

South Australian Office of the Public Advocate

ANNUAL REPORT 2009

The Public Advocate is an Independent Official accountable to the Parliament of South Australia

**South Australian Office of the Public Advocate
Annual Report 2009**

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30 September 2009


The Hon Michael Atkinson MP
Attorney-General
45 Pirie Street
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Dear Mr Attorney

I have the honour to present to you the fifteenth Annual Report of the Public Advocate, as required by the provisions of Section 24 of the *Guardianship and Administration Act 1993*.

This Report covers the period from 1 July 2008 to 30 June 2009. Part A is an overview of major matters arising during the year, and includes a review of programs, consideration of unmet need, and advocacy positions taken by this Office. Part B provides statistical data on direct client services provided by our Office.

Yours Sincerely

A handwritten signature in black ink that reads "John Brayley". The signature is written in a cursive, flowing style.

John Brayley

PUBLIC ADVOCATE

Office of the Public Advocate Annual Report

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Introduction

Welcome to this year's Annual Report. It is arranged in two parts: Part A is a summary of the issues of this year grouped according to the general functions of this Office, including Program Review, Analysing Unmet Need, Promoting Rights and Interests, and Monitoring the Act. Part B describes the direct client services provided by this Office.

Throughout the report are common unifying themes that include:

- The need to balance positive rights with negative rights.

Positive rights, the right to pursue ones goals, and live life fully can depend on having housing, good treatment and effective support services.

Negative rights that protect from unnecessary restriction, compulsory treatment, detention or restraint also depend on having good services that can be accessed early.

This determines how both mental health and disability services are planned and implemented.

- The impact of the United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol.

Particular emphasis is placed on Article 12 and the protections it applies to decision making. The Convention supports a move away from substitute decision making to supported decision making where possible. This involves developing new ways to help people make their own decisions rather than others making decisions for them.

Parallel to this is the movement to give consumers and carers more choice in deciding what services they will receive and from whom.

This Report looks closely at mental health reform, in particular the changes to long-term inpatient care and supported accommodation. The passage of the Mental Health Act 2009 is discussed with an eye to coming debates in the next year about how key provisions will be practically interpreted.

The unmet need for disability services is described. While much of the debate has been about resources, a greater transformation is required. It is suggested that a move away from a welfare-based disability system to a rights-based system could be achieved through the implementation of the UN Convention underpinned by a new Disability Act for South Australia.

Part A:

General Functions of the Public Advocate

Including Program Review, Analysing Unmet Need, Promoting Rights and Interests, and Monitoring the Act

Reviewing Programs and Identifying Unmet Need

Overview

Guardianship and Administration Act 1993

Section 21 (1) The functions of the Public Advocate are—

- (a) to keep under review, within both the public and the private sector, all programmes designed to meet the needs of mentally incapacitated persons;
- (b) to identify any areas of unmet needs, or inappropriately met needs, of mentally incapacitated persons and to recommend to the Minister the development of programmes for meeting those needs or the improvement of existing programmes;

Program review needs to be considered within a performance framework.

Broadly, human services can be assessed along nine key themes. In particular, a program must be:

- Accessible — the right service at the right time
- Continuous — uninterrupted coordinated care
- Appropriate — to each consumer's needs and based on standards
- Responsive — prompt, respectful and meets consumer needs
- Effective — the service achieves the required outcome
- Capable — the provider has the necessary skills and knowledge
- Efficient — does not waste resources that could be used to assist more clients
- Safe — avoids errors that might harm the consumer
- Sustainable — capacity to provide workforce, facilities and equipment and meet new trends.

These domains were defined by the National Health Performance Framework (National Health Performance Committee, 2001). Appendix A contains further background discussion of this framework as well as the collection of performance data on disability services based on the National Minimum Dataset for Disability Services.

While each of the performance domains are important, this Annual Report looks at themes of access, continuity, and the delivery of appropriate services as key issues emerging from review work and advocacy.

Reviewing Programs and Identifying Unmet Need

Disability Services

Introduction

This unmet need for disability services has been and continues to be a major concern of consumers, carers and the community generally. There has been some public focus on the unmet needs of people who have an intellectual disability and the needs of carers.

Access to services for people with intellectual disability, brain injury, and neurological disease requires ongoing independent, transparent review. This will require use of internal data as well as publicly available data.

This section reviews this topic, drawing conclusions on the magnitude of unmet need.

National background

The Commonwealth Government's National Disability Strategy Consultation Report "Shut Out: The Experience of People with Disabilities and the Families in Australia" paints a disturbing picture of limited access for people with a disability.

There is no reason to suggest that the findings of the "Shut Out" report would not apply to South Australia. The issues raised by this report, and the experiences described are the same as ones that can be heard when speaking with South Australian consumers, families and service providers.

This report (National People with Disabilities and Carer Council, 2009) notes that disability services are intended to assist people with a disability to participate in the community, but in half of the submissions received, respondents indicated that services acted as a barrier to participation.

Referring to services nationwide, this report states:

The disability service system was characterised as irretrievably broken and broke, chronically under-funded and under-resourced, crisis driven, struggling against a vast tide of unmet need. As a result many felt more time was spent rationing services than delivering them.

The people who responded to the national consultation said that endless assessments and forms led to a frustratingly inadequate service. The report includes an example of a person with an intellectual disability denied a service because they had an IQ of 72 (rather than less than 70), but still had significant impairments on specific sub-scales of the IQ test, impaired functioning and anger outbursts at home. While the report does not identify the state in which this occurred, this scenario can occur here in South Australia.

In a complex underfunded system, time spent on determining eligibility and negotiating services can be at the expense of actual service delivery and time spent on improvement. An

exasperated parent told this consultation: “They seem to spend more money on case managers than actual therapists”. Even when services are provided parents may withdraw children because they are not happy with the quality of services.

In speaking with consumers, families and advocates the same stories emerge. Unfortunately, in South Australia, there is a general desensitisation to the problem — while many recognise that their situation could be better, they become resigned to what the system can provide. I note that some family members who have become advocates argue passionately on behalf of others but do not really expect that their own situation could improve.

At this point, it is important to acknowledge the good work of many committed professionals, care workers and organisations. Every day our Office meets staff fighting for their consumers’ needs, and delivering excellent service. At issue is not the good work of these individuals and the specific organisations and programs that have established reputations of excellence in areas such as intellectual disability and brain injury, but the variability across the system. While there are great workers, there are also others burnt out and no longer able to deliver. There are many instances of people receiving the best possible combination of services for their needs, but there are many others where people with a similar disability and service requirement miss out.

I would also note that this Office, in advocating for services for individuals, frequently works with executives in Disability SA and the Department of Families and Communities. The commitment and the solutions offered can be exemplary. Our advocacy for people with high needs is often successful, because of the hard work and time put in by departmental leaders to deliver a result for clients. However, this is in the setting of a delivery system that is under stress and arguably, much of this additional time and energy could be avoided if the system had been able to deliver in the first instance.

Disability service provision in South Australia

The data in this section are derived from a number of sources related to the prevalence of disability in the community and from reports of services delivered under the Commonwealth–States and Territories Disability Agreement (CSTDA)¹.

In August 2008, the Australian Institute of Health and Welfare (AIHW) released a report on 2006–2007 data that provides comparisons between states. This data collection was also used as the basis for an analysis published in January 2009 in the Report of Government Services (Productivity Commission, 2009). South Australian data for 2007–2008 have also been released to the sector by the Department of Families and Communities. For estimates of people in the community who have specific disabilities, results of the Survey of Disabilities, Ageing and Carers have been used. Unfortunately, the latest data available are for 1998 and 2003. A new Survey of Disabilities is under way in 2009 but no results are available yet. These data have been tabulated in Appendix B.

¹ The CSTDA applied until 31st December 2008, when it was replaced with a new National Disability Agreement. The CSTDA gave the State responsibility for the planning, policy setting and management of specialist disability services except employment services (CSTDA Multilateral Agreement, 2008). This includes accommodation support (to accommodation settings and people’s own homes), community support (which includes case management and therapy services), community access (such as learning and life skills development) and respite case services. The State and Commonwealth are jointly responsible for advocacy services, information services and print disability services.

Disability SA eligibility criteria determine who does or does not receive a service. Significant elements are extracted in Table 1 (Department of Families and Communities, 2008). Table 2 contains details of how eligibility is determined for people who might receive services from another agency to Disability S A (such as Mental Health or Drug and Alcohol Services).

It is commonplace for disability systems to have clear criteria either defined by Parliament as legislation or defined at a policy level. At issue are not the criteria themselves but how the specific criteria noted in Table 1 might be interpreted when resources are limited, particularly when there is a potential for overlap with other services as determined by the “no duplication” principle and the scope of service response described in Table 2.

There are many examples where Disability SA has been flexible at the margins to ensure that a person who needs a service is not denied eligibility on a technicality. There are also other examples where assessment for eligibility is prolonged, and delays are caused by disputes with other providers over who takes responsibility. In these cases, the dispute is not over whether a service is required, but who funds it. Consumer needs do not fit neatly into service silos: for example, a person who has long-term mental illness, used substances and then developed brain damage may have a disability caused by both the original illness and the substance-induced brain damage. With such combinations of effects, arguments over whether a person has a mental health problem or a disability problem do not reflect the complex interrelationships that occur when a person has more than one cause of a disability.

Table 1: Extract from Disability SA Eligibility and Access Guidelines .**Date: 7 April 2008 (Date for review March 2011) Guideline number GUI-SER-001**

To be eligible for Disability SA services, the person must fit one (or more) of the following criteria:

- Children under 5 years of age who have significant global developmental delay
- Children and adults with intellectual disability
- Children and adults diagnosed with autism spectrum disorder (autism or Asperger syndrome)
- Children and adults with acquired brain injury
- Children and adults who have a physical or neurological condition that cannot be resolved with medical treatment.

In addition, as a result of the above condition(s):

- The person experiences significantly reduced functioning in most of the following areas: communication, self care, mobility, community access, health and safety, domestic activities, social, self direction, work and leisure.
- The person requires assistance from a specialist disability service.
- The disability is permanent or likely to be permanent (it may, or may not, be of a chronic episodic nature and is not likely to resolve with medical treatment).

People over the age of 65 years who are referred to Disability SA will not be considered eligible.

Decisions about priority of access include **consideration of a range vulnerability indicators** such as homelessness, access to services, age, health and capacity of carer, family situation, and isolation.

People in the following vulnerable groups are considered to have urgent need: Children or young people under the Guardianship of the Minister; People with rapidly deteriorating neurological conditions; Aboriginal people with disabilities; People with disabilities in acute care settings awaiting discharge; People under 50 years of age in danger of being placed in a nursing home.

Acquired brain injury is a brain injury acquired after birth. It may result from:

- A traumatic head injury from a motor vehicle accident, assault, accident, etc
- A stroke or cerebrovascular accident (CVA)
- A brain tumour
- An incident which causes lack of oxygen to the brain such as a near drowning experience, drug overdose, or heart attack
- Infections such as meningitis or encephalitis
- Alcohol and/or substance misuse.

Intellectual disability – a person has an intellectual disability when they meet the following three criteria:

- Significant sub-average intellectual functioning as indicated by an IQ score of two or more standard deviations below the mean.
- Substantial limitations in an individual's effectiveness in meeting the standards of maturation, learning, personal independence and/or social responsibility
- Cognitive and adaptive functioning deficits are manifest prior to 18 years.

Neurological disability is a condition, whether genetic or acquired, that affects the way the brain processes information and communicates with the rest of the body; for example, the ability to produce movement or the ability to process information. Examples include Multiple Sclerosis, Parkinson's Disease and Motor Neurone Disease.

Permanent or likely to be permanent refers to the irreversible nature of the disability, even though it may fluctuate in severity over time; that is, it may be of a chronic episodic nature. A person will be eligible if their underlying disability is permanent or likely to be permanent and they meet all of the other eligibility criteria.

The disability will not be considered permanent where there is a need for specific health services for a defined period following physical trauma or the onset of an acute episode of illness. A person in this situation may only become eligible for disability support services once their medical needs have stabilised and the long-term nature of their disability becomes apparent. Some conditions are not considered to be permanent and therefore are not considered to be a disability.

Table 2 Extract from Disability SA Eligibility Guidelines Referring to Scope of Service**Date: 7 April 2008 (Date for review March 2011) Guideline number GUI-SER-001****Principle 4.1****No duplication of services**

A person will not be eligible for a Disability SA service if they receive the same service from another agency in relation to their disability

Guideline detail 4.5**Scope of Service Response**

Some individuals with a disability or multiple disabilities have other factors impacting on their functioning (such as high health needs, dementia, mental illness, drug and alcohol abuse). In these instances multi-agency responses may be required. Where a person's disability is the principle cause of impairment, then Disability SA may undertake the role of lead agency, not negating the responsibility of other agencies to provide services. Where a person's disability is not the principle cause of impairment but the person is eligible for Disability SA services, then Disability SA's role will be limited in scope.

In its 2009 Report, the Productivity Commission in its report has estimated the number of people in the general population who might potentially use a disability service, compared with those who are current users. The results are displayed in Figure 1. Just over 40% of the population who might require a service are receiving one in South Australia. With respect to this measure of access, our state performs better than any other state except Victoria.

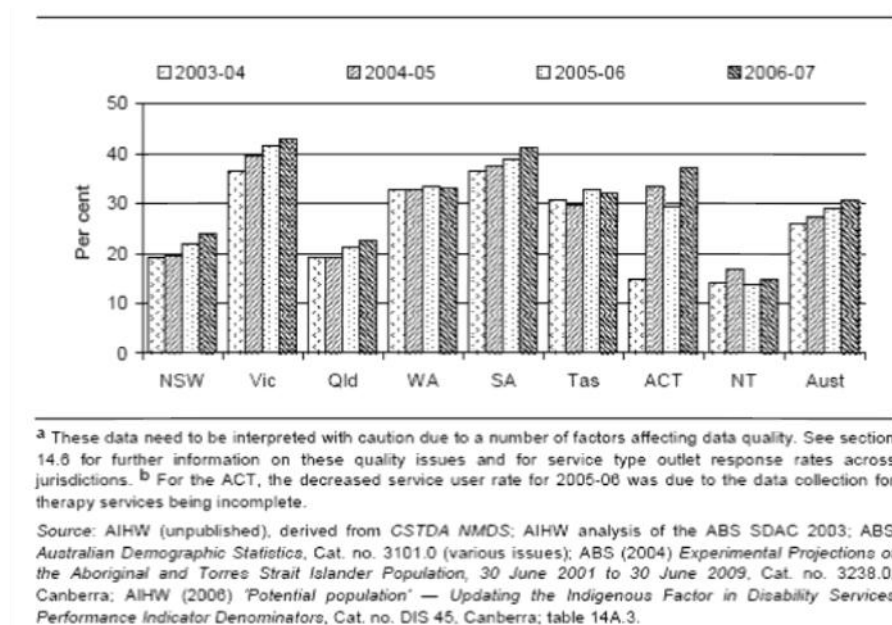


Figure 1: Users of CSTDA funded services as a proportion of the estimated potential population (Reproduction of Figure 14.6, Productivity Commission, 2009)

When the same analysis is conducted for supported accommodation services alone, which require significant resources, South Australia performs better than any other state. This is illustrated in Figure 2.

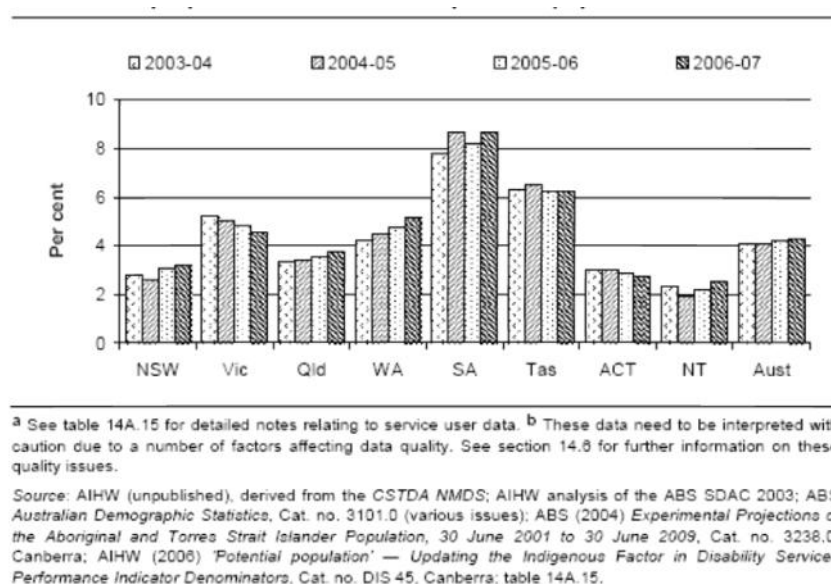


Figure 2. Users of CSTDA funded accommodation support services as a proportion of the estimated potential population (Reproduction of Figure 14.10 from Productivity Commission (2009))

Overall, South Australia has better access to disability services compared to other states. It should be noted that these published data consider all people who have a disability. To ensure equity, similar analyses need to be undertaken for people who have disabilities caused by different underlying conditions, as it is possible that a state might set up its services well to respond to the needs of one group with a disability and not another.

Without such a report at this time, it is reasonable to assume that these comparative differences would apply to the populations of concern to the Public Advocate — people with an intellectual disability, brain injury or neurological disease that might affect cognition.

Historically South Australia pursued active case finding, with publicity campaigns in the 1990s such as “lost in the wilderness” designed to alert consumers and carers that they might benefit from a service.

While South Australia is near the top in access, it is midway in funding. Funding is summarised in Table 3 below.

State	Expenditure on Disability Services (\$Million Dollars)	Adjusted figure to provide services to a total population of 1.575M people (\$Million Dollars)
Victoria	1190.4	363
Tasmania	111.0	355
New South Wales	1303.4	299.4
Australian Capital Territory	61.0	286
South Australia	269.4	269.4
Western Australia	332	251.3
Northern Territory	33.3	246.7
Queensland	622.2	237.2

Table 3: Adjusted expenditure figures for population based on expenditure on disability support services in Australian jurisdictions reported by AIHW (2008) adjusted to match the total population size of South Australia based on ABS population statistics for each Australian state and territory as of 30 December 2006.

The result of this combination — attempting to serve more people on fewer dollars — is reflected in the funding per service user. South Australia allocates less than any other state. This is illustrated in Figure 3.

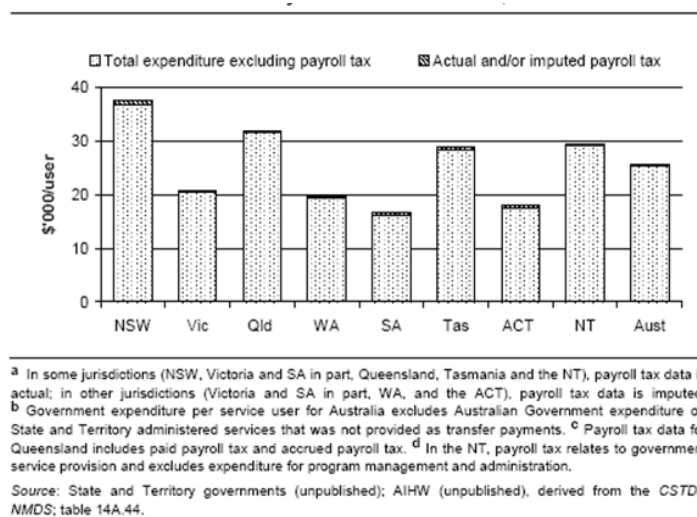


Figure 3. Estimated annual government expenditure per user of CSTDA State and Territory Administered Services (2006-07 dollars) (Reproduction of Figure 14.43 of the Productivity Commission (2009))

Further South Australian information can be derived from both the CSTDA usage data, and information on the number of people who are known to Disability SA and awaiting a service. This is the “unmet needs list”, that the Department of Families and Communities (DFC)

makes public on a 6-monthly basis — a commitment made in response to advocacy from key South Australian disability advocates including parent, carer and community advocacy leader David Holst. This unmet needs data has been linked with CSTDA data in Table 4.

2007/08 South Australian CSTDA Data			Departmental Unmet Needs List November 2008	
	Number of people	Number of Services	Number of people	Number of Services
Overall	19,350	37 361	2173	3543
Severity of disability:				
People who have a profound disability	6345			
People who have a severe disability	7501			
Frequency of primary disabilities				
Intellectual disability	36% (approx 7000 clients)			
Service types				
Accommodation support	4599	5464	1663	1884
Community support	14263	22224	512	695
Community Access	5435	7549	400	507
Total Respite	1664	2124	418	457

Table 4: 2007-2008 CSTDA Data for South Australia compared to Department of Families and Communities (DFC) Unmet Need Data.

In the unmet need group there is a higher proportion of people waiting for accommodation support. This care is likely to be more expensive than other service types such as case coordination or day care, because of the labour-intensive nature of these services. Accommodation support comprises 15% of the total number of CSTDA services delivered over a year, but 53% of the services required on the unmet needs list at the time this snapshot data was collected. Many of those waiting for accommodation support will have an intellectual disability, brain injury or neurological disease as the primary cause of their disability, or as one of multiple disabilities and will be living with overburdened carers.

Once again, it is relevant to make the caveat that a similar analysis needs to be undertaken for people with different underlying conditions to be clear about the exact patterns for people in each group reflected in the need for different combinations of support services.

Service provision for people who have disabilities with different underlying conditions

Some informal comparisons can be made between the data in the previous CSTDA tables and survey data recorded in Appendix B.

However, these comparisons are not accurate enough, as it is difficult to try to match service groups with population survey groups when data have been reported using different groupings of consumers' underlying condition, and of course come from different years (CSTDA data from either 2007–08 or 2006–07 and survey data from 2003).

Therefore, this section primarily considers qualitative factors derived from the advocacy work of our Office.

Intellectual disability.

The unmet need gap for people with an intellectual disability will have a number of components. The experience of consumers, families and advocates is needed to supplement the analysis of the figures. The unmet need gap for people with an intellectual disability has a number of components. Typical components of the unmet need as observed in OPA advocacy work are listed below.

- Not receiving a service
 - People with a disability who have not presented themselves or been referred to Disability SA.
 - People who have been refused a Disability SA service because they do not meet the IQ score threshold of “two or more standard deviations below the mean.” (This usually corresponds to a score of 70).
- Receiving a limited service with unmet needs
 - People who are receiving a service from Disability SA, such as advice or case coordination, but require additional higher cost and in-demand services such as accommodation support or respite.
 - People who have some or all of their services provided by families or carers who have been disillusioned with the quality of disability services in the past, and have chosen to provide their own care when they can.
 - People who are receiving a support service, but need increased professional input (e.g. psychological assessment and recommendations about behaviour management).
- Receiving a service from Disability SA, but not from other providers
 - People who are receiving Disability SA services, but are not effectively accessing general health or mental health services for the treatment of associated conditions to the same extent as would people without a disability for the same conditions.

As noted above, it is not possible to accurately compare prevalence data and service data, but in so far as a comparison can be made, it would seem that the number of people with an intellectual disability which severely or profoundly limits their activities is of similar magnitude to the number receiving services. The proportion of people accessing services in this group would be higher than for disability services overall but there is still a significant number of people in the population who might benefit from a service and are not accessing it. More frequently, even though a person’s need for a disability service is recognised, it would seem that a gap remains in the level of services funded.

Acquired brain injury.

