocate

Since January 2013, the Public Advocate has made a number of submissions in relation to various policy and law reform agendas and inquiries. These are listed below and, in most cases, are also available on the Public Advocate's website (www.publicadvocate.qld.gov.au).

- Inquiry into the National Disability Insurance Scheme Bill 2012 (January 2013)
- Queensland Mental Health Commission Bill 2012 (February 2013)
- Inquiry into the Involuntary or Coerced Sterilisation of People with Disabilities in Australia (February 2013) – made jointly with the Adult Guardian
- Value of a Justice Reinvestment Approach to Criminal Justice in Australia (March 2013)
- Queensland Child Protection Commission of Inquiry (March 2013)
- National Disability Insurance Scheme Rules Consultation Paper (March 2013)
- Ademption and Common Law provisions (April 2013)
- Inquiry into the Aged Care (Living Longer Living Better) Bill 2013, Australian Aged Care Quality Agency Bill 2013, Australian Aged Care Quality Agency (Transitional Provisions) Bill 2013, Aged Care (Bond Security) Amendment Bill 2013 and Aged Care (Bond Security) Levy Amendment Bill 2013 (April 2013) – contribution to AGAC submission
- Care and Management of Younger and Older Australians Living with Dementia and Behavioural and Psychiatric Symptoms of Dementia (BPSD) (May 2013).
- Queensland Disability Plan (May 2013)