Significant factors related to brain injury include:

- The need to begin services soon after injury
 - Rapid assessment and quick decisions about eligibility are required to ensure need is met.
 - Following an acute injury there is a critical time soon after release from hospital where services are needed to maximise recovery.
- Recognition of changes in planning skills, motivation and mood for people who retain the ability to undertake daily activities
 - After people have recovered from the initial period of severe physical disability and cognitive problems, a person may be able to complete daily living tasks, but still be troubled by tiredness, limited concentration, difficulty in planning, mood changes and irritability.
- Uncertainty about the “permanent or likely to be permanent” eligibility criteria
 - This can apply to patients who have a focal injury and are making improvement who in the medium term have the potential to make a significant recovery but need services in the short term to leave hospital.
 - It also applies to individuals who have substance-induced brain damage, who might remit if able to abstain from alcohol or drug use.

In South Australia, the concern from families of people with a brain injury intensified with the reorganisation of Disability SA services in 2007. Previously there were different government agencies providing and brokering services — in particular, Brain Injury Options Coordination. In 2006–2007 Disability SA was formed with the aim to implement a single entry for disability services, a single system of case management, standardised assessment of client needs, and unmet needs registration (Department of Families and Communities, 2007).

In evaluating the impact of the reorganisation, it should be possible to compare key variables for service delivery for people with brain injury, such as waiting time, nature of the service delivered, and number of hours of support provided. The benefit to people who have brain injury as one of multiple disabilities that require support also needs to be considered.

Autism spectrum disorders.

The 2003 vs. 1998 comparison demonstrated the dramatic increase in the number of people identified to have autism spectrum disorders over the previous 5-year period, 100% for all of Australia. This pressure has been noted in South Australia for services for both children and adults. Recently the Australian Government has allocated extra funding to provide additional services for children with autism.

In South Australia, services have struggled to meet the demand for care required by both children and young adults with Asperger's syndrome, an autism spectrum disorder. Special arrangements are made to fund services for individuals through the Exceptional Needs Unit. A problem that was previously either not recognised or was less common, now needs a systemic response. The Coroner in his finding of 3 December 2008 on the death of Rowan Wheaton recommended that the Minister for Disability consider a model of service delivery prepared by two key professionals, Jo Zeitz and Jenny Curran, titled "Asperger Youth: Pathways to Better Outcomes", and implement this or a similar model. Critical elements of this model include a focus on the 16–25 age group, and a focus on early intervention to avoid future deterioration, which will benefit the consumer and limit the need for Exceptional Needs Unit involvement. A response to this is still awaited.

Overview of service data and funding

The pattern from the above suggests that:

- Overall, South Australia is reaching more people who have a disability than any other state except Victoria, and provides supported accommodation services to more people with a disability than any other state.
- In order to achieve this result, each person is receiving less funding than those in other states, suggesting that a significant component of the unmet need comes from people who are recognised as requiring a service, who are registered with a provider, but are not receiving the optimal level of services.
- In so far as comparisons can be accurately made using publicly-reported summary data in South Australia, when community prevalence data and service provision data for people who have an intellectual disability are compared, the result would suggest that many but not all people with severe or profound limitations who require assistance are in contact with disability services in this state.
- More work needs to be undertaken to understand the access patterns for people who have disabilities caused by other conditions. In particular, access and eligibility for people with a brain injury require further analysis and ongoing monitoring.
- Population-based work has identified the increased number of people with autism, both children and adults, requiring services. The experience of people with this disability and their families would suggest that services have been struggling to keep up. While there have been recent initiatives for children, a systemic response is still required for adults with an autism spectrum disorder.
- Future unmet need work is an ongoing function of the Department of Families and Communities, but at times departments commission external bodies to undertake external analyses. Should this occur, the Office of the Public Advocate is available as an independent body to oversee such work.
- Under its charter of monitoring unmet need, the Office of the Public Advocate will continue to review service-use statistics and link these to the experiences of consumers and carers.

Individualised funding as a mechanism to improve outcomes and cost effectiveness

Individualised funding allows a person to make decisions about which services they purchase and from whom. The following discussion is based on a population assessment of need. The process of individualised funding requires a needs analysis for each person receiving a service.

Stainton (2008) puts forward the following working definition:

...funding allocated directly to an individual or in the case of a child their parents or legal guardian, to provide the support necessary to meet disability related needs and to assist individuals to become contributing citizens. It has two fundamental characteristics:

The amount of funding is determined by direct reference to the individual and/or family's specific needs, and aspirations;

The individual and/or their family determine how funds are used to meet those needs eligible for funding.

In South Australia, there has been broad support for individualised funding models from consumer and advocacy groups. The Julia Farr Association has led the discussion and worked to ensure that the disability community and policy makers are well informed of the evidence for individualised funding, preparing key reviews that have guided the policy discussion (Williams, 2007) and maintaining a reference base on individualised funding².

There are now clear examples of the effective implementation of individualised funding providing better outcomes for individuals and families, greater self-determination, and cost-effective support service provision.

This mechanism can go hand in hand with the reform of guardianship systems, in line with the United Nations Convention on the Rights of Disabled Persons, to support more people to make their own decisions rather than appoint a substitute decision maker. This is described in more detail in the section on monitoring legislation and determining capacity.

For people with an intellectual disability, brain injury or neurological disease, support to make decisions may be necessary so that they can get the most benefit from an individualised funding system and can exercise their right to choose services and providers from the funds allocated to them.

Stainton (2008) has described the transition in British Columbia in Canada. To a large degree it has moved from a system where government social workers acted as “both gatekeepers and support workers to families and helped them access a range of direct government and contracted agency services” to one where the entire system has been devolved to a government agency with a board appointed by a Minister. Stainton (2008)

² Julia Farr maintains a repository of information on individualised funding on its website – www.juliafarr.org.au

considers the key to this system has been the separation of planning and support functions from decisions about eligibility and funding.

In Australia, there have been positive results from the evaluation of a local area coordination system applied by the Disability Service Commission in Western Australia, and of trials of individualised funding in Victoria (Laragy, 2008).

A recent review jointly commissioned by the Queensland Office of the Public Advocate, the Queensland Adult Guardian, the National Disability Services and the Queensland Mental Health Branch has reviewed progress across Australia, identifying a range of approaches to individualised funding with no single model standing out (Chenoweth and Clements, 2009). However, within the spectrum of models some give more control to the consumer than others, while some appear to be individualised but in reality do not conform to the principles of individualised funding. The review also describes a transition in quality control approaches with service users taking a greater role in determining the quality of services.

It should also be noted that just because a consumer has chosen a service, this is not in itself a protection from poor quality, errors or for that matter abuse. The need remains for protections such as quality assurance programs (based on the same quality approaches that are used in private and public industries) and abuse protection programs such as community visitors.

A recent major evaluation of individualised funding — the Individualised Budget Evaluation Network (IBSEN) — based at York University in the United Kingdom was completed and reported in October 2008. The results of this research of 959 service users across 13 different sites were mixed. The project was rigorous in that it was a randomised trial with individuals allocated to either individualised budgets or standard services. However, the period of follow-up was short, just six months, and in that time a number of people with more complex needs had not established their program. The outcomes for younger people with physical disabilities were promising — people with individualised budgets reported higher quality care and greater satisfaction. For people with “learning disabilities”, those receiving individualised budgets were more likely to be reported as not being fully occupied compared to people receiving a standard service, and to have lower levels of health, although there were no differences in physical functioning. Different results were obtained when people who needed proxies to speak for them (usually relatives) were excluded, and results were only analysed for people who could speak for themselves. People who had a learning disability received a median weekly value of funding of £250 per week. Mental health service users received a median payment of £150, which was more than many would have received through standard funding.

Older people on individualised budgets had lower psychological wellbeing than those in the comparison groups, and many older people were reported as not wanting the added burden of planning and managing their support. Mental health service users overall did well with a higher quality of life, with users reporting an ability to access more appropriate support. These and other details have been published in a summary report of the trial (Glendinning et al., 2008).

These mixed findings need to be treated with caution. Direct funding in some form has been available for many years in the United Kingdom, and a number of people in this evaluation in both the individualised budget and control arms had past experience of direct funding.

Also, the 6-month follow-up time was brief, as evidenced by some people who were yet to fully establish their programs in that time. In addition, individualised funding coordinators had to work with four different funding sources.

In summary, individualised funding as an approach can be effective — it gives control to the person who is receiving services and decides which service is received. The mixed results from the most recent United Kingdom trial should not act as a deterrent, given the previously described general benefits from this approach in different parts of the world (Williams, 2007). Like any new program, when individualised funding operates in Australia, it will need to be continually developed and refined. As we inevitably move towards individualised funding, careful evaluation will be needed to maximise the benefit in our Australian setting and permit this refinement.

Conclusions

Overall:

The information above predominantly considers unmet need. A debate that focuses on unmet need as a funding issue alone will inevitably be insufficient.

It is not the role of the Office of the Public Advocate to put forward policy options and plans; however, flowing out of the review process, suggestions can be made.

The recently ratified United Nations Convention on the Rights of Persons with Disabilities can be used as a trigger to develop a rights-based rather than a welfare-based disability system. To achieve this, a transition in service aims, design and planning is required.

Below are a set of suggestions derived from the discussion in the review, legislation and advocacy sections of the report. It suggests a combination of legislative and funding changes to bring about the desired outcomes.

Holistic approaches are commonplace in service reform so this proposal is not radical. For example, in the sphere of mental health, South Australia has reformed both legislation and service planning at the same time.

The delivery of services is a human rights issue, not a welfare matter³. Services exist to allow people to fulfil their potential, not to set limits on what they can do if someone else chooses the services that are available to them. Legislation can set the approach.

This could set a new path driven by individual rights for people with an intellectual disability, brain injury, or neurological disease. Components would include:

- Law reform of both the *Guardianship Act 1993* and the *Disability Act 1993* to reflect the UN Convention. (Possible *Guardianship Act* changes are discussed in the section of this Report on monitoring legislation).

³ This point is made by Chenoweth and Clements (2009) in setting the case for individualised funding.

- A reformed *Disability Act* could legislate for individualised funding, as well as how eligibility for services is determined, and provide mechanisms to ensure the ongoing quality and safety of services.
- A new Act could also incorporate an appeal mechanism for people who are considered ineligible for a service who wish to appeal their eligibility for services through a relevant tribunal.
- A senior professional role such as “Senior Practitioner” could drive service standards broadly as well as limiting restrictive practices (see section of this Report on adult protection).
- A population-based funding formula could be implemented to ensure that there are sufficient funds in the pool for an individualised funding budget. Such an exercise should be transparent, and either undertaken or reviewed externally, for example by the Office of the Public Advocate.

Individualised funding as a further catalyst for change

The malaise of disability systems Australia-wide has been well documented, most recently by the Commonwealth’s Shut Out Report.

Individualised funding can return decision making about need to the person using the services. These systems constructively separate planning service interventions and the making of choices about different options which are roles for consumers and carers, from the decisions about eligibility and funding entitlement.

The process of determining resource allocation for each individual is in essence a needs analysis for that person, which can also be used to quantify any residual unmet needs after an individualised budget is allocated and services purchased. Information calculated on unmet need for each service user can be summed to give a more accurate estimate of the entire level of unmet need for all service users.

Reviewing Programs and Identifying Unmet Need

Mental Health Services

Introduction

Reform of mental health services in South Australia is comparatively more advanced than reform of disability services with new legislation and an across government plan.

The policy settings and strategic direction for mental health services have been determined through the Social Inclusion Board's review and consultation about South Australian Mental Health Services that was published in early 2007 (Social Inclusion Board, 2007). Legislative reform has been achieved with the passing of the new Mental Health Act 2009.

The Social Inclusion Board review was well received and there has been little public, scientific or political debate with its recommendations and directions. After a period of uncertainty in the mental health sphere following the death of the Director of Mental Health Margaret Tobin in 2002, the Social Inclusion Board Report has provided a clear direction forward, not only for the South Australian Department of Health, but also across government.

The report made 41 recommendations. It proposed a stepped system of care with community mental health at the centre, as well as a focus on prevention and early intervention and other strategies.

This is summarised diagrammatically in Figure 4, which has been reproduced from the report.



Figure 4. A stepped model of care (reproduced from the Social Inclusion Board Stepping Up Report, 2007)

The review of programs and unmet need for mental health services can be considered in the context of the Social Inclusion Board Report — in particular, the Government's response to the Report, and how it is implemented.

The Social Inclusion Board Report carefully analysed data and identified key areas to intervene in the system to create change. One area is the response to people with complex needs who frequently re-present for acute admission. The service system should identify these people and provide a coordinated response. A second area is the response to people presenting early in their illness, where the provision of effective treatment can potentially reduce future illness and disability.

The Department of Health has produced a number of key documents as part of the process of implementing the Report including an Adult Community Model of Care for mental health services in metropolitan Adelaide (Department of Health, 2009a) and a proposed Mental Health Policy for South Australia consistent with the Stepping Up Report (Department of Health, 2009b).

Critical success factors of implementation will include:

- The effectiveness of early intervention provided by the system
- The impact of improved care for people who have chronic and complex needs
- The reform of community mental health as the driver of the system
- The effective use of intermediate care facilities — the new community-based beds that will be available for people in crisis, and will increase the number of beds overall for people in need of care.

At this time, the response to reform in these areas is very much a work in progress.

On the ground, the most noticeable changes to the system are related to new or additional services rather than changes in existing services:

- A greater access to non-government support services so that it is now quite common for people with significant illness to have a rehabilitation worker visiting daily to provide support in the community. In the past, many of these people would have been fending for themselves in between less regular visits by clinical staff.
- The operation of three community-recovery centres in the south, north and west of the city that admit people for 3–6 months for residential rehabilitation.
- Improved inpatient accommodation with the opening of newly constructed units for adults and older people.

There is progress in implementing the Report, but at the service delivery level, much has still to change. Stepping Up said that South Australia must fast track the development of a response to first- episode and early psychosis, sited and managed as a specialist service. This service has only just started in mid-2009, so understandably clinicians report little change in the way that first-episode illnesses are managed in our clinics generally.

Similarly, while work has occurred to identify people who have complex and chronic needs, at the coalface the response has not significantly changed, although the greater availability of non-government services in itself has made a positive difference.

The Government allocated \$1.47 million for improvement work to redesign how our system responds to this group. This will not only benefit the people themselves, but also reduce the avoidable use of emergency services that results as people present repeatedly if necessary follow-up is not available. This is another work in progress. The principal response for adults with high needs continues to be by existing mobile assertive care services, which have a limited capacity and only operate in metropolitan Adelaide.

One area that is of particular concern is progress towards improving the system's response to Aboriginal people.

Aboriginal people are overrepresented in our mental health services. The Social Inclusion Board noted that 9% of community mental health service users were Aboriginal people, compared to 1.8% of the population. At any one time, 3.8%–7.0% of beds are occupied by Aboriginal people (Social Inclusion Board, 2007).

There are many different reasons for this. However, a significant observation of many practitioners is that many Aboriginal people do not access early intervention. They are seen late when illness is established. The solution is not just increasing availability of acute services, but making it possible for Aboriginal people to access a service early.

Yet speaking with Aboriginal people who are either consumers or their families, it becomes apparent that it can be very difficult for them to access services, whether they are living in regional areas or the city. Even when an acute admission has been provided, ongoing therapy, counselling and regular follow-up can be difficult to obtain and the result can be further admissions. This creates anguish for both consumers and their families, and ongoing risk.

Throughout the state, there are many examples of innovation and development. This reflects the work of staff and community members working in both mental health and Aboriginal health, by service providers outside of mental health (for example the operators of accommodation services) who have a broad interest in seeing the mental health needs of clients addressed.

In a number of regional areas the benefit of better links between local Aboriginal health services and specialist mental health services are having a positive effect. In some instances new specialist resources have been provided with allocated funding — for example in northern suburban Adelaide, where new services were funded in 2006 — and have quickly established a significant role in meeting a hitherto unmet need.

This good work needs to be acknowledged. The gaps, however, are significant. This is not a reflection on the good work of the local services that are developing initiatives. Rather to tackle this, in addition to these local initiatives, the Social Inclusion Board wanted to see leadership at the highest level to progress better mental health for Aboriginal people, and the provision of a state-wide specialist service.

There is no reason at this time to suggest that these recommendations were incorrect, and in fact, every reason to see how these recommendations could act as a further catalyst for progress across the state at this time.

The remainder of this review focuses on one aspect of this reform — access to long-term beds, as our system shifts to a stepped model and the provision of forensic mental health services. The implementation of the stepped model will now be affected by the delay in the construction of Glenside Hospital announced in the Mid-Year Budget Review, with completion anticipated in 2013–14, extended from the original completion date of 2011–12 (SA Treasury, Mid-Year Budget Review 2008–09) which prolongs the transition phase of reform.

Access to medium- and long-term mental health beds in South Australia

Independent monitoring of the reform to supported accommodation and long-stay beds will be an ongoing role for this Office under our program review and unmet need functions. The closure of long-stay beds and the provision of modern supported accommodation and rehabilitation services can offer new opportunities for people with mental illness to live a more fulfilling life. Needless to say, it has to be done properly. With the right level of support and sufficient access to rehabilitation and treatment, it can work very well.

The difficulty is that the term “supported accommodation” encompasses the whole gamut of services ranging from a care worker dropping in a couple of times a week, to high level supported accommodation with 24-hour on-site supports that are designed to assist people who have complex needs, and in the past might have been admitted to a long-stay hospital bed. It is the needs of this group that are particularly considered in the following discussion.

It is necessary to be very precise about what is being described. There is a broad community need for supported accommodation for people with mental health problems. For example, Andrews et al. (2006) from the World Health Organization Collaborating Centre for

Classification in Mental Health made the following calculations in their influential Tolkien II report. This estimates the community support requirements for 15 adult disorders.⁴

Stepped Accommodation (Tolkien II)	Mean Length of Stay	Beds per 100, 000	Beds for South Australia
Acute Beds (not including some additional crisis beds not costed in the model)	7 days	10	162
Rehabilitation Beds	180 days	8	130
24-Hour Supported Accommodation	2 years	17	275
Visited community accommodation		34	550

Table 5 Estimates of 24-hour accommodation and visiting support

The Andrews et al. model provides for less acute beds, but considerably more rehabilitation beds and 24-hour supported accommodation than is planned in South Australia. There are a number of reasons why models vary, including definitions of psychiatric disorder. For example, whether or not harmful alcohol use is included amongst the conditions covered and how dual diagnosis with other disabilities is considered.

The additional beds in South Australia in the stepped model represent the needs of a core group of people who previously may have been admitted to Glenside who need accommodation with good quality 24-hour support. It should not be confused with other accommodation types — such as the “visited community places” where NGOs regularly visit a person’s home but are not constantly present. The latter are generally cheaper but can fail to meet the needs of the most complex and disadvantaged groups, including those people who in the past might have lived at Glenside.

Prolonged waits in acute hospital beds

It was not uncommon during 2008–2009 for people in need of a long-term mental health bed or supported accommodation to have prolonged stays in acute hospital psychiatry wards while waiting for eventual placement. Some patients waited on medical wards. People could wait for months and be in an acute ward for 6–12 months or longer.

A statistical analysis of the duration of stays has not been completed for this report. The Office of the Public Advocate has raised this matter, and is aware that the Department of Health has been active in identifying people who are waiting in acute beds for other services. Our Office has not requested data to undertake an independent analysis at this time. However, on most occasions when visiting acute psychiatry wards it was not uncommon to be advised by ward staff that at least two, sometimes more patients (up to five), were waiting for an extended period for either a long-stay bed or community supported accommodation or alternatively had “revolving door” admissions through lack of suitable accommodation. For most of these patients, admission to a long-stay ward was an option under consideration.

⁴ Andrews et al. (2006) derived their estimate by considering the needs of people who have the following conditions: Major depressive disorder, Bipolar Disorder, Panic Disorder with agoraphobia, Social phobia, Generalised anxiety disorder, post traumatic stress disorder, harmful alcohol use, alcohol dependence, schizophrenia, anorexia nervosa, bulimia nervosa, neurasthenia, obsessive compulsive disorder, and borderline personality disorder.

These long waits have been a feature of the South Australian mental health system for some time, so without a statistical analysis it is not possible to confirm whether the problem is now worse than in previous years. Many clinicians believe that this is the case, and irrespective of the numbers, there are new reasons for people waiting related to the transition to new services.

Before considering this further, it is worth recapping on the reform.

The stepped model for 24-hour care is illustrated below in a diagram (Figure 5) that includes the existing beds in the system (Stepping Up Brochure, 2007). As already noted, the number of secure extended care beds was subsequently increased to 40.

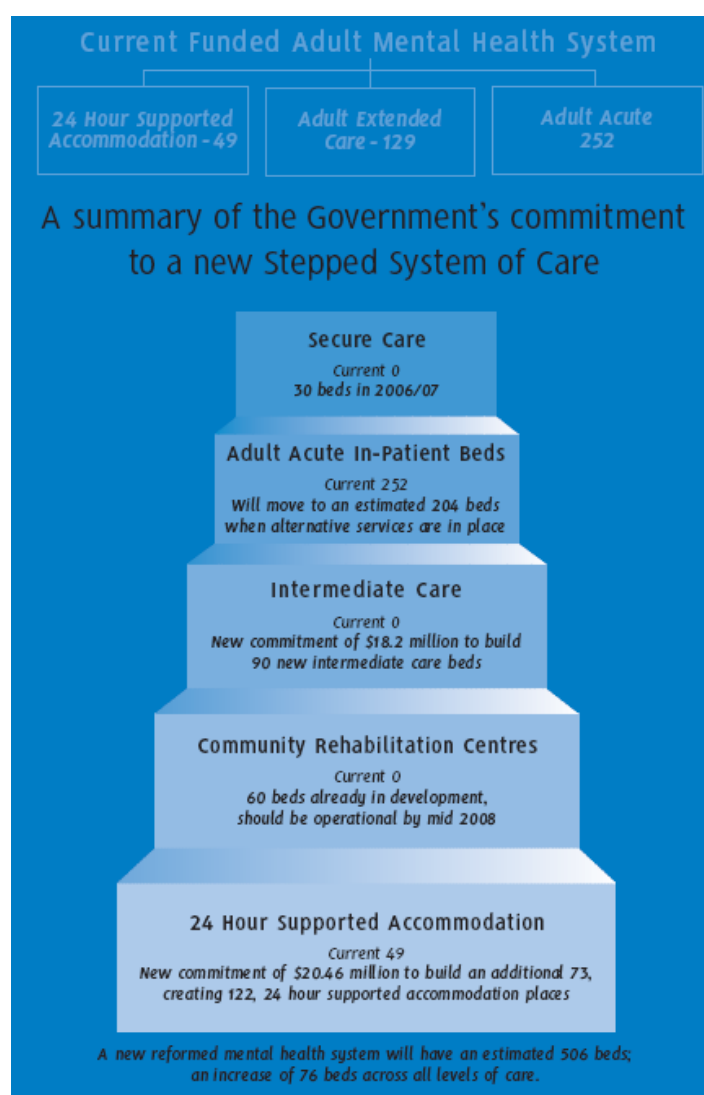


Figure 5. Stepped System

The process of transition to the new model that focuses specifically on the longer-term bed components of the stepped model is tabulated below.

Medium to Long Term Mental Health Beds	Pre-existing prior to reform	Mid-2009	Estimate for Late 2009	Completion of reform
Traditional “extended care” beds	129	60	~40	0
New Secure Extended Care	0	0	0	40
Community Recovery Centre	0	60	60	60
New 24-hour supported accommodation	0	0	Work commencing	73
TOTAL	129 beds	120 beds	100 beds	173 beds
Additional intensive community support. (Not 24-hour support) “Returning home”	0	50	Expected to be 80	Transition funding to be ongoing added to the pool of NGO funds.

Table 6 : Transition in long term bed numbers (figures for the eventual final number of beds obtained from Stepping Up brochures, Government of South Australia, Feb 2007, June 2007, August 2007 and updated brochure April 2008) 2009 estimates have been made by the Office of the Public Advocate based on information obtained in discussion with officials and clinicians.

Each of the steps is explained more fully in the Social Inclusion Board Report.

Just prior to reform, there were 129 long-term beds at Glenside Hospital. People in these beds included some patients who were long-term residents of Glenside and others who were admitted for treatment and rehabilitation for shorter periods ranging from 3–12 months.

Some long-term patients were admitted to Glenside in the past when an intensive community support service of the type that is routinely available now was not available. People in this group now can live in the community assisted by non-government rehabilitation workers. These services have been provided as part of the “Returning Home” program.

The ability to do this reflects advances in our understanding of rehabilitation and recovery, more effective treatments including better medication for people who in the past had conditions that were considered “treatment resistant”, and the expansion of NGO funding in the state. People in this category may be visited once or twice a day by a care worker, who can spend a number of hours with the person. This is in addition to visits by clinical staff.

The success of this program is still to be evaluated — however, the anecdotal reports from clinicians and rehabilitation workers have been generally positive. There have been success stories of people flourishing and establishing new lives, who previously could not do this in institutional life. There are other instances where people at least initially have needed repeat acute ward admissions when first discharged, but then eventually settled. There are also some people originally considered for the Returning Home program, where the provision of a few hours’ support per day is insufficient, and 24-hour support will be needed.

Within the new 24-hour model of care, the stepped system will have available:

- Supported accommodation with 24-hour staff availability.

This caters for people who might have previously lived at Glenside either for a few years or indefinitely.

To do this, independent units generally need to be clustered together so that it is efficient to have staff available 24 hours a day. These are the 73 additional 24-hour places described in the Government's Stepping Up response.

- Community recovery centres with 24-hour on-site care

These three 20-bed units are catering for people who otherwise would have been admitted to Glenside for rehabilitation for a shorter period. All three are now commissioned.

- Secure extended-care ward

This is the more traditional hospital environment providing higher-level care. This increases the number of longer-term beds with security and clinical care.

Also within the 24-hour category are Supported Residential Facilities (SRFs,) although they are not counted in the scheme above, as it focuses on more intensive 24-hour support options that would replace the role of the former psychiatric hospital beds. The level of support in SRFs is considerably less than this. There is a small daily subsidy to the proprietor with a few hours of additional non-government support available to residents. The Department of Families and Communities has now established an SRF intake team one function of which is to ensure that people are not placed into SRFs who need higher levels of support. In the past the inappropriate placement of people in SRFs leading to sequential evictions has been a significant issue.

Transition difficulties associated with the implementation

All levels of care in the planned system provide 24-hour on-site support by either a care worker or a nurse, depending on the nature of the support required.

People who would have otherwise lived at Glenside would be catered for in the 24-hour supported accommodation.

People who might require rehabilitation would receive it in the community at one of the community recovery centres, offering 24-hour oversight and rehabilitation by professionals.

People who need a higher level of clinical care would be admitted to a secure extended-care unit for intensive treatment. These are different needs. While it is possible that the same person may require all three steps at different stages of their illness, at any given time different people will require different care.

This is the origin of the current concern. As can be seen by the tables above, after two-and-a-half years into the five-year program there has been excellent progress at opening the community recovery centres. There are now 60 places available and this need is arguably

better catered for than it was in the former system. This comment of course is an impression and a formal evaluation will be needed to draw an objective conclusion about the outcome. Clinicians advise that these centres admit people who might have previously been referred to Glenside, but are also accessed by a wider section of the population. Clinicians express frustration that many of their patients with high needs are not considered suitable for these centres.

At issue is access to longer-term hospital beds or supported accommodation for people who may not be suitable for admission to community recovery centres.

Secure extended care is a significant component of the stepped model. The further two-year delay in its construction and operation will defer the implementation of the overall stepped model. As is the case now, people who would ideally be admitted to secure extended care will continue to be admitted to acute wards — to both the closed and open sections of these wards.

Similarly, people who need supported accommodation will also wait, as although these new 24-hour beds are to be fast tracked, none of the purpose-built 24-hour supported accommodation centres as part of this program have come on line. (A recent positive development, however, was the opening of 12 supported accommodation beds at Catherine House which was announced as accommodation provided by Housing SA.)

The remaining current Glenside beds are generally full. The number of acute beds in our hospital system is determined on benchmark calculations that assume that there are sufficient long-term beds in the system. If this is not the case the effect of just two or three patients on an acute ward who need long-term care can be significant. (Because the average length of stay in an acute bed is usually 14 days or less, each bed would be used by about 26 people a year. Therefore, for each bed used for long-term purposes on an acute ward, 26 people need to be either squeezed into the remaining beds or may not get an inpatient service.)

Potential response strategies

The above problems are mostly issues of timing. Because one service is being closed and replaced by another, it does not make sense to close beds unless replacement services are on line.

It would also seem that the people with high and complex needs are bearing most of the burden of the transition at the moment, because their access to any sort of 24-hour care is limited, particularly compared to what it will be at the end of the reform. Conversely, the people who need rehabilitation admissions are now better served.

As ongoing decisions are made, the following could be considered as strategies:

- To only close long-stay beds at Glenside, as newly constructed 24-hour supported accommodation facilities come on line to replace them.

This is arguably more important when the last 60 remaining beds are closed than when the first 60 were closed as the first group would have included more people who could be catered for with community NGO supports or receive alternative care at community recovery centres than the remaining group.

- To rigorously define which supported accommodation beds are part of the count for stepped supported accommodation and which are not.

This can make it clear then which beds are the replacement for the Glenside beds (building costs funded by the \$20.46 million commitment as part of Stepping Up, and recurrent costs funded by money formerly allocated to Glenside) as opposed to other supported accommodation, which may not target the same group with complex needs.

- To acknowledge the significant long-term role currently undertaken by acute wards when reviewing acute bed numbers prior to the opening of secure extended care.

There are planned closures of acute beds when intermediate care facilities come on line. These closures are predicated on the assumption that all these beds are currently performing an acute role.

This is not our experience — we know of patients staying 3–18 months in acute wards. At times there are possibly 15–20 acute beds at any one time across the state being used for long-term purposes or for patients quickly readmitted soon after discharge through lack of supports (based on estimates by hospital clinicians, not a formal audit).

Therefore, some of this bed capacity may need to be kept open to cater for this need, in addition to the current planned acute bed numbers.

As 40 secure extended care beds are planned for that unit, while waiting for that unit to come on there should be 40 functioning secure extended-care type beds operating in South Australia, whether they operate from the Glenside campus or are scattered across acute units at other locations.

MGH - OPA — Country Health Partnership Project

To assist its function of reviewing programs, the Office of the Public Advocate has formed a number of strategic collaborations with academic institutions, consumers and providers. This year Dr David Grelotti, a psychiatry resident from the Massachusetts General Hospital International Psychiatry Division in Boston and a clinical fellow of Harvard Medical School visited South Australia in February.

His project was to observe how people who have a dual diagnosis (mental health and substance use disorders) are treated in country South Australia. Dr Grelotti visited mental health consumers and practitioners in regional and rural South Australia during his four-week visit, during which he learned about our State's mental health services. His focus was on plans to improve services for people who have both a mental health and substance use disorder. This project work was done with excellent support and collaboration from Country Health SA, staff and country consumers. His observations will be fed back to consumers and practitioners in country SA who assisted with the project.



Dr David Grelotti, Visiting Fellow to the OPA from Boston.

Reviewing Programs and Identifying Unmet Need

Protecting Vulnerable Adults

In South Australia, as in other states, the need to improve the protection of children has been a high priority. The Mullighan Inquiry in South Australia (Mullighan, 2008) has recorded the tragic impact of the failings of our child protection system over decades to protect children who have relied on the protection of the state.

How do our systems for the protection of vulnerable adults fare in comparison? How will our successors look back at the legacy of the work that we do now? The Mullighan Inquiry has documented the experiences of children with a disability who have come forward to the inquiry as adults and described their experiences in South Australian institutions for people with disability.

We know that people aged over 18 in these places suffered similar traumas, and because of their disability were just as vulnerable as the victims under 18 but the process of documenting this has yet to occur.

Unfortunately, many vulnerable adults never tell of their experiences. There is a noticeable difference between the information that has emerged about our past failings in child protection, and what we have learned about adult abuse.

The position of this Office on this topic can be summarised as follows:

- The extent of abuse and neglect of vulnerable people in the past and occurring now remains unknown.
- South Australia does not have many of the basic protection mechanisms in place for vulnerable adults which are present in other jurisdictions in Australia.

If it seems that we have fewer public reports of assault, abuse and neglect of vulnerable people than other states, it would be unwise to assume that this is because our services are intrinsically safer. This is more likely to be due to the fact that we do not have the same range of strategies in place to ensure that people can safely come forward with their reports, that incidents are detected, and police advised.

- There is a need to broaden the responsibility across health and social service providers for adult protection.

Across Australia, guardianship is seen as the principal response to adult protection concerns. In other countries that have approached this problem with a broader focus on adult protection, a greater range of responses is offered to protect people.

The types of protection that may be needed for vulnerable adults include:

- Protection from abuse and neglect by service providers
- Protection from abuse and neglect by family and community members
- Protection from abuse by fellow service users
- Protection from systemic failures in the safety and quality of health and social service delivery.

The last point is a broad category. There is a “growing concern” in Australia about the safety and quality of health care (National Health and Hospitals Reform Commission, 2008). This is avoidable harm — such as wrong procedures, medication errors, failure to recognise that a person’s condition is getting very serious, failure to arrange follow up, etc. Failure at times can lead to injury or even death. Avoidable harm will disproportionately fall on the population with disabilities who are more likely to require health care services, and then be at greater risk while accessing them. Whereas health consumers generally are encouraged to challenge and speak up if they believe that there is a potential difficulty, people with a disability may not be in a position to recognise a problem, or if they sense that something is about to go wrong they might struggle to communicate the problem, at times not be listened to, or not be able to request a second opinion. These are ongoing concerns for people with a disability and their advocates in South Australia.

Protection Strategies in other Australian jurisdictions that could be further developed in South Australia

Key adult protection mechanisms available elsewhere in Australia but not in South Australia are community visitors schemes, policies of mandatory reporting of serious physical assault and sexual abuse, effective professional, technical and regulatory inspections and the provision of forensic disability services.

Community visitors schemes

In South Australia, there has been long-standing advocacy for Community Visitors Schemes for the key sectors of disability accommodation (institutions and small group homes in the community), supported residential facilities (rooming accommodation that provides additional support for people who have a mental illness or other disability) and psychiatric inpatient settings. Recently Parliament legislated to establish a Community Visitors Scheme for one of these sectors — psychiatric wards under the *Mental Health Act 2009* — but there are no plans as yet for the disability and supported residential sectors to be provided with similar schemes.

Community visitors open up facilities to general community standards and expectations. As people have moved from institutions to live in small homes with 4–5 other people, new issues can develop. Just as there was a need to have a transparent opening up of practices in the large institutions of the past, the need remains in community settings to ensure that people remain safe in their new accommodation scattered throughout the suburbs.

In these settings, community visitors can get to know residents and can gain their trust. Because the same visitors will return on a monthly basis, residents develop trust in their visitor and know they are less likely to experience retribution if they raise concerns. The visitor can check that matters have been followed up, and that the resident has not been disadvantaged in some way because a visitor has spoken up or initiated action on a resident's behalf.

While difficult to objectively prove, it is reasonable to assume that in some way this transparency and openness can prevent serious abuse, as well as attending to other rights matters. It is important not to overstate this benefit, as abuse can still occur even when there is ongoing contact between a vulnerable adult and other adults who know them well. However, it is better to have the openness than not have it, and predators will find it harder to conceal criminal behaviour in an open environment than a closed one.

Adult protection needs multiple strategies. Another is a regime of mandatory reporting in disability services. Just as we do not have community visitors, South Australia does not have mandatory reporting of sexual assault and serious physical assault. New South Wales and Victoria do.

Mandatory reporting of abuse in government-operated and funded residential settings

Mandatory reporting has been controversial. It can be argued that if citizens generally have a right to either report or not report a matter to the police, then the same right should be afforded to a person with a disability. Nevertheless, the protection afforded by mandatory reporting has been introduced elsewhere in Australia in response to the high rates of both physical and sexual assault experienced by people with disabilities, and the reality that a person with a disability living in residential care may be so disempowered by their circumstances that they are unable to effectively exercise their right to report a matter to the police. (In aged care the Commonwealth has a mandatory reporting requirement in nursing homes.)

The Victorian policy “Responding to Allegations of Physical or Sexual Assault” (Department of Human Services, 2005) requires that:

All allegations of physical or sexual assault as defined for the purposes of this document must be reported to the Police, whether or not the victim has consented to the matter being reported.

The document then goes on to describe the “category one” and “category two” incidents of assault that require a report, and lists exceptions such as minor incidents, for instance when there is shoving between clients.

South Australians living in Disability SA accommodation, or in government-funded accommodation (such as non-government supported accommodation and supported residential facilities) should be protected by a mandatory reporting policy.

Further discussion is needed about what responses should be for people supported in their own home. The response is more likely to be one of offering assistance to individuals to take the matter to the police.

Effective professional, technical and regulatory overview

While community visitors might offer certain safeguards, visits by professionals for accreditation purposes, or by regulators to ensure that relevant legislation, regulations, standards or guidelines are followed are necessary complementary processes. Foundation stones to avoiding abuse include good facilities that provide space and privacy, effective care planning that is mandated in legislation and closely scrutinised, and the operation of senior professional roles setting standards and leading best practice.

With respect to Disability services, the Office of the Public Advocate is yet to formally review the adequacy of existing legislative and supervisory regimes, so it would be premature to draw conclusions about what changes might be required.

However, it would seem that review and modernisation of relevant legislation in this state (in particular the *Disability Act 1993* and the *Supported Residential Facilities Act 1992*) could provide added protection to community members affected by this legislation, by offering tighter provisions to protect their health and safety. Legislative change could act as a catalyst for more general reform in each of these sectors, enhancing protection for individuals, and improving outcomes.

What is evident on preliminary review is that the South Australian *Disability Act 1993* is minimalist in comparison with the more recent Victorian *Disability Act 2006*, which sets out in considerable detail the requirements for establishing care plans for individuals, and the responsibilities of operators of residential facilities towards people who have a disability. The Victorian Act, as well as establishing a Community Visitors Scheme, also provides for the Office of the Senior Practitioner in Disability who oversees the use of restrictive practices, providing an additional safeguard against abuse when restraint or seclusion is required.

With respect to supported residential facilities, a regulatory framework is in place in South Australia. (The *Supported Residential Facilities Regulations 1994* were replaced by new (substantially similar) regulations as of 1 September 2009. These regulations seem to provide limited protection for the health and safety of residents in these facilities. Key areas include privacy, space and personal safety. Lack of these can make people more vulnerable to abuse. In addition, the nature of the environments is not always conducive to good physical health, creating additional risks — for example, through lack of air conditioning on hot days, or the provision of palatable balanced meals to residents in some homes.

This Office is now reviewing the impact of the regulations, and is yet to draw a conclusion on what needs to change. We are aware of significant instances of individual risk but do not have the same breadth of information available to interstate Public Advocates who can access the intelligence gathered by community visitors. With respect to our current South Australian legislation, there are divergent views in the sector. One view is that the current regulations are adequate and require more intensive enforcement. Another is that the regulations could be more stringent, and additional resources invested in enforcement in a consistent way across the state. It is also possible that some of the deficiencies that detract from the health, safety and wellbeing of residents in supported residential facilities may never be addressed by periodic regulatory enforcement alone, and require regular observation and intervention by community visitors.

Forensic disability services

South Australia does not have designated forensic disability services. While forensic issues are the exception for people with a disability, there are always a small number of people with disabilities who due to behavioural disinhibition, irritability and poor judgement can become a risk to others — often fellow residents in homes and institutions.

Our state would benefit from a forensic disability unit that could provide specialist support to people in the community, as well as operate a small residential facility to provide intensive supervision and care.

While this topic might be considered elsewhere in this report, it is placed in this section under adult protection, because the provision of effective treatment to potential offenders can reduce risk to possible victims who all too often are other people who have disabilities. A functioning forensic system is a component of a safer system overall.

Alleged perpetrators of violence or abuse may need to be separated from potential victims and then closely supervised when they interact with others. Our services in South Australia can be seen to respond promptly to situations that come to their attention. However, without a designated forensic residential service, unique solutions have to be developed for each individual incident. Practitioners with relevant experience are sought out to provide advice and develop behavioural plans. If a person cannot safely live with others, special housing needs to be sourced, and then carers rostered on a 24-hour basis. This happens now in South Australia, and it is a positive response to risk situations that in the past were too often ignored in disability services. Yet these one-off solutions are not only expensive, but miss the opportunity to develop specialist expertise and practice in the forensic area that would be gained by staff working in a dedicated forensic residential disability unit and providing consultancy to general disability community services.

There is a need for this service for people where allegations are made, even if charges are not pursued within the justice system. At times lawyers will argue that their clients should not be placed on a forensic order, because they know that with a lack of beds their client may wait in remand prior to being admitted. Because the person does not have a psychiatric illness, they might wait longer as other patients with a specific psychiatric diagnosis requiring acute mental health treatment are likely to be admitted first.

Similarly, there are people with disabilities who are now admitted into the forensic mental health ward, who do not fit in well to that environment — potentially putting them at risk if their behaviour clashes with others on the unit. Many of these people could serve their “limiting term” in a specialist forensic disability unit, rather than on a forensic mental health ward.

The capacity of such a service needs to be quantified, as well as the current impact of continuing to operate without such a building block. At this point it is possible to identify the need, but more work needs to be done on models of care. There are certainly cases that we are aware of where alleged perpetrators might receive effective and prompt treatment from a specialist team, and thereby have a greater chance of reducing future offending. There are other instances where people are inappropriately placed in a forensic mental health facility rather than a forensic disability environment and either deteriorate or fail to make gains that they might have otherwise made with more appropriate interventions.

Planning for an accessible forensic disability service that can offer best practice interventions is one way of reducing future risk to other people — in particular to other people with a disability who may live and work in close proximity to the person with an offending behaviour who without treatment might continue offending.

Adult protection models overseas

Considering the history and approaches to adult protection overseas can give greater insight into the gaps and limitations of Australian approaches to adult protection.

In particular, there are examples overseas of adult protection responses that are broad, and involve a wide range of services working closely together.

There are elements of these systems that if we chose to replicate them in Australia would be costly and therefore at least in the foreseeable future are unlikely to get off the ground — for example the employment of adult protection officers, working alongside child protection officers.

There are other elements of models overseas that could be more easily replicated without substantial new resources. In particular establishing formal local protocols between health, disability providers, other social services and law enforcement about how instances of alleged abuse and neglect of adults are responded to, and who acts as the lead officer in each situation.

At a greater cost, a 24-hour adult protection phone-in line could be established. This could receive reports from both professionals and members of the community about vulnerable adults at risk, and then assign a relevant service to offer assistance to the individual involved. While reports from supported residential services should be mandatory, because of the ongoing debate about the benefits and risks of mandatory reporting, reports from the community would be voluntary but encouraged.

Following several serious incidents, the United Kingdom took decisive action in 2000 with the release of the “No Secrets” report (Department of Health, 2000). This report uses a broad definition of a vulnerable adult:

...who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation.

In interpreting this, local adult protection networks in the UK will respond to people with learning disabilities, mental health problems, older people, and people with a physical disability or impairment.

Similarly, “No Secrets” provides a broad definition of abuse:

Abuse is a violation of an individual’s human and civil rights by any other person or persons.

This might comprise physical abuse, sexual abuse, psychological abuse, financial or material abuse, and neglect or acts of omission (Department of Health, 2000).

The practical implementation of “No Secrets” has involved establishing partnership networks of relevant government agencies across the UK. The approach of protecting vulnerable adults is generally described as “safeguarding”, and protocols to achieve this are clear about responsibility for tasks.

Safeguarding practice in the UK has continued to develop in the last nine years with reviews of the agreements, as well as the process of undertaking serious case reviews when services have not protected an individual. In 2009, advocates in that country have been intensifying the argument for specific adult protection legislation to replace the “No Secrets” guidance.

There is a similar approach in the United States. Once again, the emphasis is on protection of broadly defined vulnerable adults. This breadth is important because, for example, US data on elder abuse suggest that approximately 60% of victims have mental impairment while other risk factors include conflict with family and friends, social isolation and psychiatric illness (as cited by Dyer et al., 2005). In situations of severe forms of self-neglect leading to squalor, 70% of people who present have an identifiable mental disorder, leaving 30% who do not (Snowden et al., 2006).

In the US, the Adult Protection Service workers assist people with capacity. Only 7% of cases nationally require legal interventions such as guardianship, involuntary mental health commitments and emergency removals (Dyer et al., 2005). The APS workers participate in multidisciplinary teams that have health, social service and legal members. There can be a strong emphasis on initiating civil or criminal legal action against the perpetrator. In summary, the overarching philosophical principles of APSs in the US are:

Advocating for each individual’s constitutional right to autonomy
Preserving the rights of individuals with capacity to make their own decisions
Selecting the least restrictive alternative amongst service options (Dyer et al., 2005).

Typical components include an adult abuse hotline, usually with a requirement for mandatory reporting. Services can provide a mobile response. The aim is to see emergency cases within a day. Most states will aim to see all people within 14 days. APS workers in some states will also act as guardians but in other states, the roles are separate.

Positive lessons from these overseas approaches include:

- A specific focus on adult protection, not only guardianship. A guardianship service — providing substitute decision making — is only one component of the adult protection response.
- A focus on vulnerability rather than mental incapacity. People who have mental capacity but who may be vulnerable are assisted — such as young people who have a physical disability or older people who may be frail.
- An emphasis on team work and partnership between social services, health and the law, which is formalised by an agreement.
- Providing a range of practical assistance services to keep a person healthy and safe.

- Using the courts to pursue perpetrators and minimising the use of legal mechanisms directed at the victim (such as appointing a guardian).

The South Australian experience by comparison

As noted above, there is a range of adult protection strategies. South Australia, like all other states has principally developed its guardianship system without having a systematic adult protection response as is seen overseas.

I would note that the following discussion needs to be on an Australia-wide basis, because what happens in South Australia is similar to what occurs in other states.

Without the breadth of strategies there can be a greater reliance on guardianship, when other approaches to keeping a person safe without taking away their decision-making rights might do — similar to strategies for example that are used in domestic violence where specialist services, health services, and police have a highly coordinated approach.

An emphasis on mental incapacity can place the focus on the victim of abuse and neglect, rather than the perpetrator. This can be particularly harsh for people with moderate intellectual disability or for people in the early phases of dementia. These people might otherwise not require a substitute decision maker, but lose their decision-making rights as a result of the actions of others — simply because they might have the misfortune to know a person who is predatory towards them in some way.

Overemphasising adult guardianship as the key response to adult protection carries risks including:

- Not investing sufficiently in preventing abuse of other vulnerable populations who retain mental capacity such as the frail elderly and people with chronic illness and physical or sensory disabilities.
- A focus on the victim of the abuse, rather than on the perpetrator.
- A lack of a systemic protocol to take other practical steps that do not require guardianship to ensure that a vulnerable person is safe.
- A risk of seeking to prove incapacity so that a person can receive protection services that might otherwise be provided without the need to prove incapacity if those services were readily available.
- A risk that adult protection can be seen as someone else's responsibility — in particular, of the Guardianship Board and the Office of the Public Advocate. (In contrast the UK approach has all levels of social services, health and law signed up to make adult protection everybody's concern, with clearly defined responsibilities).

Key advantages of a systemic response with adult protection protocols in place at a local level include:

- The potential for faster reaction times by local service providers to suspected abuse and neglect

- Clarity about who in any situation is finally responsible for coordinating a response to a person who is experiencing abuse or neglect
- Greater preservation of decision-making rights. This may permit the use of supported decision-making as an alternative to substitute decision-making
- Good generic adult protection is therefore consistent with the objectives of the UN Conventions of the Rights of Persons with Disabilities.

At this point, it is important to acknowledge the excellent work that already occurs from organisations and professionals in this area. Advocacy agencies use advocacy as a tool to tackle abuse and neglect — perhaps the best example is the work of the Aged Rights Advocacy Service in elder protection. This organisation, funded by the Department of Families and Communities, and involving the Office of the Public Advocate amongst others as partners, has led the implementation of state-wide strategies to prevent elder abuse. Another key group are hospital social workers who perform extensive adult protection functions as part of their work.

When systems fail, it has often been left to the extraordinary goodwill of people in particular organisations to make the difference. Examples include the efforts of Royal District Nursing staff to look after vulnerable adults who have been discharged from hospital without support. They have in turn then relied on the goodwill of other organisations going the extra mile. Another example is the work of local government health authorities who coordinate responses for people showing signs of self-neglect and living in squalor.

Because the system and the protocols have not been pre-planned, it is then left to dedicated individuals to pursue a time-consuming path of customising a response for individuals.

The need for across-government directives in adult protection

The current work that is undertaken in elder abuse prevention is commendable.

The “kickstart initiatives” from the Department of Families and Communities include amongst others, working with the Advanced Directives review, investigating and recommending changes to address older people’s barriers to the law, contributing to state legislation via discussion and position papers, promoting the use of protective conditions for financial powers of attorney, as well as strategies to provide education and training, raise awareness, support the further development of interagency regional networks, and support research and innovation (Department of Families and Communities, 2007).

This is a starting point. The protection of vulnerable adults of all ages now needs across-government direction.

Such strategies have been applied in South Australia for child protection and disabilities.

The UK “No secrets” approach has some key ingredients. It is blunt — it does not encourage collaborations, it tells organisations they must work together. Chief Executives need to sign off on local agreements. In any situation it is absolutely clear who has the final responsibility

for responding to an adult protection matter (for example, whether the matter arises in hospital or outside hospital), but that responsible person is not left alone to deal with the matter. They can access the support of other necessary services through partnership arrangements and pre-planned protocols. This is a far cry from the situation of South Australian community nurses or health inspectors struggling to get other agencies quickly involved and responses underway.

Proposing the UK model as a way forward may attract criticism and the suggestions dismissed because of reported failings of the systems in both the UK and US. Critics can point to various facts such as ongoing serious incidents in adult protection in the UK and some of the states in the US that have difficulty responding to mandatory reports.

However, even appreciating this possible criticism, there must be intrinsic benefits in clearly defining ahead of time how services will work together, who has responsibility for what, and ensuring that all participants take an active responsibility for protecting vulnerable adults. For this to work, these agreements need to be implemented in every local region in South Australia.

While networks can employ existing staff, in the future there needs to be consideration about how adult protection resources are applied — particularly the provision of local and mobile responses, and 24-hour help lines.

Promoting Rights and Interests

Guardianship and Administration Act 1993

Section 21 (1) The functions of the Public Advocate are—

- (c) to speak for and promote the rights and interests of any class of mentally incapacitated persons or of mentally incapacitated persons generally;
- (d) to speak for and negotiate on behalf of any mentally incapacitated person in the resolution of any problem faced by that person arising out of his or her mental incapacity;
- (e) to give support to and promote the interests of carers of mentally incapacitated persons;

Overview

In the work of this Office, there is often a powerful reciprocal relationship between positive rights and negative rights — whether the issues apply to a group of people or individuals.

Positive rights are those that allow people to choose and pursue their aims and goals in life. For people with disabilities this may require access to good services — such as housing, personal assistance, or good health care so that underlying conditions are treated as well as possible.

Negative rights refer to the imposition of controls and restrictions. These can include involuntary treatment, powers to direct a person to conform to the decisions of a substitute decision maker, detention, restraint and the use of force.

This is not just a moral, philosophical and legal divide. Invariably, when scientifically assessed, the benefits to the individual and the community through the proper provisions of housing, support, rehabilitation and treatment are greater than when these provisions are not made. The alternative is to allow a person's circumstances to worsen so that confinement, control and restriction are required which will deliver poorer outcomes at greater cost.

For example, if a person who is homeless cannot access housing, they are less likely to receive treatment and then more likely to be gaoled or be involuntary admitted to hospital. Or if a person who has an intellectual disability with behavioural difficulties does not receive sufficient support services, professional intervention about behaviour management, and be cared for in a suitable environment, they are then more likely to require physical or chemical restraint.

When economic analyses have been undertaken, while it may initially seem cheaper to limit the provision of services that maintain positive rights, inevitably the costs will be greater to the community for providing the restrictive care.

In summary — what is good for rights, is good for outcomes. Almost invariably, it costs more to provide the wrong sort of care, than it does to deliver what is needed in the first place. In

this section, this approach is applied to topics of discussion and debate in 2008–2009: the use of Community Treatment Orders, the new Mental Health legislation, the application of detention and restraint in disability services, delays in provision of community services for people “stuck” in hospital, and forensic mental health care.

Community Treatment Orders

The 2009 Mental Health Act, when implemented, will increase the ease with which a Community Treatment Order (CTO) can be commenced. A CTO provides for the compulsory treatment of a person who might otherwise not accept treatment. In most instances, it is applied when a person has a serious mental illness, does not recognise the need for treatment and therefore does not wish to consent to its administration. There also must be a risk to that person or others if they do not receive therapy — usually an antipsychotic medication delivered by injection as a long-acting preparation administered every two to four weeks.

CTOs have been used in Australia since the 1980s, and are a common component of psychiatric practice in our current system. Under the 1993 Mental Health Act, doctors apply to the Guardianship Boards for CTOs to commence. With the new legislation, CTOs will be able to be initiated by doctors and authorised medical practitioners but then reviewed by the Board within 28 days.

This discussion questions our current reliance on CTOs. In essence, although a CTO may now be considered necessary for many patients, it is likely that far fewer patients would need CTOs if they had access to a broader range of services including early intervention. In a well functioning system, CTOs should have a limited role, so that each time one is initiated, great consideration is given to the necessity for it.

To explain this it is necessary to consider some of the literature about CTOs and international differences in practices. While the use of CTOs has been commonplace in Australia for many years — South Australian practice being similar to other states — there has been significant debate in the United Kingdom and the United States about their use, and doubts about their benefit if used in a widespread way. It is curious that such debate has not impinged greatly on Australian clinical or legal practice.

While a CTO may be an instrument of law, it is also a treatment intervention. Therefore, it can be subject to scientific analysis. The Cochrane Collaboration is a global network dedicated to evidence-based medicine and has commissioned a systematic review of the evidence for the use of CTOs (Kisley, 2005). This review found only two suitable studies that randomly assigned patients to either CTOs or usual care without compulsion. Review of data from about 416 people indicated that CTOs did not improve health service use, mental state, quality of life, homelessness or satisfaction with care. People on a CTO were thought less likely to be a victim of crime. Their analysis suggested that it would take 85 CTOs to prevent one readmission, 27 to prevent one episode of homelessness and 238 to prevent one arrest (Kisley et al., 2005).

In this setting, the UK Department of Health commissioned its own review of international experiences of using community treatment orders, which was undertaken by the Institute of

Psychiatry. This paper summarised the empirical evidence of 72 data based studies (Churchill et al., 2007). The key conclusion was:

It is not possible to state whether community treatments orders (CTOs) are beneficial or harmful to patients.

Comments in the papers discussion included:

Given the coercive nature of CTOs, there is a need to consider whether any potential therapeutic gains might be better delivered by enhancing the quality and assertiveness of community treatment for high risk patients through, for example, assertive community treatment (ACT) (page 15).

There is little specific consideration in the CTO literature of why individuals needing community-based mental health treatment fail to obtain or receive it, and how applying a court order actually addresses this. A better understanding of these factors would help to determine not only how best to facilitate treatment compliance during the CTO, but also following its expiry, and might even obviate the need for a court order altogether (page 15).

There are genuine concerns that CTOs might be used as an alternative to providing a comprehensive package of effective community mental health services (page 16).

This paper highlighted the need for quality research in this area, which is now being undertaken in the UK.

Once again, there is a dichotomy between positive rights and negative rights. A key element of positive rights is access to high quality services. As it happens, the evidence for the benefit of such services is strong. In particular, the Assertive Community Treatment approach seeks to maintain contact with people who are reluctant and to develop a relationship with them (Marshall & Lockwood, 1998). This approach does not depend on a CTO being in place.

Similarly, there is evidence of the importance of providing housing to people with serious mental illness (Pathways to Housing, 2005). In the first instance, it can be more important to put a roof over a person's head than insist on compliance with medication, as once housed, a person can be visited regularly and supported.

So on the one hand there is evidence for the approaches that maintain a positive freedom — providing sufficient clinical and support services, and ensuring that a person is housed. On the other, the evidence for imposition of negative freedom — CTOs — is lacking. It is reasonable to conclude that CTOs will have a role but that significant questions must be asked each and every time one is sought. Furthermore, while a CTO may be required with the current availability of mental health services and other supports, it is also relevant to consider whether it might be avoided if sufficient clinical follow-up were available along with other assistance such as access to housing.

A stepped and balanced system will also seek to intervene early in the development of an illness — at a time that a person may seek treatment, and interventions such as cognitive behaviour therapy and low-dose antipsychotic drugs might prevent future illness. It should

be noted that the benefit of this early intervention is yet to be proven (Marshall and Rathbone, 2006; Ruhrmann et al., 2009). It is reasonable to expect a system to assign sufficient resources to treat a person when they first show signs of illness, at a time that a person might voluntarily engage and they can be protected against further deterioration.

The use of CTOs cannot be considered in isolation from other interventions in the mental health system.

This approach to Community Treatment Orders has been outlined by the Public Advocate in 2009 in presentations to the Australian Heads of Mental Health Tribunals, and to a number of different groups of mental health professionals. The purpose of raising awareness of this issue has been to promote greater reflection on the use of compulsory community treatment in individual cases and the provision of early intervention and assertive care as alternatives.

In doing so, it is recognised that decisions still need to be made in our existing system of care with its limitations. Many of the people who are seen for CTOs have not had early intervention, and do not have intensive support services. They already have an established illness and views about receiving mental health care formed over many years. For some of these people, CTOs have negatively coloured their view of mental health services. The clinic is seen as a place that they are forced to attend so that they can be injected with medication. There is little engagement in therapy and other programs. Relationships with treating staff are strained. For some families who have to provide evidence in Guardianship Board hearings supporting a CTO, their relationship with their family member can also be strained.

The clinic is often not valued, so it is not uncommon that when the CTO finally ends people in this situation rapidly sever their connection with the mental health service.

The removal of unnecessary compulsion and therefore the improvement in negative rights can only be realised with improvements in positive rights, in this case service provision. Within the limits of what is currently available, a CTO may still be required and a person could be at risk without it, even if in an ideal situation it might have been avoided. Alternatives should still be explored.

Mental Health Act 2009

This consideration of the balance between positive and negative freedoms is relevant to the implementation of the *Mental Health Act 2009*.

The Public Advocate contributed to discussion on a number of points:

- Objection to the lowering of the criteria for involuntary treatment so that more people can be detained or subjected to community treatment orders.
- Providing an opportunity to appeal a decision to transport a patient interstate (supporting a position put forward by the Law Society). Amendments were made to the Bill to implement this provision.
- Definition of apparent harm. It was noted that for initial orders it was intended that a person only need to *appear* to have a mental illness. This was in line with a recommendation from Palmer in his review of the Detention of Cornelia Rau. The drafting of the new Bill placed the word *appear* in the initial paragraph so that the person now only needs to *appear* to be at risk. No amendments were made. This

point is unlikely to be significant in most cases, but could be relevant in some instances.

Broadening involuntary care in South Australia

The advice not to broaden the criteria was based on the reasoning in the previous section — there is evidence for providing more services, but not for providing more compulsion.

The United Nations Mental Health Principles require that before a person is detained there must be a *serious* likelihood of harm, or a risk of *serious* harm.

The new South Australian Act has done away with the word *serious*.

The advice of the Public Advocate on this matter was that the word *serious* be reinstated. This advice was not accepted, although it was raised in Parliamentary debates.

The purpose of recapping this matter in this Annual Report is not to challenge the final decision of Parliament. The matter was considered and a decision made. The Mental Health Act is now law, and we now have the task of implementing it.

This discussion is included for two reasons. Firstly, the criteria are still yet to be interpreted by the courts. This discussion is part of setting the background for these considerations when they occur. Secondly, this legislation covers a rapidly evolving area in science and the law. It is inevitable that there will be ongoing debate, and how we understand and interpret the law will be influenced by both developments in the scientific evidence that underpins it, evaluations of our models of care that seek to implement the models (such as early intervention and intensive community support), and emerging developments in the law.

Because the threshold criteria for this Act are new, they will require interpretation by clinical practitioners and then by the courts. It is likely that when CTOs and detentions are appealed to the District Court there will be a number of significant initial appeal decisions that will further clarify meaning and help draw the line between liberty and compulsion for people who have psychiatric disability.

The Law Society in making its case for the existing threshold criteria to be retained, noted that the meaning of the words “in the interests of his or her own health and safety or for the protection of others” in the current *Mental Health Act 1993* are now well understood legally. This follows a number of appeal matters where the Court considered the meaning of this test.

Ian Bidmeade, in “Paving the Way” recommended the adoption of criteria from the UN Mental Health Principles. These criteria have been carefully considered internationally. He said:

14.2 It should be clarified that a mentally ill person can be detained or ordered to have treatment where there is a serious likelihood of immediate or imminent harm to the person or others, or serious deterioration in the person’s physical or mental condition.

The new *Mental Health Act 2009* contains as a criteria for community treatment orders and for detention:

...because of the mental illness, the person requires treatment for the person's own protection from harm (including harm involved in the continuation or deterioration of the person's condition) or for the protection of others from harm;

Accompanying this is a requirement that the person has a mental illness, that facilities are available for treatment and that no less restrictive means of treatment is available.

If there was any doubt about the intent to expand the reach of compulsory treatment, it was put to rest by Minister Lomax-Smith who made the following statement in her second reading explanation of the Mental Health Bill (inserted into Hansard without being read on 12th November 2008):

This set of criteria is also intended to address the problems identified by Australian researchers of mental health law. According to their research, mental health laws, which place the emphasis on involuntary intervention only when persons are assessed as dangerous to themselves or others, result in poorer outcomes for these people. They convincingly argue that placing the emphasis on the dangerousness of the person often results in the period of time between the first onset of the mental illness, usually psychosis including schizophrenia, and the time at which the illness is diagnosed and treated, being longer than necessary. This delay in receiving treatment can lead to a poorer prognosis for the patient and potentially homicide.

Recent data from both New South Wales and the United Kingdom show that the risk of a patient committing homicide during their first psychotic episode is in the order of one in 500 new cases. In contrast, the annual risk of homicide by patients who have received treatment is only about one in 10,000 per year. The researchers note that the lethal assault was usually preceded by frightening delusional beliefs and most of the victims were family members or close associates. Only 15 per cent of victims were strangers.

It would be remiss of me not to point out that most people with a mental illness are not violent and that patients with psychosis are not generally violent once they have been treated and can be safely managed in the community. However, it is now clear that untreated psychosis in particular can lead to violence and that mental health law in general, and the criteria for involuntary intervention in particular, can reduce this risk. The greatest risk of potential harm for people with mental illness arises from the potential for suicide if they are not treated. The suicide rate for people with a mental illness is up to one in 10 compared to an average of one in 100 for the whole population. The criteria in the Bill place the emphasis on the person's need for treatment with the aim of ensuring that patients who need an assessment and treatment will fall within the new legislative scheme. Enabling people to obtain an early assessment, and

treatment if required, is designed to reduce the risk of both suicide and homicide arising from untreated illness.

The second reading explanation will be a significant resource when the law comes into effect as the second reading speech is traditionally used as a reference by the court when there are disputes about what Parliament intended by particular provisions of an Act.

There is nothing intrinsically wrong with the facts or the arguments put forward in the second reading explanation. It is a valid approach. The Office of the Public Advocate though has put forward a different argument, based on the links between the use of legislation on the one hand, and the availability of services on the other. There should always be ongoing debate as scientific findings are applied to policy and legislation.

It is worth considering the problems and solutions raised in the second reading explanation — the need to provide care for people who are in the early stages of psychosis, responding to the risk of early psychosis, not using dangerousness criteria to make decisions, and the impact of broadening the net of compulsion.

Involuntary treatment and early psychosis

As it happens, the emphasis of modern services set up specifically to provide treatment for young people in the early phases of psychosis is not on compulsory treatment. It focuses on engaging with young people early. It is often the case that a young person in the very early phases of an illness will either seek help or be amenable to being seen by a professional. The focus is on connecting with youth, providing psychological support, education to families, and the prescription of low-dose antipsychotic medication, as the approach to drug treatment for first-episode illness is different to that of established illness and requires special skills.

The approach is about providing a service rather than seeking a mental health law solution. For example, the Orygen Youth Health service in Melbourne serves a catchment area of 960,000 and at any one time has about 900 young people in treatment. The approach is about good access, being youth friendly and being assertive in follow-up. Community Treatment Orders and detention are used as a last resort.

If the aim is a better response to early psychosis, then best practice interstate would suggest that an investment is required in a substantial early psychosis service. Catching more people with the net of involuntary treatment is not a recognised strategy. Even if it were to be applied there would need to be a greater investment in services to provide the care for the larger number of people.

The Stepping Up Report by the Social Inclusion Board recommended that the human and economic benefits of early intervention for younger people with early psychosis be promoted and that a specialist service for first episode and early psychosis be “fast tracked”. The 2007–08 Budget allocated \$400,000 a year for four years to provide an early psychosis service (“Stepping Up — 2007–08 Budget Brochure). Appointments were made to key positions in this small service in mid-2009.

The response to the early psychosis need in South Australia is modest and has been slow. The new staff of the early psychosis service are dedicated and committed, will do good work, but will have a massive task to ensure that all young people presenting for care at mental health clinics in the state receive the recommended treatments — particularly as existing

staff in mental health clinics are busy with their current clients and the early psychosis regimes of therapy, education and extended support are time-intensive.

There is an imbalance in the South Australian response to early psychosis. Using the paradigm of positive and negative freedoms, increasing the likelihood of a swing towards the negative interventions — CTOs in particular — that have less evidence of their effectiveness, if sufficient interventions to support positive freedoms (such as youth-friendly mental health services) are not provided.

In short, it is not possible to consider the effect of the legislation by examining the legislation alone, without looking at the broad spectrum of service responses to early psychosis.

The potential negative impact will be an over-reliance on legislative provisions for compulsory treatment in the absence of an assertive early intervention response.

The danger of focusing only on risk in early psychosis

The second reading explanation by Minister Lomax-Smith refers to the dangers associated with first episode psychosis. This research work cited in the second reading explanation demonstrates the greater risks associated with the first episode — before a person might have commenced treatment and does not yet have some relationship with mental health services.

This work can be considered in at least two different ways.

Firstly, this research draws the attention of clinicians to the risk of first episode patients. So even with ‘serious’ risk criteria, it provides extra evidence that people with first episode illness are at greater risk, and this might justify involuntary treatment under existing criteria.

Secondly, it provides evidence for doing away entirely with a dangerousness-based model and reverting to a capacity model.

This is the “fusion” approach championed by authors such as John Dawson and George Szmukler that promotes a fusion of mental health and mental capacity (guardianship) legislation (Dawson and Szmukler, 2006).

Decisions about mental health treatment would then be made for people who have a mental illness, in the same way that decisions are now made with respect to physical treatment for people with a dementia or brain injury, using substituted judgement principles.

Recently the chairs of the Tasmanian Mental Health Tribunal and the Guardianship Tribunal have been jointly promoting a similar idea of bringing together mental health and guardianship legislation in Australian jurisdictions.

Matthew Large and Olav Nielsson, the Australian authors alluded to in the second reading explanation, have identified the increased risks associated with first episode populations in Australia. These authors have also argued that we should make the transition to a single Mental Capacity Act (Large et al., 2008).

This argument has gained momentum in recent years since the completion of the South Australian Review of mental health legislation. It has been a significant theme in the community consultation in Victoria for their new Mental Health Act, led by former Victorian Public Advocate Julian Gardner (Gardner et al., 2009) although the government in that state plans to continue with a separate Mental Health Act rather than a single Mental Capacity Act.

In short, the proponents of the capacity-based approach argue that it: (1) better preserves individual rights by aligning decision making about mental illness to the same approaches used for making decisions about physical illness; (2) ensures that people who are unwell receive treatment — this includes people who may not be dangerous to themselves and others, but would have chosen to have treatment if it were not for losing judgement through illness; (3) does not rely on the presumption that it is possible to accurately predict risk, which is often not the case; and (4) provides clarity as to criminal responsibility. With respect to the last point, it is not uncommon to hear from families and neighbours of people who have a behavioural disturbance that neither mental health services nor police act decisively. In a capacity-based system, it is very clear whether responding to a disturbed behaviour is a mental health service responsibility (when a person lacks capacity) or a law and order issue (when a person retains capacity).

The South Australian response has been to retain traditional risk-based dangerousness criteria but has watered them down with a reference to harm, rather than serious harm. This criterion is potentially broad, as it can be argued that any untreated illness will be associated with harm. The legislation does have a requirement that the least restrictive means be used, and consideration be given to whether or not treatment can be provided on a voluntary basis is considered. This, however, is different to having these requirements *as well* as either the presence of serious risk if a dangerousness model is used, or an inability to make one's own decisions if a capacity model is used. With the new Act both clinicians and the Courts will need to determine where to draw the line.

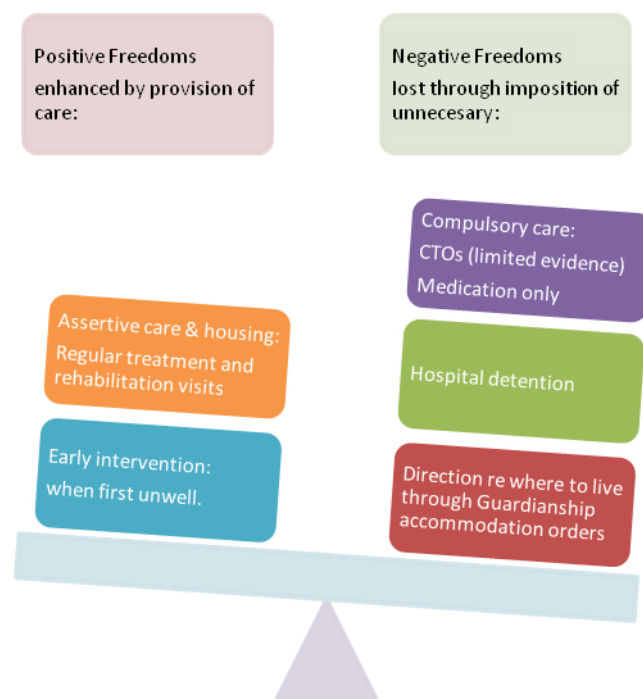


Figure 7: Positive vs. Negative Freedoms applied to the relationship between the use of mental health legislation and provision of services

Considerations for the Public Advocate with the new Act

During 2009–2010, the Office of the Public Advocate will be involved in a number of activities related to the new Act.

The enquiry service of this Office has traditionally provided independent information to consumers, carers and professionals about the Mental Health Act, and we expect that this role will continue. The Office is frequently the first port of call for information for people in hospital who wish to appeal their detention, and people on Community Treatment Orders seeking to lodge an appeal. The Office also maintains a list of legal practitioners who provide representation for people making appeals against decisions under both the Mental Health Act and Guardianship and Administration Act.

With respect to our role promoting rights and interests, we will do more work to develop a complementary appeals and systemic advocacy strategy.

In particular:

- Appeals will lead to the Appeals Division of the Guardianship Board and the District Court interpreting the meaning of the new criteria. The same process has occurred over many years for the current Act's criteria.

The Office of the Public Advocate will seek to participate in this process, to ensure that the criteria are interpreted in a way that best promote the rights and interests of people with a mental illness and are based on evidence.

- The *Mental Health Act 2009* provides some exciting opportunities to advocate for good services — which in turn can support positive freedoms.

In particular, the *Mental Health Act 2009* contains a new requirement that people have treatment and care plans that not only address medication provision, but also other needs. This applies to voluntary inpatients as well as people under detention or CTOs.

This will be an excellent opportunity to advocate for people to receive the full range of services for their condition, as described in recognised clinical guidelines.

There should be opportunities through the Guardianship Board and District Court to pursue these matters. Particular scrutiny will be applied to cases where services request community treatment orders, but other basic interventions have not been provided previously, or will not be a part of the treatment plan. The focus will not be on the individual practitioners, but the system's capacity to deliver an adequate standard of comprehensive care to each individual.

Delays in providing community supported accommodation by both Disability SA and Mental Health Services for hospital inpatients

During the year, a number of people under Guardianship of this Office experienced prolonged stays in hospital, where the need for either medical or psychiatric treatment no longer existed, but the person stayed in hospital as no community service was prepared or available to pick them up.

These cases involved people who generally had both a disability caused by a brain injury — such as from a fall, or substance-abuse — and a behavioural disturbance related to a psychiatric diagnosis.

These prolonged stays are invariably harmful to the individual concerned who would prefer to be home. It is not uncommon for people confined month after month to a hospital ward to become unsettled and agitated. Detention and restraint (both physical and chemical) is then required whereas if the person were at home or in a community environment these measures could often be avoided, because they would have a more settled spacious environment, their chosen activities and support staff who know them.

The costs are financial and personal. Inevitably it costs considerably more to provide the wrong sort of care than it does to provide what is needed. Inpatient costs extend into the hundreds of thousands of dollars over a 6-month period. There is personal cost to other members of the community. There is considerable pressure on both medical and psychiatric beds. As people queue for admission in emergency departments, the presence of people within the hospital who neither want nor need to be there, and are occupying beds that could be used by others does no-one any good.

These matters were raised with both Ministers for Disability and Mental Health. At one point, a matter was raised formally under the Act, as described in that section of this Report.

The case of one man in this situation was reported by the Independent Weekly Newspaper in May 2009 (Gout, 2009).

Restrictive and coercive practices in disability settings

As already noted, the use of restrictive and coercive practices needs to be considered in the light of available services.

Historically the use of physical, chemical or mechanical restraint or the use of seclusion, were generally thought of as reflecting the consumers' needs.

Work in the United States demonstrates very clearly that the use of seclusion and restraint reflects institutional variables and not consumer variables. In other words whether you are held down, tied or put in a seclusion room is determined more by how you are being cared for, rather than your actual needs.

The same principles apply across sectors — hospitals, homes for troubled youth and accommodation for people who have a disability.

In the United States, the Substance Abuse and Mental Health Services Administration established a national initiative to reduce and eliminate the use of seclusion and restraint in mental health settings (Currie, 2005). This program has had spectacular success, with states such as Pennsylvania leading the way. Elements include finding alternatives to seclusion and restraint prior to an incident — this can involve planning with a consumer about what to do when the person becomes unwell and how best to settle that person without restraint — and rigorous auditing of instances of restraint and seclusion to see how they might have been prevented.

Units across Australia are working collaboratively to improve practice. South Australian units are participating in this initiative and operating key “beacon” sites.

In May 2009, the local branch of the Australasian Society for the Study of Intellectual Disability (ASSID) — which links research findings to clinical practice for professionals — and the South Australian Council on Intellectual Disability (SA CID) have worked to increase awareness of the need for South Australia to take system-wide action.

Jeffrey Chan, Senior Practitioner for Disability Services in Victoria visited South Australia in May to present at a joint ASSID and SACID conference on this topic. He described the very open and transparent system that operates in Victoria. The use of restraint and seclusion needs to be part of a management plan approved by the Office of the Senior Practitioner. That Office considers the need for the proposed restrictive practices taking into consideration both a rights-based and professional review of the proposed measures and their justification. The rights-based review is modelled on the Human Rights Charter that operates in that state. The number of approvals and the overall use of restrictive practices in the Victorian disability system are then publicly reported by that Office.

In South Australia, restrictive practices might be applied under either the *Mental Health Act 1993*, for patients detained to a mental health facility, or under the *Guardianship Act 1993*, for people placed elsewhere.



Presenting to the Australasian Society for the Study of Intellectual Disability (ASSID) and the South Australian Council on Intellectual Disability (SACID) combined conference on Restrictive Practices: Jeffrey Chan, Senior Practitioner, Disability Services, Victoria; Dell Stagg, Chair of SACID and John Brayley. (Photograph by the Independent Weekly Newspaper).

Use of restrictive practices in South Australia

While a guardianship appointment gives authority for a guardian to make substitute decisions for a person, there is no enforcement of those decisions unless additional powers are sought under Section 32 of the *Guardianship and Administration Act 1993*.

These are known as “Section 32 powers”. The Board must be satisfied that:

...if such an order were not to be made and carried out, the health or safety of the protected person or the safety of others would be seriously at risk.

The threshold test for these powers is that health or safety is seriously at risk. There is no particular reason why this threshold might need to be lowered, or that the adjective “seriously” creates a problem (see previous section on the Mental Health Act for further context).

The powers are divided into three parts that allow the Board to: (a) direct where a person lives or that they live where a guardian decides they should; (b) authorise detention; and (c) authorise the use of force as may be reasonably necessary for care and treatment.

In the Act, these Section 32 (a), (b) and (c) powers are described as follows:

32—Special powers to place and detain etc protected persons

- (1) The Board, on application made by the guardian of a protected person—
 - (a) may, by order, direct that the protected person reside—
 - (i) with a specified person or in a specified place; or
 - (ii) with such person or in such place as the guardian from time to time thinks fit,according to the terms of the Board's order; and
 - (b) may, by order, authorise the detention of the protected person in the place in which he or she will so reside; and
 - (c) may, by order, authorise the persons from time to time involved in the care of the protected person to use such force as may be reasonably necessary for the purpose of ensuring the proper medical or dental treatment, day-to-day care and well-being of the person.

These powers can be applied for by both private and public guardians. Therefore, it is not possible to review Office of the Public Advocate data alone to determine the use of these powers in South Australia. For this reason, there is still benefit in maintaining separate databases to monitor the use of restrictive interventions along the lines of the public data collated by the Office of the Senior Practitioner in Victoria.

The Public Advocate had the opportunity to compare some internal Disability SA data for residents who had a management plan in place to deal with aggressive behaviour (as of late May interventions for 95 people had been recorded), with the public data from Victoria for a 6-month period of 1868 cases, collated and published by the Office of the Senior Practitioner.

This comparison was limited for a number of reasons, including gaps in the coverage of the Victorian data, (which at this stage cover chemical restraint and mechanical restraint but not physical restraint), and a planned transition of current Disability SA data to a new recording system.

Two conclusions can be drawn from these limited data and comparison:

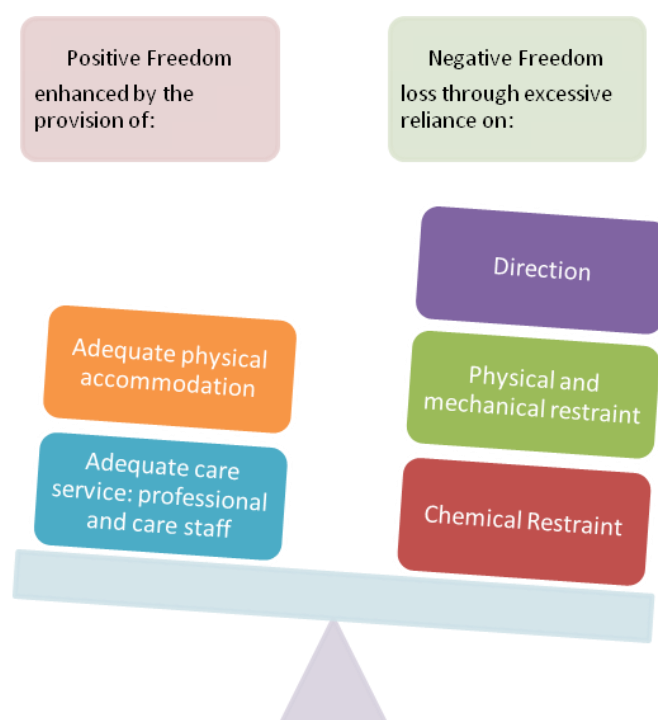
- The recording of SA data on the use of restraint of people with a disability should be extended beyond government-provided accommodation to all disability settings. There might be hundreds of additional cases that the Victorian system would review, and South Australia does not.
- The recognition of what constitutes chemical restraint seems limited in SA. For example, in 2008 19% of 63 service users had received chemical restraint, and in 2009 7.36% of 95 people recorded in the first five months of the year. In contrast, the use of chemical restraint occurred in 96% of the 1,836 cases recorded in Victoria in the last six months of 2008.

While one possible conclusion is that South Australia uses less chemical restraint than Victoria, it is more likely that because of the legislative requirements in Victoria, practitioners are more often identifying when the prescription of drugs constitutes restraint and seeking approval.

The prescription of psychotropic medication is considered chemical restraint, when the drugs have been provided to control behaviour rather than to treat an underlying illness such as a mood disorder, anxiety disorder or psychosis that the clinician genuinely believes to be present.

In the Victorian system, the use of drugs prescribed in this way is drawn to the attention of the Senior Practitioner. Psychologists can then consider whether sufficient non-drug options of behavioural control had been considered prior to giving authorisation for ongoing medication.

Once again, there is a balance between positive and negative freedoms.



Positive vs. Negative Freedom in the use of compulsory directions and forcible restraint for people who have a disability

Below are some South Australian data for the Calendar Year 2008 of the use of Section 32 (a) direction (b) detention and (c) force as reasonably necessary by underlying diagnosis.

Section 32 Enforcement Powers Calendar Year 2008

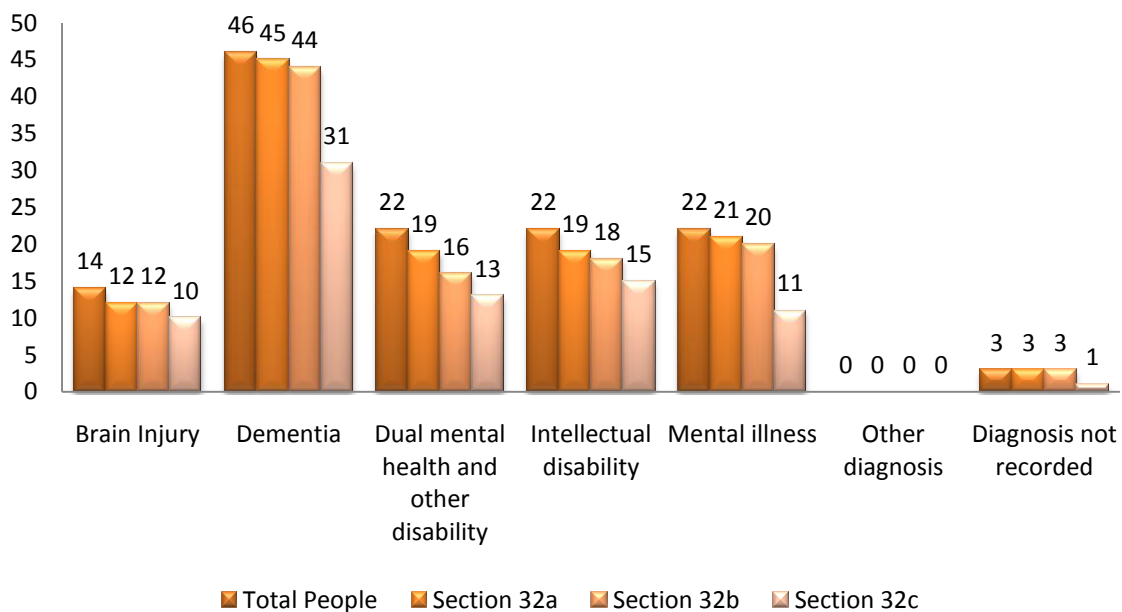


Figure 8: Use of Section 32 (a), (b) and (c). This graph describes the number of orders. Some people have (a) alone. Others will have (a) and (b), (a) and (c), or (a), (b) and (c). The last column is for diagnosis not recorded on the computer system, although it would be available on the file.

Each of the key diagnostic groups can be seen in the above diagram (Figure 8). It should be noted that this is data for people under public guardianship only. Private guardians, including those appointed under an enduring power of guardianship can apply to the Board for enforcement powers.

The largest group are older people with dementia. Section 32 powers are frequently used to place a person who is no longer coping at home because of their disability, and object to going to a nursing home. Detention may be required for a short time so that they do not leave.

The remaining data describes people who have a disability secondary to intellectual disability, a head injury, mental illness, or a dual diagnosis with a combination of an intellectual disability and mental illness or a head injury and mental illness.

While these data are illustrative of the pattern of application of restrictive practices across groups, the absolute numbers are not particularly meaningful as they do not cover practices administered under private guardianship.

In Queensland where new restrictive practice legislation is in force, there has been a significant upsurge in guardianship appointments. It is possible that if more intensive approval and monitoring were to occur within services, more practices would be identified that would lead to additional appointments and use of Section 32 powers.

While the frequency of use of Section 32 powers can be a concern – particularly when the powers may be required because of insufficiencies in the care system to deliver care without

such restrictions, it is also imperative that these powers are applied for when needed. It is illegal for direction, detention and force to be used outside of such powers in the care setting. The Queensland experience would suggest that when practices are closely analysed – in particular the use of restraints and medication for people with disability – there is a need for additional guardianship appointments to ensure that such practices are formally assessed, challenged if inappropriate, and transparently administered with reports back to a tribunal.

In summary South Australia could benefit from:

- Routine professional state-wide overview of restrictive practices of restraint and seclusion.

It has been suggested earlier in this Report that the creation of a Senior Practitioner role could be a component of a new Disability Act for South Australia.

- Careful analysis of the use of psychotropic medication for people with disability, as there may be under-recognition of situations where drugs are prescribed as a form of restraint rather than as treatment for an underlying psychiatric condition.

This requires improved access to psychological advice to be used as an alternative to medication. The implementation of behavioural programs needs to be supported by further skills based training of care providers.

- Strategies to reduce and eliminate the use of restraint in mental health services could be adapted and applied to disability services.

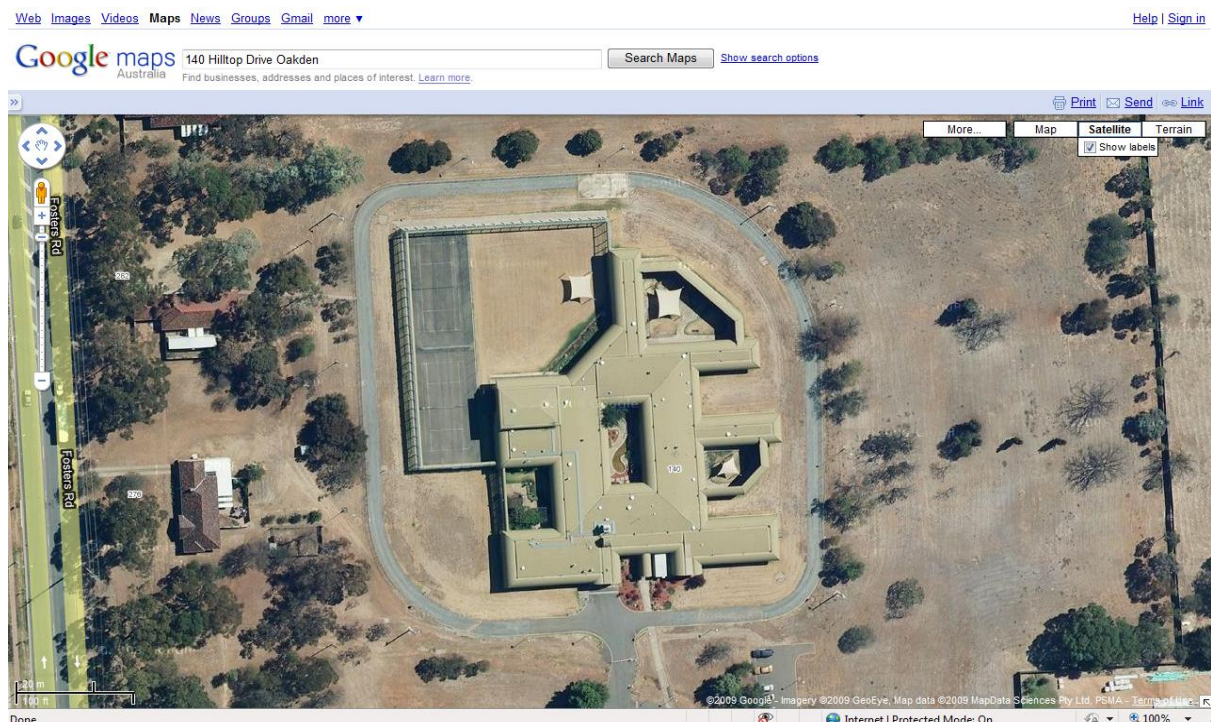
This would require strategic professional leadership and attention to environmental and care factors such as inadequate personal space for individuals, the amount of care provided, and the training and support of care staff in behavioural management.

Forensic Mental Health

The application of similar principles applies to Forensic Mental Health Care. While these services have both a community and inpatient component, the provision of inpatient care in particular was once again a focus in 2008–2009 because of delays in admission to the existing unit, and uncertainty about the fate of a rebuild of the facility.

Background

Forensic inpatient services are now delivered from 30 beds at James Nash House at Oakden, and 10 beds based at Glenside. Staff estimate that at any given time about 70% of these beds are occupied by people who have been charged with a crime but are considered to be not guilty by reason of mental impairment and the remaining beds by mentally ill prisoners in need of treatment. There is often a considerable waiting list for these beds, with forensic patients treated in either general mental health beds or left to wait in prison.



Google satellite photograph of James Nash House. There is limited access to the larger exercise yard for Birdwood Ward (North west). Small prison like yards are next to both Birdwood and Aldgate (East), and a yard is connected to the Clare step down unit (South West).

The current James Nash House was built a little over 21 years ago. There are two key problems with this facility:

- First, most of it was built as a gaol with cells rather than hospital facilities, which is the current standard.

Like a gaol, security is built into the design of the building with prison-like cells provided for most patients. In contrast, the modern approach is to build a hospital. Security is then provided through the construction of a high tech perimeter fence, but internally the facility is designed as a healing hospital environment.

Victoria has set best practice in Australia with its 120-bed Thomas Embling Hospital, opened in 2000 and built on a campus model.

- Second, the facility is too small to cope with current demand. There are now 40 beds available in South Australia. This Office estimates that at least 60 beds, possibly 65, are required (Office of the Public Advocate, 2008).

James Nash House was to be rebuilt four years ago so that South Australia could have an appropriate therapeutic facility. The sum of \$16.5m was set aside for the rebuild (Hansard, Legislative Council 28 March 2007). Unfortunately, with the escalation in building costs it would now cost more to not only rebuild to provide 40 beds (the existing 30 at Oakden plus the 10 at Glenside) but also increase capacity by another 20 beds.

These plans were shelved with the decision to relocate James Nash House to be part of the Mobilong development. Now that the latter has been shelved because of the economic impact of the global financial crisis, it will be necessary to revert to the old plan of rebuilding the unit. There is already a head start, as budget papers for 2007–08 record that an estimated \$500,000 has already been spent on the planning of a new Oakden facility. The decision not to proceed with the Mobilong development now requires an urgent decision from the government about the future of the existing 30 beds at James Nash House, the 10 beds currently at Glenside, and an additional 20 beds to cope with current demand. The solid structure of the existing James Nash building makes meaningful renovation difficult as the current problems have been considered to emanate from the fundamental design, relationships and lines of sight available within the existing building. For this reason a rebuild as initially planned at Oakden some years ago, and then Mobilong is still needed, as well as building extra beds.

Unfortunately, the care of people who require mental health treatment is not a topic of great community concern. While it is true that most people with mental illness are not violent (and in fact are more at risk of becoming victims of violence rather than perpetrators), there are sad and tragic circumstances, thankfully small in number, when unwell patients become a risks to others. In some cases, inpatient treatment is necessary under the care of forensic mental health professionals.

First and foremost, James Nash House is a hospital. Some people can receive treatment there for many years. Good quality hospital care can offer hope and improved quality of life to the individual with an illness. Good quality care can also make the community a safer place.

Life as an inpatient in James Nash House

The problems that beset the ward are noticed by the people who use it. The following views of consumers of forensic mental health services were recorded in August 2009 by the Public Advocate and a Senior Advocate & Guardian (Julie-Anne Dowling) from this Office during a visit to the facility.

- Access
 - At admission: prolonged waits for people to get a bed. Existing patients are concerned about people who are sick waiting in gaol for a hospital bed. They

see that it is “much better to be with other people who are mentally ill than to be with prisoners” when unwell.

- One patient commented on the unfairness of the lack of beds to people who are sick as they can be switched around between ward and prison due to the lack of James Nash House hospital beds. One mentally ill person was understood to be in G Division in canvas waiting to come into James Nash House.
- Transfer on discharge: difficulty getting a bed at Glenside prior to discharge. A period of step down at Glenside had been a traditional part of the “step down” from James Nash House prior to discharge to the community at the end of the “limiting term.” This is now not readily available.
- Prison-like environment in Birdwood and Aldgate wards
 - Not conducive to people with a mental illness.
 - Difficult to supervise, so patients are locked in cells overnight and the lock-ins can be relatively early in the evening.
- Outdoor and other recreational time can be limited because of poor design
 - Poor vision of staff means that outdoor activities are dependent on adequate staff numbers, as well as the weather. This has meant at times that people on one ward have only been able to get out as little as once a week.
 - Access to the occupational therapy room and to the computer was also limited.
- Privacy and overcrowding
 - Limited because of the crowded conditions.
 - Birdwood is like a “sardine can.”
 - Another resident noted that it was “hostile, harsh and encroaching — it should be serene.”
 - There is a tunnel effect with noise in Birdwood ward. Additional communal living space is required.
 - If one patient “goes off” others will readily know.
 - Because of ward design, the number of times people can move between their bedroom and the communal areas is limited, so it is difficult to escape from the company of others.
 - The lack of blinds on cell windows can mean that there is no privacy for people to change their clothes — this can apply to both men and women who share the same ward.
 - Visitors’ facilities are inadequate because of the limited places that patients can meet with visitors.

- Lack of recreational facilities
 - A poorly air-conditioned converted brick storeroom serves as the work-out gym for patients who often are confined within the building and need to exercise.
 - It is described as “boiling hot” in summer.
 - Rooms have no power sockets or television and patients can listen only to one radio station.
 - There is no outdoor setting.
 - There could be a canteen and a shop
- Food
 - Basic hospital food is provided by the Royal Adelaide Hospital. While this may be suitable for a short, acute hospital stay, James Nash House residents will be on this diet for many years.
 - Choice of fruits is limited — while bananas, oranges and apples are provided, only people at Glenside get a choice of seasonal fruit.
 - Staff put on a barbeque at Birdwood once a month, but this is not considered enough — inpatients would prefer once a week.
 - There is general concern about this diet when also taking medications that put on weight and can cause diabetes, and where exercise facilities are limited.
- Oppressive environment
 - When asked to describe a ward at James Nash House, expressions were used such as chaotic, dull, and old fashioned, housing people who should be more active.
- Unsuitability of mixed facilities
 - Women can be inadvertently observed, to the embarrassment of men as well.
 - Separate shower facilities were requested along with a women’s only area.

There was common agreement among the patients that they were better off not going to Mobilong. This had also been the view of staff previously, but it was also expressed by patients who were concerned that the collocation with the prisons at a distant place could create a more prison-like environment for them to live in.

After a ward meeting, a female resident at James Nash House showed our Senior Advocate her cell. The following notes were made:

She had a window looking out onto an outdoor area accessed by other inpatients. There were no blinds/curtains for the window and she had taped magazine pages to the lower portion of the window as a privacy screen. There is no switch for the bedroom light in her room; this is in the corridor outside. At night when the doors are locked, she cannot turn on the light to read or go to the toilet. She has to feel her way to the toilet in the dark. She would like to be able to read if she cannot sleep at night.

In considering the above points, it is worth reflecting on some relevant facts:

- The people in James Nash House are there because they are sick, and need treatment.
- Forensic patients are not guilty. Because of significant illness they have been found not guilty of a crime.. They have fewer facilities than many prisoners.
- People with mental illness can also end up in gaol due to factors related to their illness once there require treatment
- It is in everyone's interest for treatment to be effective: both for the person themselves and for the community. People should be released after a limiting term following a period of treatment and therapy.
- Access to recreation is more limited for patients receiving treatment in James Nash House than it is for people receiving punishment in prison.

The limitations of James Nash House reflect the buildings' design flaws. Modern wards use clever design so that there is good line of sight, and other security features to allow people to move around as much as possible without requiring staff escorts. The lack of this in the 1980s building limits people's opportunity to go outside, and to participate in recreation activities.

It also means that a fundamental rebuilding of the wards is required to achieve better design for the comfort and safety of both residents and staff.

James Nash House needs to be rebuilt for all the people who use it. Particularly vulnerable groups are young people who are early in their illness and need a more sheltered environment, and women who need greater separation, privacy and women-only recreation space.

In contrast to the above visit, the Public Advocate a few years ago had the opportunity to visit the Thomas Embling Hospital in Melbourne. Having negotiated formidable security on the perimeter with guards, high tech iris scanners and other devices, once inside we found the environment resembled a modern hospital. Wards were homelike in appearance. Patients had access to an onsite TAFE training centre, swimming pool, and gymnasium, and could cross plentiful grass lawns as they walked between buildings.

The staff at James Nash House are excellent. They do very good work. However, when a person leaves that hospital after several years in a gaol-like environment for most of that time, will they be as recovered as they could possibly be? How would they compare if they had spent the same time at Thomas Embling in Melbourne compared to James Nash in Adelaide? The skills of the staff may be the same, but the result of hospital care in a healing hospital environment as opposed to a crowded gaol-like environment must be better. Good patient care is good for patients and creates a safer community.

Supporting and Promoting Carers Interests

During 2008–09, the Office of the Public Advocate has not undertaken systematic reviews of carers' issues. However, it should be noted that a number of the themes of this Annual Report have been either promoted or seriously considered by carers and their organisations — in particular, responding to unmet need and the provision of individualised funding support. Lack of sufficient respite care is an ongoing theme.

The brunt of unmet need is met either by the consumers themselves, or by a carer, if there is one. The needs of the consumer may be protected, but at the carer's own expense.

On 1 May 2009, the House of Representatives Standing Committee on Family, Community, Housing and Youth released its report "Who Cares...? Report on the inquiry into better support for carers (Parliament of Australia, 2009). The key themes that emerged from that inquiry included:

- A lack of recognition of the role and contribution of carers, and a lack of a national and strategic approach to supporting carers and their families
- Difficulty accessing information on supports and services for carers and lack of assistance to carers
- Financial stresses facing carers
- Dissatisfaction with community care systems. Concerns about the complexity of services, unmet need, cost of services, inflexible delivery, questionable quality of care
- Lack of opportunities for carers for participation in the workforce or education
- Physical, emotional and social impact on carers.

At an extreme, the impact on carers can lead to neglect and harm. A briefing paper produced this year by the Julia Farr Association on this topic highlighted similar factors such as families attempting to get the support they needed but with little success, concern over lack of accommodation, concern for the future when carers are gone, and lack of support at the time of diagnosis of a disability.

That paper then considers solutions through the provision of necessary services, and information and assistance to families.

The setting of a carer seeking to valiantly struggle on can be one where allegations of neglect and abuse can arise leading to investigation and the potential appointment of the Public Advocate as guardian.

Carers and Consumer Advocacy

The 2005 Review of Mental Health Legislation (Bidmeade, 2005) made the following recommendation:

The role of the Public Advocate in assisting the interests of carers should be made better known. It needs to be clear that it involves information and systems advocacy, rather than individual advocacy, to avoid conflicts of interest in assisting consumers under the guardianship of the Public Advocate.

In most instances advocacy for carers parallels advocacy for consumers and there is an alignment of interests. Carers in these situations are acting as advocates for consumers' service needs and they call this Office seeking advice. Mostly it is about access to services.

The response of the Office to a carer issue will depend on the role that it takes in a particular case. In the situation described by Bidmeade (2005) above, a guardian cannot effectively "walk in the shoes" of the consumer and advocate for a carer as well. This is particularly the case when there is a conflict between the best interests of consumers and those of the carers. In these situations, independent advocacy for carers is needed for those who may feel overwhelmed by the interventions in their family. In South Australia, the independent organisation Family Advocacy will take on this important role.

In some instances, consumers and carers will have different positions to put to the Guardianship Board or the Appeals Division of the District Court on either Guardianship matters or Mental Health matters. The Office provides information to assist all people in the process, whether they be consumers and carers, or different members of the same family in conflict.

The Office also is approached when people are dissatisfied with the outcomes of Guardianship Board hearings — whether it be a consumer unhappy with an order that has been placed upon them, a carer unhappy when the Board has not made an order, or a family member unhappy when they have not been appointed to a guardian and administrator role. Assisting people to understand the process and access their appeal rights is a key part of the information response.

The ongoing contact with carers who offer their perspective based on their personal experiences helps set systemic positions. System reform based on positive rights approaches and the UN Convention on the Rights of People with Disabilities must meet the real concerns of carers while advancing consumer autonomy. This requires services to be available when needed, and if there is to be less reliance on compulsion, that viable alternatives are put in place.

Other Advocacy Topics

Matters raised by the Public Advocate in discussions with Ministers, governmental officials, and submissions to inquiries have included:

The Redevelopment of Glenside Hospital — a submission was presented to the Upper House Committee by the Public Advocate accompanied by two mental health consumer representatives. Material presented included the outcome of a consultation with consumers about the new facility (an overview of the submission is available on the OPA website).

Welfare and safety of residents of Supported Residential Facilities — a review of this topic has commenced.

Assisting people who have pathological gambling — a submission was made to the Independent Gambling Authority's inquiry into barring arrangements (a copy of this submission is also available from the OPA website).

The chaining of mentally ill prisoners in general health facilities — only preliminary inquiries have been made on this topic at this time. The Office would welcome contact from any prisoner, family member, advocate, or health professional who is aware of situations where prisoners receiving mental health care in general hospitals have been chained when this has been considered not to be clinically necessary and antitherapeutic.

Failure of hospital staff to identify mental incapacity in older people and to plan for safe discharge. This topic was raised with this Office in 2008–2009 by a community-based organisation. Work has yet to commence on this review, which will be undertaken in 2009–2010. Once again, the Office would welcome information from any patient, family member or health professional about situations where people have been discharged from hospital without supports.

Raising Matters with the Minister

Guardianship and Administration Act 1993

22—Public Advocate may raise matters with the Minister and the Attorney-General

- (1) The Public Advocate may, at any time, raise with the Minister and the Attorney-General any concerns he or she may have over any matter arising out of or relating to the performance of his or her functions under this Act or any other Act.
- (2) If the Public Advocate so requests, the Attorney-General must cause a report of any matter raised by the Public Advocate under subsection (1) to be laid as soon as practicable before both Houses of Parliament.
- (3) The annual report furnished by the Public Advocate under this Act must include a summary of any matters raised by the Public Advocate under subsection (1).

During 2008-2009 the Public Advocate met with relevant Ministers and Members of Parliament in an advocacy role.

The Public Advocate sought appointments with Ministers to discuss a range of legislative, policy and funding issues. The timing and frequency of these meetings reflected the approaches made by this Office based on the nature of issues as they arose. Access has been excellent. Between meetings queries on issues were made to Ministerial staff.

Meetings with Ministers:

Minister for Mental Health and Substance Abuse

Minister for Disability

Attorney General

Meetings with Members of Parliament:

Vicki Chapman MP, Shadow Minister for Mental Health

David Windlerlich MLC

Anne Bressington MLC

Kris Hanna MP

Section 22 (1) Formal matters

During the year only one matter was formally raised with a Minister under the provision of Section 22 (1) and is therefore to be included in this report under Section 22 (3).

This matter was raised with the Minister for Disability and concerned a lack of available community care for people in hospital who had a disability, and required Disability SA services before they could be discharged. In particular, within this group some people required detention and restraint in hospital as they were confined to an inappropriate environment — restrictions which would not be needed if they were to be discharged home.

There is a legislative requirement to report on matters formally raised in this Annual Report. A copy of a letter sent to the Minister and her reply is reproduced in Appendix C.

Give advice on legislative powers: Guardianship and Administration Act 1993

Guardianship and Administration Act 1993

Section 21 (1) The functions of the Public Advocate are—

- (f) to give advice on the powers that may be exercised under this Act in relation to mentally incapacitated persons, on the operation of this Act generally and on appropriate alternatives to taking action under this Act;

Advice about the Act was provided through:

- The enquiry service
- Education sessions

This work is reported in Part B of this Report.

Monitor Legislation: Guardianship and Administration Act 1993

Guardianship and Administration Act 1993

Section 21 (1) The functions of the Public Advocate are—

- (g) to monitor the administration of this Act and, if he or she thinks fit, make recommendations to the Minister for legislative change;

Guardianship and Administration

Internationally, thinking in this area has developed in response to Article 12 of the United Nations Convention of the Rights of Disabled Persons, and an improved understanding of the decision-specific nature of mental incapacity.

Consideration of Article 12 of the United Nations Convention

Article 12 Equal recognition before the law

- Persons with disabilities have the right to recognition as persons before the law
- Persons with disabilities enjoy legal capacity on equal basis with others in all aspects of their lives
- Persons with disabilities access the support they may require in exercising their legal capacity
- All measures that relate to the exercise of legal capacity are safeguarded to prevent abuse; they respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest possible time and are subject to regular review by a competent, independent and impartial authority or judicial body.

Innovations associated with the new *Mental Capacity Act (2005)* in the United Kingdom and the development of supported decision making in Canada are generally considered consistent with these principles and indicative of the direction of future law reform.

The UK *Mental Capacity Act*'s starting point is a clearly stated presumption of capacity. Adults have a right to autonomy — to make their own decisions. A person should also be offered help to make decisions to maximise their own input. The purpose of this is to prevent unnecessary interventions in the lives of people with a disability (Department of Constitutional Affairs, 2007).

The United Nations Secretariat for the Convention on the Rights of Persons with Disabilities cites the Province of British Columbia in Canada as an example of good practice where a person can enter into a “representation” agreement with a network of supporters who can assist with making decisions and provide representation when needed (UN Enable, 2008). If there is evidence of a trusting relationship then such an agreement can be entered into without the need for a person proving their capacity.

Stainton (2008) has explained these representational agreements further, noting that incapacity is often a function of a lack of support, and expressing a preference for representatives speaking for a person rather than a guardian:

...i.e. those who know them best, are empowered to represent them and, recognition that incapacity is often a function of lack of support rather than inherent in the person. This is essential for individuals who cannot directly articulate their wants and needs if they are to avoid having them solely determined by professionals or formal guardians who have little knowledge of who they are as individuals and whose interest in them is structurally professional rather than the personal.

It is also clear that to move towards supported decision-making and to operate in these new ways, historical resource allocations need to be reviewed. The United Nations Secretariat suggests that existing guardianship resources should be redistributed — moving the current effort in making decisions for people to systems such as support networks that will assist people to make decisions themselves (UN Enable, 2008).

In Australia, Victoria is leading the way in considering the impact of the Convention on its existing *Guardianship and Administration Act 1986* — which will be relevant to us because the Victorian Act greatly influenced the development of the 1993 South Australian Act. Critics of the current Victorian legislation such as the Victorian Council of Civil Liberties, (2009) highlight both the lack of promotion of disability rights, and the need for more criteria and guidance when guardianship is granted. They cite a recent appeal judgement in the Victorian Supreme Court critical of the approach of their state’s tribunal. In *XYZ vs State Trustees and Anor*, the plaintiff who was placed under administration following a stroke, argued against the appointment of an ongoing administrator. Cavanough J expressed concern that there may be a need for that state’s tribunal to “...re-examine the exercise of its guardianship and administration jurisdiction generally to determine whether the balance has swung too far in favour of paternalism and protection as against individual autonomy”. [*XYZ vs State Trustees and Anor* 2006].

The Victorian Law Reform Commission announced its review in June 2009. That State Government’s Terms of Reference for this inquiry include the following considerations of the Convention:

- *the principle of respect for the inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons, and the other General Principles and provisions of the United Nations Convention on the Rights of Persons with Disabilities (the United Nations Conventions);*
- *the need to balance the protection of the interests of an adult with impaired capacity by a guardian or an administrator with the person’s exercise and enjoyment of the*

human rights, such as the right to freedom of choice, association and movement, including consideration of whether the Act strikes the right balance between facilitating action in the best interests of an adult with impaired capacity and the person's rights as expressed in the United Nations Convention.

The review will also consider the introduction of the Victorian Charter of Human Rights and Responsibilities, the extension of Guardianship and Administration to 17-year-olds, and the role of the Public Advocate (see Victorian Law Reform Commission, 2009). This review will report in 2011.

In South Australia, our existing Act has principles that apply to decision making by the Guardianship Board, Guardian or Administrator, but does not have principles stating a presumption of capacity, and a requirement to take all practicable steps to assist a person to make their own decision before taking over that person's decision-making ability. The Public Advocate's position is that such principles should be added to our existing Act. Possible wording is summarised at the end of this section.

Such a change could significantly alter the work of the Office of the Public Advocate along the lines suggested by the United Nations' Disability Secretariat. There would be less guardianship appointments of this Office, but more time spent assisting people to make their own decisions.

An improved understanding of mental incapacity

In recent years, there has developed a greater consensus between legal and health professionals about the nature of capacity, how it is assessed, and importantly how it is linked to decisions. There are three broad models of capacity (as summarised in a review paper by Calcedo-Barba et al., 2007) and it is the first of these three models that is now generally applied. This first model is a *legal-philosophical model*. Capacity is defined as the ability to express desires, comprehend risks and benefits, understand the consequences of decisions and be able to reason. The second model is the *medical model*. If a person has a particular neurological or psychiatric condition with specific symptoms, they are considered not to have certain thinking abilities and therefore be unable to make decisions. The third model is a *functional model* that measures behaviour and ability but is not linked to a particular disorder (Calcedo-Barba et al., 2007).

This legal philosophical or "decision-specific" model is expressly incorporated into the UK *Mental Capacity Act 2005*, which states that "... a person lacks capacity in relation to a matter if at a material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or disturbance in the functioning of, the mind or brain".

In Australia, in April 2008 the NSW Attorney General's Department released its Capacity Toolkit. It describes the decision-specific nature of capacity. This guide notes that generally a person has capacity to make a decision when they can:

- understand the facts involved
- understand the main choices
- weigh up the consequences of the choices
- understand how the consequences affect them
- communicate their decision.

The South Australian Act has a broad definition of incapacity:

...the inability to look after his or her own health, safety and welfare or to manage his or her own affairs as a result of...

A range of causes are then listed.

This broad definition then permits discussion of capacity to span all three models described above, with the risk that a person could be presented as having an incapacity because of diagnosis or performance on neuropsychological tests. While this evidence might be important for defining an underlying condition causing incapacity, the addition of an extra principle to our Act that capacity is decision-specific would lead to a greater focus on a person's actual ability to make necessary decisions. Suggested wording is at the end of this section.

The Public Advocate considers that capacity should be defined as decision-specific, as is the case in the UK and in NSW, and is consistent with the UN Convention. A principle could be added to our existing Act defining the decision-specific nature of mental incapacity. This would have an impact on both Guardianship Board decisions and how guardians and administrators operate.

This principle, in combination with the other two principles (presumption of capacity, and all efforts to assist a person to make their own decisions) is not radical, is commonplace in many jurisdictions and would affect decisions of the Guardianship Board and the approach of both guardians and administrators. Such changes would redirect some of the time of this Office from substitute decision-making (as there should be less guardianship appointments) to supported decision-making, and to work towards helping services and the community generally support people with their decisions. In essence, this would be a move away from making decisions for people towards helping people, where possible, make their own decisions.

Aims of existing South Australian legislation and the role of the Public Advocate

The South Australian Guardianship and Administration Act 1993 is now 16 years old. The reforming legislators of that time had many of the same aspirations as reformers now in seeking to avoid guardianship by the state by providing for alternatives.

In his second reading speech for the Act, The Hon M.J. Evans (Hansard, 9 March 1993, p. 2350) introduced the Act creating the Public Advocate, as “an important watchdog.” The Office was not to be limited to guardianship work — “The Public Advocate will seek to resolve problems so that, unless appropriate, the legal processes of the Board need not be invoked. When they are invoked, the Public Advocate will provide significant assistance.”

In the same speech the then Minister noted “The Public Advocate will operate on the fundamental principle of promoting agency and community responsibility rather than seeking to develop an extensive service provision role for its staff.”

The tools to resolve matters without advocacy that are included in the Act are those related to advocacy and giving advice, including “appropriate alternatives to taking action under the Act”. These goals are not very different to the current movement to provide supported

decision making. This creates a balanced approach, and a stepped range of interventions that involves assisting people to make their own decisions, getting necessary services through advocacy, and education of the community so that family and friends can properly take on the guardian role.

The need for the system's advocacy approach was well explained in the 1989 Review of the Guardianship Board and Mental Health Review Tribunal. It recommended that "The Public Advocate should have a wide knowledge and experience of health and welfare systems and should have senior administrative status" having noted advocacy issues "...that require sustained and intensive pressure to effect change often lapse and are dealt with on a more expensive, less effective individual basis." The review recommended the Public Advocate be supported in this work by a team of professionals including lawyers, accountants, psychologists, nurses and social workers and those experienced in working with people with disabilities. While part of the role of the Office of the Public Advocate would be to take over the work of the former social work section of the previous Guardianship Board (that Board employed 10 social workers) the functions and expectations would be greater.

With the new legislation, the mix of roles of the Public Advocate was carefully put together, even those that on the face of it might seem contradictory — such as acting as a rights advocate on the one hand, but guardian on the other.

This reflects an inherent contradiction in the whole jurisdiction which authoritative authors Terry Carney and David Tait describe in their 1997 monograph "The Adult Guardianship Experiment."

At the heart of the jurisdiction is a contradiction. The ideology of freedom is linked to a set of legal tools to restrict freedom through the appointment of substitutes. Guardianship laws use a modern rhetoric of personal rights promoting autonomy, fostering independence, and assisting citizens to participate in social life. And yet the main task of guardianship forums is to strip citizens of rights, entrust proxies with the exercise of legal decision-making, and sometimes authorise incarceration through physical and chemical means. The strange paradox of using coercive forms to achieve emancipator purposes raises practical questions about what could possibly constitute successful intervention in this Alice in Wonderland world? (Carney and Tait, 1997).

It is helpful to acknowledge this apparent contradiction and work with it. There is an innate tension between autonomy and freedom on the one hand, and care and protection on the other. It should be the case that the Office of the Public Advocate sits on the side of autonomy and freedom when advising and seeking to influence the Guardianship Board as well as having these principles influence its own decisions when acting as Public Guardian.

Carney and Tait (1997) see the Public Advocate's role as one that is critical in providing accountability to tribunals such as the Guardianship Board and setting the culture or "dominant narrative". Accountability comes from overview of policy issues and individual decisions, cooperating to find systemic solutions, and being prepared to conduct reviews (Carney and Tait 1997, p.202). Culture setting includes "...the systemic inclination, the willingness to take on powerful agencies, the alliance with the client, it might seem, against the state."

So where do we sit in South Australia in all of this? Without question, there has been a drift in the 13 years of operation of the Office of Public Advocate. The case is made above for balanced services that can assist people to avoid being placed under the guardianship of the state. Originally, there were resources allocated to advocacy and providing education to the community. With increasing demand for guardianship services over the years, staff allocated to this work have been reassigned to guardianship duties. To the extent as reflected in Annual Reports in recent years, most systemic advocacy is undertaken personally by the Public Advocate, some by the Assistant Public Advocate, and other activities are limited as well.

While the drive for more guardianship appointments is certainly affected by external factors such as the ageing of the population, a self-perpetuating cycle develops when a system develops an imbalance with an emphasis on high-end work such as guardianship without providing an easily accessible early intervention such as advocacy and supported decision-making. If work to prevent guardianship is not occurring, then more and more people will be brought under guardianship. If advocacy services are limited, then guardianship will become a vehicle for people without sufficient services to receive advocacy, when this advocacy should be available to them without giving up their decision-making rights. A similar imbalance occurs with the appointment of private and public guardians. If there is insufficient education and support to private guardians then the Board will be more inclined to appoint a public guardian when it might otherwise have the confidence to hand the task to a family member knowing that they will receive support. A cycle is established — more guardianship appointments means less resources are available for advocacy and assisting the community generally, which then means that even more state guardianship is required. Similarly, less time spent on systemic review and advocacy, means more time repeatedly addressing the same problems on an individual basis for people under guardianship.

Addressing this issue is even more critical because of changes in our community that will increase demand in the future for both supported and substitute decision-making for people who have incapacity.

A more balanced system is needed now as it was when the current legislation came into being. One strategy of this Office over the past year has been to go back to the 1993 Act and contrast what the Act intended to occur, with what over the last 13 years has become the routine practice in the sector and also within our Office. While existing practice conforms to the Act, we believe that some aspects of the legislation can be used in different ways. Our Office has had excellent administrative law analysis and advice from Crown Law as we have considered these options. This remains a work in progress.

A second strategy is to take the opportunity presented by the current mood for reform in Australia created by the UN Convention. Such a change can be a catalyst for reorganising the work of the Office. Some of the people who are now under guardianship may instead be offered an advocacy service and assistance with decision-making. When appointments are made, they would almost invariably be limited, rather than full guardianships. For decisions outside the formal appointment, support and advocacy would be provided as an alternative to substitute decision-making.

It may be that eventually, more substantial law reform will be required as is now happening in Victoria. In the interim, the existing Act with its excellent aspirations could be amended to describe these aims in modern unambiguous terms. This is outlined in the next section.

Additional principles for the Guardianship Act

A proposal of this office is to amend the Act to add new principles about presumption of capacity, the decision-specific nature of capacity, and the need to provide all possible assistance to people to make their own decisions.

Many stakeholders will wish to express a view about these, but the principles are put forward in this report to promote discussion between interested persons and agencies.

A proposal for additional Section 5 principles. 5 -Principles to be observed

Where a guardian appointed under this Act, an administrator, the Public Advocate, the Board or any court or other person, body or authority makes any decision or order in relation to a person or a person's estate pursuant to this Act or pursuant to powers conferred by or under this Act—

- (a) *the decision maker must begin their consideration from a presumption of capacity, that is:*
 - (i) *an adult will be assumed to have capacity to make their own decisions unless it has been established that the person lacks that capacity*
 - (ii) *mental capacity is decision specific. Capacity must be determined in relation to the specific function or task and the decision that needs to be made at a particular time,*
 - (iii) *a person is not to be treated as unable to make a particular decision unless all practicable steps to help the person to do so have been taken without success*
- (b) consideration (and this will be the paramount consideration) must be given to what would, in the opinion of the decision maker, be the wishes of the person in the matter if he or she were not mentally incapacitated, but only so far as there is reasonably ascertainable evidence on which to base such an opinion; and
- (c) the present wishes of the person should, unless it is not possible or reasonably practicable to do so, be sought in respect of the matter and consideration must be given to those wishes; and
- (d) consideration must, in the case of the making or affirming of a guardianship or administration order, be given to the adequacy of existing informal arrangements for the care of the person or the management of his or her financial affairs and to the desirability of not disturbing those arrangements; and
- (e) the decision or order made must be the one that is the least restrictive of the person's rights and personal autonomy as is consistent with his or her proper care and protection

Private Guardians vs Public Guardians

A stepped and balanced system will have strategies to encourage private guardianship and provide support and overview where possible.

In South Australia, the Office of the Public Advocate is appointed as a guardian of last resort but there is no formal support system or supervision for private guardians.

By way of contrast, a system has been put in place in the United Kingdom where the Office of the Public Guardian is responsible for supervising private guardians and administrators (called ‘deputies’ in that system), and keeping registers of guardians and administrators, as well as registering those appointed under advanced directives. The Office of the Public Guardian will ensure that a private guardian complies with their order, will visit the guardian and the person lacking capacity and maintain regular contact. Supervision fees are paid to the Office of the Public Guardian for this service, based on providing the cost of this supervision (Office of the Public Guardian, 2009).

The performance of this new UK system will need to be analysed but the aspiration of providing a safeguard through overview where possible is a positive one. The question is whether or not here in South Australia, this Office could take on both a support and supervising role as an alternative to being appointed substitute decision maker in cases where a private guardian may be available and willing to act, but because of family conflict or some other reason requires assistance.

The legislation has given us the capacity to support private guardians, as we are expected under our general functions to give advice under the Act. There is no legislative provision to monitor, oversee or supervise private guardians, but our Office is considering how we might take on a monitoring role as a joint guardian through specific provision in the order of appointment rather than be appointed as a joint decision maker. This is yet to be resolved.

It is worth recapping the fundamental ethical and legal considerations that make the appointment of a family guardian desirable.

Buchanan and Brock (1990) in their influential text “Deciding for others — the Ethics of Surrogate Decision Making” (p.136) put it this way:

The chief reasons in support of the presumption that the family is to serve as surrogate decision maker are both obvious and compelling. The family is generally both most knowledgeable about the incompetent individual’s good and his or her previous values and preferences, and most concerned about the patient’s good.

In 2003, an Appeal Court in Queensland made this statement with respect to the Adult Guardian in that state, who has a similar role to that of the Public Advocate in South Australia with respect to guardianship:

The Adult Guardian is a functionary of the state which, very properly, endeavours to protect the helpless and defenceless. But where such a person has friends or family who are able and willing to provide the requisite support and assistance it is, in my view, preferable that they be allowed to do so rather than be supplanted by a bureaucrat, no matter how well intentioned. To take any other view is to deny the expression of

what is good in human nature. Decision of the Supreme Court of Queensland in *Adult Guardian v Hunt* (2003).

In South Australia Section 29(4) of the Act states:

(1) The Public Advocate may be appointed guardian, or one of the guardians of the protected person, but only if the Board considers that no other order under this section would be appropriate.

This is usually paraphrased as the “guardian of last resort”. The Public Advocate has argued that the appropriateness of each potential guardian should be considered, and all potential guardians should have been excluded as inappropriate before the Public Advocate is appointed. This approach may or may not be accepted by the Guardianship Board.

The appointment of the Public Advocate when the main problem is one of family conflict is a particular issue. There is a common expectation that when there is significant conflict — say between the children of an older person with a mental incapacity — that the Public Advocate will be appointed guardian. In these families, there may be two or more people capable of acting as private guardian, without any serious suggestion that they might then be responsible for abuse, neglect or exploitation if they were guardian. However, adult children can have strong objections to the appointment of their siblings.

If a choice is made between feuding family members rather than appointing the Public Advocate, there should be checks and balances. This might be at the Board level or through the Office of the Public Advocate. A short initial period of guardianship would allow the Board to review the performance of a private guardian in these situations. With respect to the Office of the Public Advocate, a designated private guardian support program could assist if established in the future. (Staff time would need to be created for such a program through a reduction in guardianship appointments.) If there were such a program the Board could gain greater confidence in appointing a family member if they were prepared to engage with the process. Finally, there is the option of becoming involved in an overseeing role if this can be achieved with our Act. In the current UK system, there are three levels of supervision and when there is family conflict, a guardian or administrator will receive the highest level of supervision from the Office of Public Guardian (Office of Public Guardian, 2009).

In terms of early intervention, it is also worth noting that the best way for a person to ensure that their affairs are managed by the person they choose is to have a valid advance directive — in particular, both an Enduring Power of Guardianship and an Enduring Power of Attorney. Such advance directives are good for individuals, families and the guardianship system overall which will have difficulty coping with increasing demand from the population if it needs to make decisions for people who might otherwise have had enduring powers in place.

Components of a stepped model

The diagram on the next page (Figure 9) illustrates what a more balanced, stepped system might look like.

Features include:

- Access to supported decision-making to help individuals make their own decisions.
- Access to private guardian support and supervision, so that family can be appointed with support and safeguards in place in situations where the Public Advocate might otherwise be appointed.
- A greater reliance on “one-off” decisions made by the Guardianship Board. The UK Court of Protection will make a one-off decision for a person, where possible, so that the person can still make their own decisions in the future. With respect to medical consent, The Board in South Australia has the power to give consent without appointing a guardian.

A Stepped Approach to Supported and Substituted Decision Making



Figure 9: Acknowledgement: Photograph of the ABC Building Collingwood taken by Angus Kingston and downloaded from Flickr <http://www.flickr.com/photos/kingo/2005521722/>

Monitor legislation: Mental Health Acts 1993 and 2009

Rotary Partnership Project

Threshold Test for Involuntary Inpatient Care and Community Treatment Orders



On behalf of the team partners John Brayley receives a plaque from Allan Wilson of Rotary Australia. Pictured are Jeremy Moore (President, Guardianship Board), Di Chartres (Executive, Attorney General's Department), Andrew Alston (Associate Professor School of Law Flinders University) and Jennifer Corkhill (Appellants Lawyer). Absent Margaret Honeyman (Chief Advisor in Psychiatry)

Rotary Project

In late 2008 The Office of the Public Advocate (OPA) co-ordinated with several partners to develop a project to research how decisions are made about involuntary mental health care.

The project title is *'The Threshold Test for Involuntary Mental Health Treatment – Reducing Practitioner Variation in Invoking Orders and Implementing the Least Restrictive Option'*.

The threshold test concerns the decision that is made by a doctor to detain or not to detain a person who has a mental illness, or to apply to a tribunal for a Community Treatment Order. Under the new *Mental Health Act 2009*, a broader group of professionals can be authorised to make initial decisions.

It is important to reduce variability between practitioners. Overseas studies have shown that detention decisions, which should be entirely based on patient need, can in fact be affected by external factors such as bed availability, and location of assessment (Engelmann et al., 1998). Personal factors about the clinicians can also affect decision making including psychiatric level of training and the personal attitude to risk of the clinician (which can be measured using an objective scale, and correlates with detention decisions) (Sattar et al., 2006).

The result of this variability can have a profound effect on the maintenance of individual rights, outcomes and safety for people who have a mental illness.

The project brings together a steering group comprising Associate Professor Andrew Alston, an academic lawyer based at Flinders University; Jennifer Corkhill, Appellants Lawyer; Dave Tapley, Consumer Advocate; Jeremy Moore, President of the Guardianship Board; Margaret Honeyman, Chief Advisor in Psychiatry for South Australia; Di Chartres, Executive Attorney General's Department, and John Brayley, Public Advocate.

The Project received funding from the Australian Rotary Health Research Fund for \$60,000 in 2009.

While the results will be particularly relevant to South Australia, the project has been designed as a formal research project and the results will have applicability nationally.

Rotary Partnership Project

Mental Health Law: Protecting Rights and Improving Outcomes



Supported by an

Australian Rotary
Health Research
Fund Grant 2009

Phase 1 of the project has involved the analysis of detention forms and community treatment orders that are routinely collected by the Guardianship Board. Detention forms have been systematically sampled and their content recorded. This will be compared to the requirements of the Act. A similar analysis will be undertaken on the grounds for seeking community treatment orders.

Phase 2 which is about to commence involves interviewing consumers about their views about detention and involuntary treatment and how decisions were made about them. Results will be analysed using a formal qualitative research method. Contact has been made already with consumer groups who have shown interest in this work, and the opportunity it presents to them to describe the consumer experience of involuntary care.

Part B:

Direct Services

Provided to the Community by the Office of the Public Advocate

Public Guardian

Guardianship and Administration Act 1993

Section 29 —Guardianship orders

- (1) If the Board is satisfied, on an application made under this Division—
 - (a) that the person the subject of the application has a mental incapacity; and
 - (b) that the person the subject of the application does not have an enduring guardian; and
 - (c) that an order under this section should be made in respect of the person, the Board may, by order, place the person under—
 - (d) the limited guardianship; or
 - (e) if satisfied that an order under paragraph (d) would not be appropriate, the full guardianship,of such person or persons as the Board considers, in all the circumstances of the case, to be the most suitable for the purpose.
- (4) The Public Advocate may be appointed as the guardian, or one of the guardians, of the person, but only if the Board considers that no other order under this section would be appropriate.

What is guardianship?

A guardian is appointed by the Guardianship Board (under Section 29 of the *Guardianship and Administration Act 1993*) to make decisions on behalf of some other person, who, because of a mental incapacity, is unable to do this for him or herself. The Public Advocate is appointed as guardian of last resort where no other suitable private guardian exists.

A person under guardianship is referred to as the protected person. Their guardian assists them by making substitute decisions on their behalf and protecting their rights and interests. They can deal with all matters that can affect a person's health, welfare or lifestyle, except financial and legal affairs.

The Public Advocate provides public guardianship through a team of guardians who hold delegated authority to act as guardian for particular protected persons..

In December 2008 the Office commenced a trial of streaming the work into two teams.. The 'short term' team takes on guardianship for people who are likely to be under guardianship for 6 months or less, and also undertakes investigations. Because of the nature of its work, this team tends to provide guardianship for older people. The 'longer term' team, in turn tends to have more younger people with a disability.

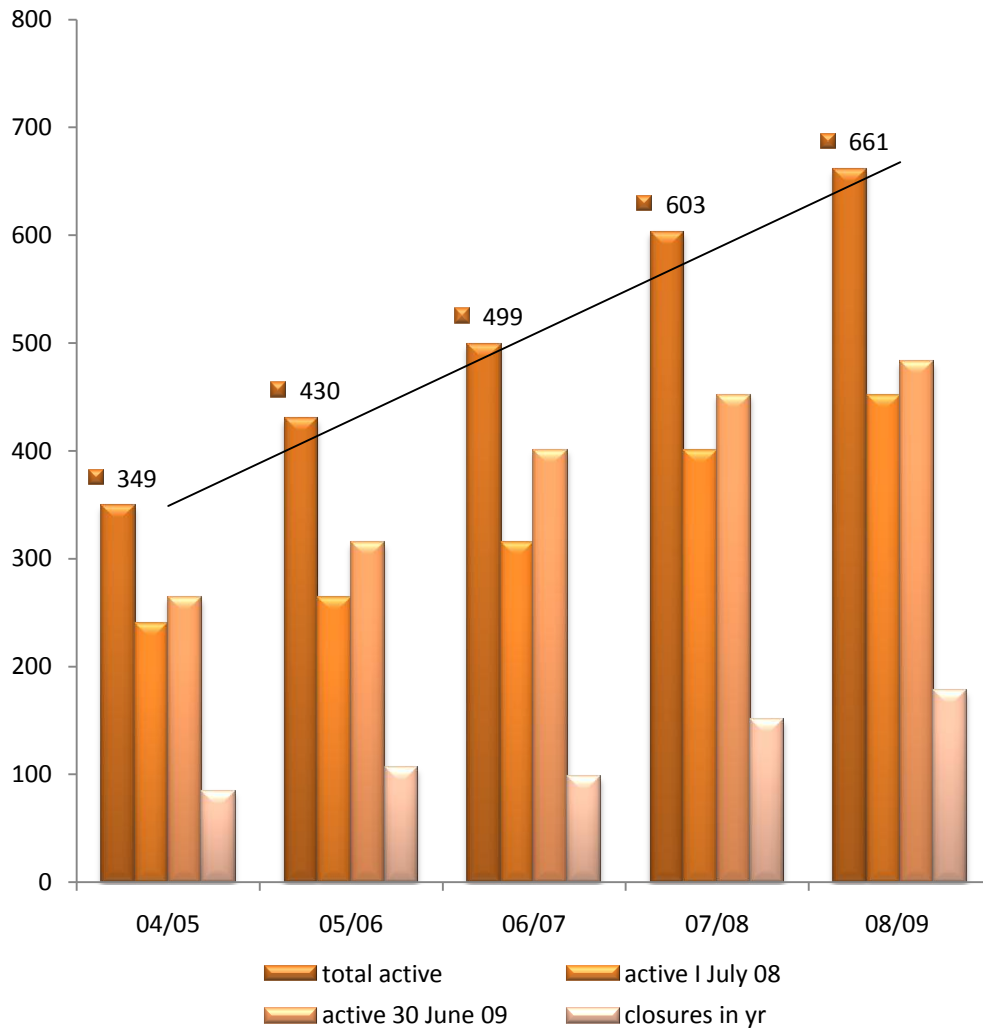


Frontline advocacy/guardian and administration staff of the OPA prior to a regular meeting of the new “long term team”: Margi Keville, Maria Atkins, Trish Bull, Julie-Anne Dowling, Andrew Sarre, Elicia White and Michelle Howse .

During 2008-09, the Office of the Public Advocate provided guardianship services under the *Guardianship and Administration Act* on behalf of 661 people (603 in 2007-08). This represents a 9.6% increase over the previous year and a continuing upward trend. In the previous two reporting periods, the increases were 17% and 16% respectively.

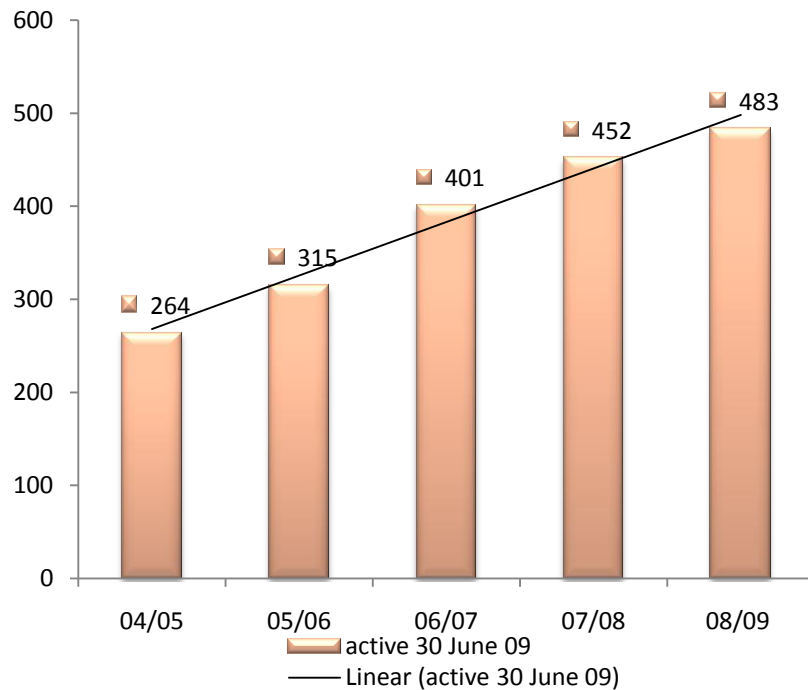
The number of active cases managed by the Office continues to grow. This is contributed to by the number of new cases each year, the length of time of each guardianship appointment and rates of closures. These factors have a cumulative effect on active workloads.

Guardianship Services 2004-2009



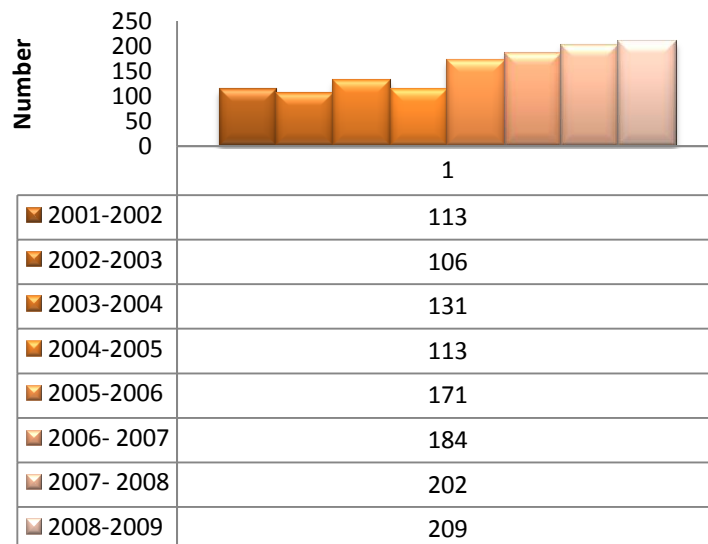
As at 30 June 2009, there were 483 active guardianship cases compared with 452 at the beginning of the year — a 6.9% increase in active cases at year end. This represents an 83% increase since 2004–05.

Active Cases at June 30th



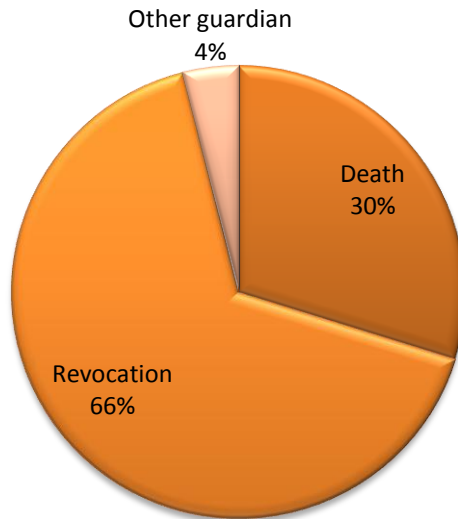
This year 209 new guardianship appointments were made a 3.5% increase on last year's figures (202). The following graph shows a continuing upward trend.

New Appointments



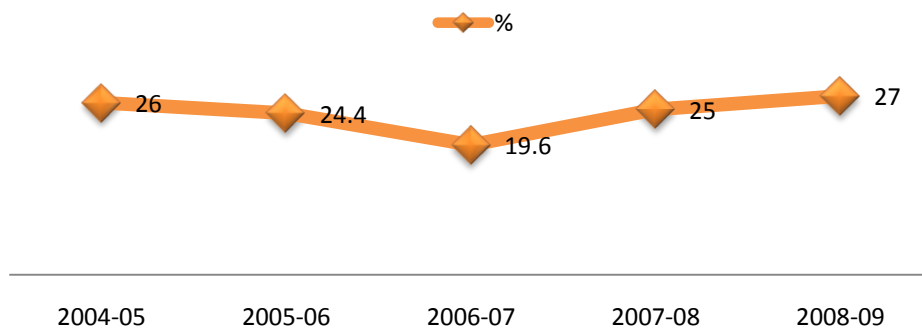
During 2008–09, 178 cases were closed — an increase of 17.9% (27) when compared to 152 closures in 2007–08. Of the 178 closures, 118 were due to revocation of orders, 53 due to death, and 7 due to private guardians being appointed. The OPA recommends revocation when satisfied that orders are no longer needed.

Reasons for Guardianship Closure 08/09



The rate of closures in 2008–09 was 27 %. This compares to 25% in 2007–08, 19.6% in 2006–07, 24.4% in 2005–06 and 26% in 2004–05.

Annual Closures Rate (Percentage of all Public Guardian cases)



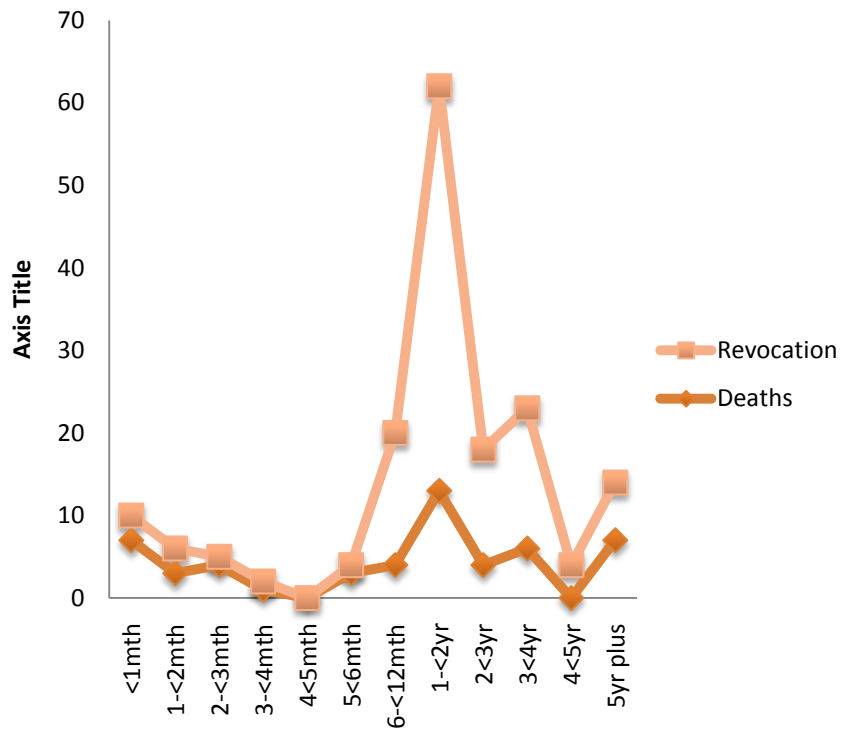
Closures as % of Guardianship Services Provided		
	2007/2008	2008/2009
Closures	152	178
Services	603	661
%	25.2	26.9

Reason for Closures						
	2007/2008			2008/2009		
Reason	Number	% of Closures	% of Guardianship Services	Number	% of Closures	% of Guardianship Services
Revoked	96	63%	16%	118	66%	18%
Deaths	51	34%	8.6%	53	30%	8%
Private guardian appointed	4	3%	0.6%	7	4%	
Missing	1	-	-	-	0	1
Closures	152	100%	25.2%	178	100%	27%

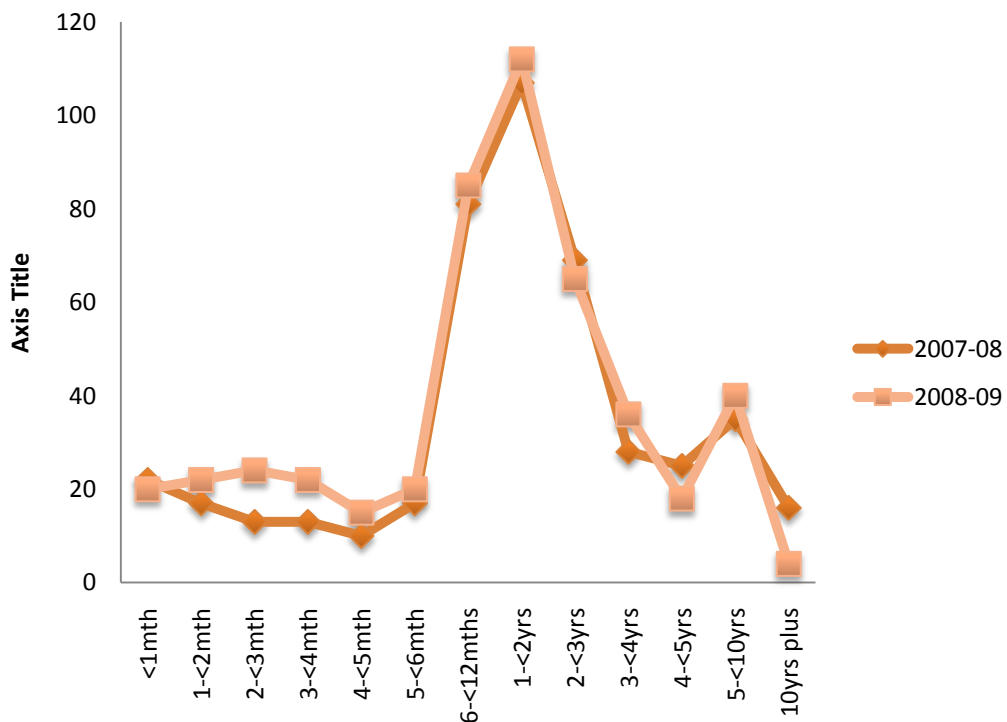
For those clients whose guardianship orders were revoked during the year, 21% were under guardianship for less than 12 months, 42% for less than two years and 12% for less than three years. In the current reporting period, only seven were closed due to the appointment of a private guardian.

For 2008–09, the average length of cases that were active at any time during the year (this includes cases that remained active as of 30 June 2009 as well as those closed during the year) was two years, and the median length 1.3 years (same as previous year).

Length of Closed Cases 2008-2009



Length of All Active Guardianship Cases 07/08 vs 08/09



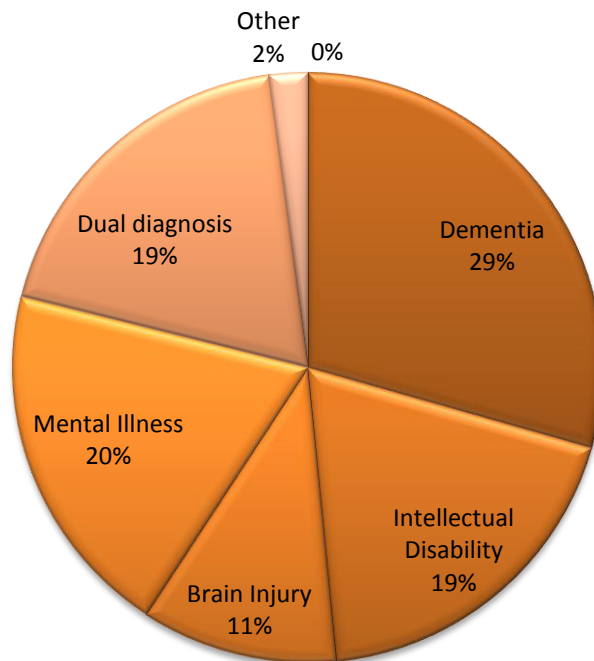
The age profile of active and new guardianship cases as at 30 June 2009 was similar to the previous reporting period. New guardianship cases reflect the ageing of the population and demand in this area.

Profile of Active and New Guardianship Cases 2008–2009

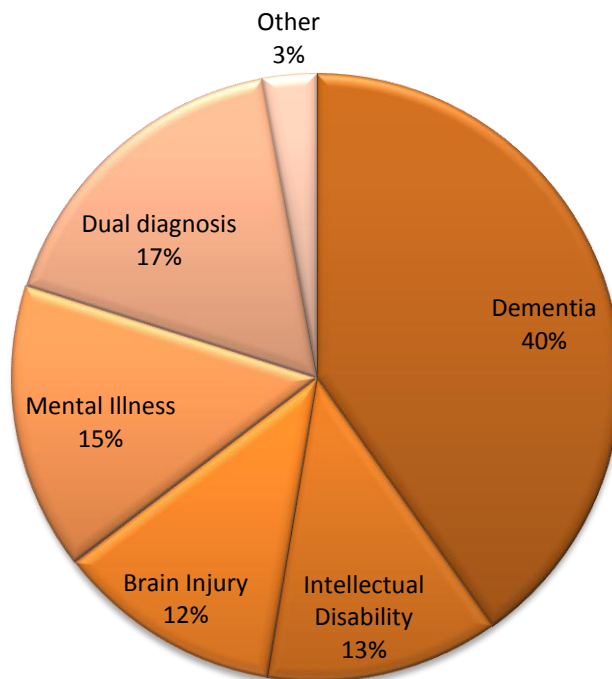
	Active Guardianship Cases	New Guardianship Cases
Age		
< 41 years	33%	18%
41 to 70 years	33%	41 %
> 70 years	33%	41%
Gender	females and males were equally represented.	52% percent of new clients were female.

Diagnostic profiles are illustrated in the following charts. People with dementia represent a greater proportion of new cases (40%) and closed cases (45%) reflecting that for many people their guardianship order can be revoked once they have settled in a nursing home. It also reflects the death rate of this aged population.

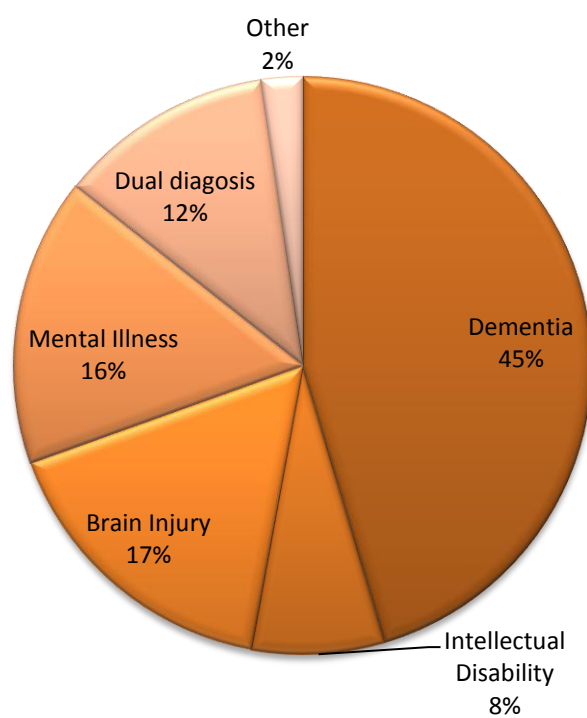
Diagnostic Profile Active Cases 30th June 09



Diagnostic Profile New Cases 08/09



Diagnostic profile: Closed cases as of 30 June 2009



Investigations

Guardianship and Administration Act 1993

Section 28—Investigations by Public Advocate

- (1) The Public Advocate must, if the Board so directs after an application has been lodged with the Board for an order under this Part, investigate the affairs of the person the subject of the application.
- (2) On completing an investigation carried out at the direction of the Board, the Public Advocate must furnish the Board with a copy of the report of the investigation.
- (3) The Board may receive the copy of the report in evidence and may have regard to the matters contained in the report.

The Guardianship Board can direct that the Public Advocate conduct an investigation under Section 28 of the *Guardianship and Administration Act 1993*. This year this work was shared by the three guardian staff of the Short Term Intake team (in addition to their other guardianship duties).



Senior Guardian Elly Nitschke prioritises new investigation referrals with Administration Officer Michelle Howse.

The Office of the Public Advocate responded to 44 requests from the Guardianship Board to investigate matters before the Board.

- 6 were open at the beginning of the reporting period,
- 38 were opened during the year and
- 3 remained open as at 30 June 2009.

Investigators aim to provide a balanced concise report on the circumstances of the person, relevant to the application before the Board.

Investigation reports are then presented as evidence at Guardianship Board hearings, and can be considered along with other evidence presented.

The provisions of section 28 are very broad and could allow an open ended inquiry into all aspects of a person's life. Social work staff undertake these investigations by meeting with relevant parties to obtain their views and assessing the information obtained.

Increasingly staff undertaking these investigations have been requesting that the Board be quite specific about the nature and the extent of the investigation it requests so as to avoid unnecessary intrusion into people's lives, and minimise delay.

The Office of the Public Advocate is currently reviewing the nature and processes of its investigations aiming to clarify the scope of investigations, and the extent to which investigations should make determinations on the facts of the matter and the nature of the reports provided to the Guardianship Board.

Attendance at hearings for new appointments

This is not part of the investigation process but is a parallel activity of the Office in that it involves reviewing potential appointments.

Whenever an applicant to the Guardianship Board nominates the Office of the Public Advocate as a guardian for an individual, the Office will consider the application. Wherever possible a staff member from this Office attends the hearing.

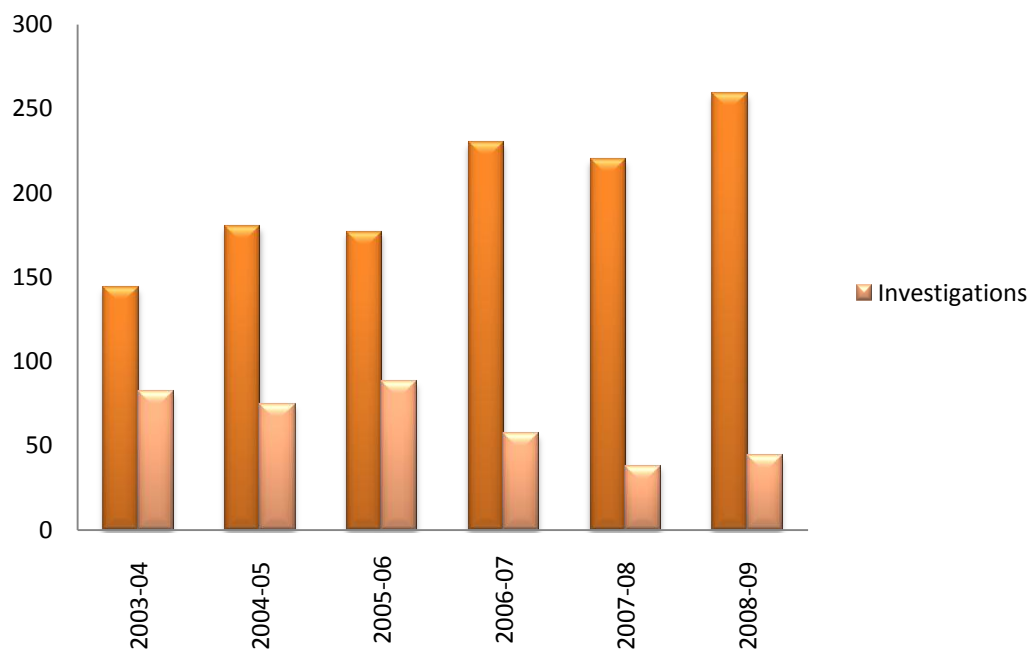
In some cases, additional information is obtained from the applicant and family members prior to the hearing.

The Office is then able to offer an informed view about its potential role. Given the Office's focus on autonomy and self determination and the significance of family members, in some cases the Office will suggest alternatives to guardianship (eg advocacy for services or accommodation), the appointment of a family member as guardian, or a more limited appointment than initially requested by the applicant.

The Office of the Public Advocate reviewed 259 applications where it was nominated for appointment as guardian.

Combining the number of investigative activities performed in each year, the following picture emerges:

New Hearings Attended and Investigations 2003-2009



Applications for Warrants by the Public Advocate

Guardianship and Administration Regulations 1995

7—Annual report (Public Advocate)—prescribed particulars of warrant applications (section 24)

For the purposes of section 24(2) of the Act, the particulars relating to applications for warrants made during the year that must be included in the Public Advocate's annual report are as follows:

- (a) the number of applications for warrants made during the year;
- (b) the age, sex and details of the alleged mental incapacity of the persons to whom the applications related;
- (c) the grounds on which the applications were based;
- (d) the number of applications withdrawn during the year;
- (e) the number of warrants issued during the year;
- (f) the number of warrants refused during the year;
- (g) in relation to warrants issued—
 - (i) the age, sex and details of the mental incapacity of the persons to whom the warrants related;
 - (ii) the grounds on which the warrants were issued;
 - (iii) the action taken under the warrants.

During 2008-2009 there were no applications for warrants made by the Public Advocate.

There were instances where warrants were considered, but it was generally possible to work with persons of concern to ensure that they were seen, and their case could be brought before the Board.

Therefore warrants were not required or applied for.

Individual Advocacy

Guardianship and Administration Act 1993

Section 21 (1) The functions of the Public Advocate are—

- (d) to speak for and negotiate on behalf of any mentally incapacitated person in the resolution of any problem faced by that person arising out of his or her mental incapacity;

The Office of the Public Advocate undertakes extensive advocacy for people under guardianship. In addition, advocacy forms part of our enquiry service, which as well as giving information, at times also makes calls on behalf of individuals to ensure that they receive assistance.

When ongoing advocacy is required, referrals are made to external advocacy services, which find it difficult to meet demand on them, but nevertheless endeavour to fill the gap.

A small number of individual advocacy matters were taken on by the Office. There were 44 individual client advocacy matters during 2008–09, 27 of which were new cases. This compares with a total of 50 in 2007–08 and 59 in 2006–07.

With respect to mental health matters, the Office of the Public Advocate:

- Receives telephone enquiries from people who are detained or are the subject of an application for community treatment order.
- Provides telephone advice about appeals
- Maintains a list of lawyers used by the Guardianship Board to allocate a legal representative for persons lodging an appeal. Legal representation is available at no cost when the appeal is lodged by the person who is subject to an order.

This is a limited response and more can be done. For example, in Victoria, when the Office of the Public Advocate in that state receives a request for information from a person who has been detained, the Office can despatch a community visitor to meet with a detained person and provide more information and support for that person. In the future, this should occur in our state with the establishment of the Mental Health Community Visitors Scheme as part of the *Mental Health Act 2009*.

Lack of routine advocacy before the Board for both Guardianship and Mental Health Act matters, remains a gap. This applies to applications for orders under the *Guardianship and Administration Act 1993* and for applications for Community Treatment Orders, Continuing Detention, or Electroconvulsive Therapy under the *Mental Health Act 1993*.

In our existing legislation, it was envisaged that the Office of the Public Advocate would take a greater role than it does in providing advocacy before the Board. The Act provides for this Office to appear before the Board on behalf of persons who are the subject of proceedings. Mental health consumers are routinely advised in writing that the Public Advocate can lodge an appeal on their behalf.

This is particularly relevant for the hearings of the Board where legal representation is not available. For these matters, there would be a benefit in either extending the current legal representation scheme to cover Guardianship Board matters that are not covered, or by ensuring that people have access to a lay advocate from this Office or elsewhere.

Court-Related Matters

If a person with a mental incapacity is unable to instruct their lawyer, the Public Advocate can be appointed by the court in order to provide those instructions under the relevant court rules (e.g. as litigation guardian). This is consistent with the mandate of the Office of the Public Advocate to promote and protect the rights and interests of people with a mental incapacity.

In addition, under the provisions of the *Wills Act 1993*, the Public Advocate is informed of matters involving applications to the court to alter the wills of people who have lost testamentary capacity.

In 2008–2009, 10 matters were classified as court-related matters. Seven of these were opened during 2008–09.

Education

The Office of the Public Advocate has continued to respond to requests from organisations and individuals to participate in a range of activities.

The Office of the Public Advocate accepted 29 invitations to speak at conferences and meetings during 2008–2009.

Community Education has formed a part of activities discussed elsewhere in this Report, including work with the Alliance for the Prevention of Elder Abuse, and the provision of printed information sheets about the *Guardianship and Administration Act 1993* and the *Mental Health Act 1993*.

The information resources of the Office of the Public Advocate available on the web are well used. In 2008–2009, the daily average number of visitors is 70 individuals.

Ongoing work in this area will be influenced by:

- The need to update existing resources to be consistent with the *Mental Health Act 2009*.
- Responsibilities likely to be associated with any new proposals emanating from the Advanced Directives Review.
- Ongoing participation with the Alliance for the Prevention of Elder Abuse and the Aged Rights Advocacy Service “Kick Start Initiatives” Program, both of which have a primary focus on prevention through education and information strategies

The Alliance for the Prevention of Elder Abuse

The work with the Alliance is reported here under ‘education’ but spans both advocacy and service improvement.

In late 2008, a number of South Australian agencies combined their efforts with a view to improving and challenging the way that abuse of older people is understood and addressed. The Alliance for the Prevention of Elder Abuse (APEA) consists of representatives from the Aged Rights Advocacy Service, the Office of the Public Advocate, Legal Services Commission, the Public Trustee and South Australia Police.

During the last twelve months, APEA has been successful in achieving a number of goals flowing from the State Plan, ‘Our Actions to prevent the abuse of older South Australians’, written by the Office for the Ageing (OFTA). Funding from ‘Our Actions’ (provided by OFTA) supported the appointment of a Project Officer (.4) to APEA for 12 months (based at the Aged Rights Advocacy Service) who coordinated a number of APEA activities including:

- The production of a 5-pamphlet kit to assist older people to maintain control of their lives and plan for a safe financial future
- Development of the APEA website
- Development of a protocol flowchart for APEA services
- Development of strategies to assist financial institutions to identify and deal with financial abuse
- Community Education forums providing information about advance directives
- Delivering papers and participation in panel discussions at the annual ARAS World Elder Abuse Awareness Day (WEAAD) conference.

The APEA is most appreciative of the funding made available by the OFTA for the Project Officer, as this role was vital in achieving the goals set by 'Our Actions'. The challenge for the APEA in the coming twelve months is to source and secure funding to enable the continuation of a project officer to assist in furthering the aims of the APEA to address the abuse of older citizens.

University of South Australia Collaborative Research Project on Mediation

The Office of the Public Advocate continues its commitment to the prevention of abuse of older South Australians by collaborating with the University of South Australia, the Minister for Families and Communities, Relationships Australia, Alzheimer's Australia (SA) and the Guardianship Board to secure an Australian Research Council Linkage Grant. This two-year study aims to design, pilot and evaluate specialised models of older-person centred family mediation for both primary and secondary levels of intervention as strategies to prevent the abuse of older people by their family members in situations where the older person has capacity, diminished capacity or lacks capacity.

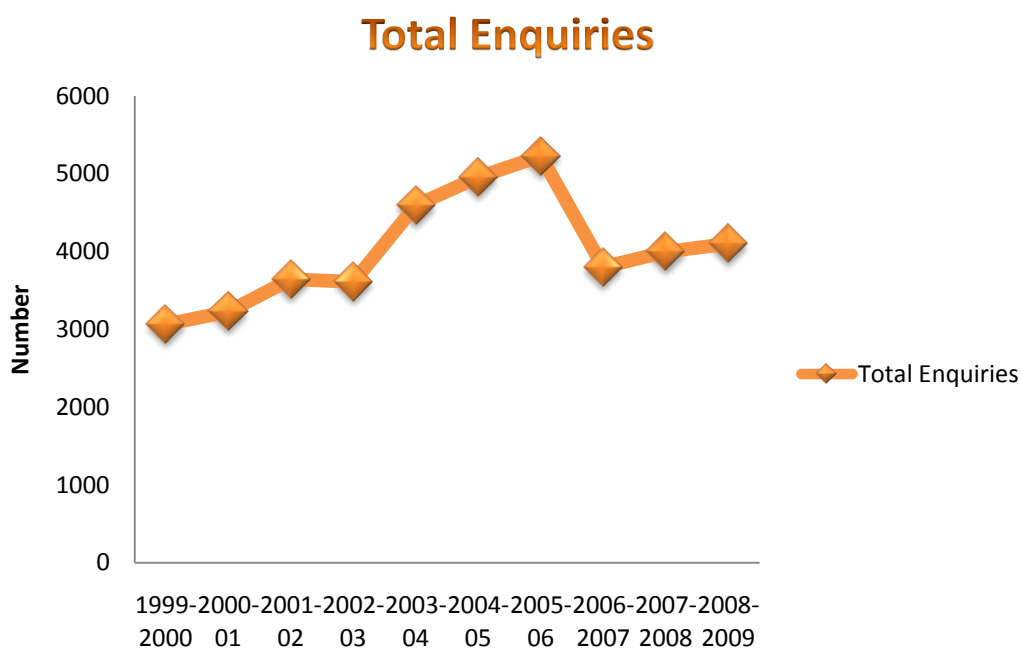
The Office of the Public Advocate is pleased to have the opportunity to work in collaboration with our research partners. The Office of the Public Advocate will contribute in-kind support, which will include the provision of a qualified mediator, experienced in mediating with older people and their family members. This work is consistent with our role providing alternatives to guardianship. As a member of the Reference Group, The Office of the Public Advocate will provide valuable advice and guidance, based on our experience.

Enquiry Service

The OPA allocates 1.2 FTE PO1 staff to its enquiry services. This section receives telephone enquiries from people who have a disability, their family members, health care professionals and others providing services.

Each person contacting the service may call on a number of occasions and make more than one enquiry. Hence, the data below reflect the number of enquiries not the number of people making enquiries

This year, there were 4098 discrete episodes of enquiries. A comparison with previous years is graphed below.



Common reasons for calling included requesting information about

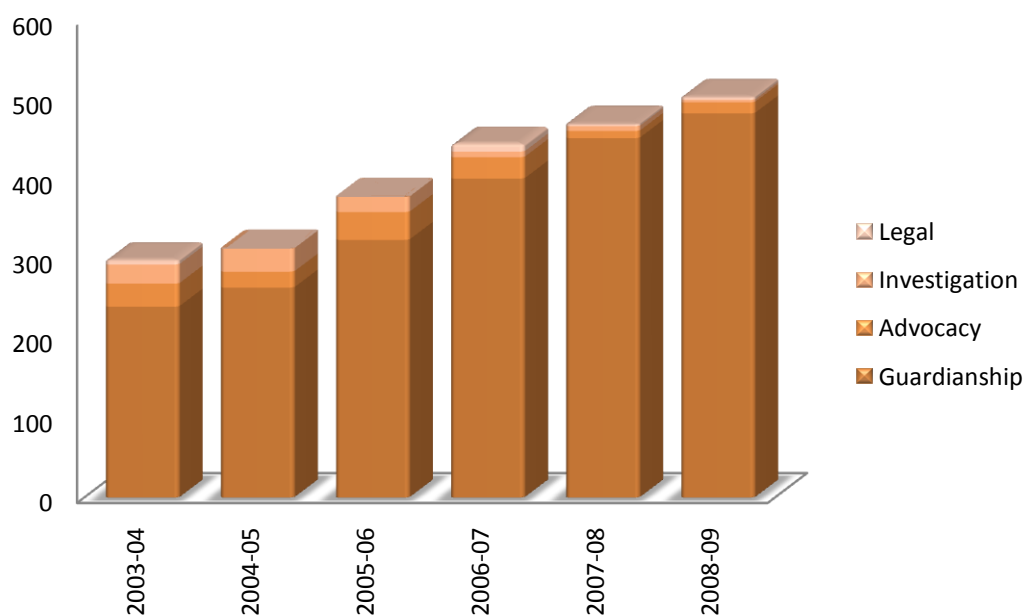
- advance directives
- guardianship and administration
- mental health appeals.

Balance of overall work

This graph illustrates the end-of-year active cases for the past six financial years by type categories of cases. Note that guardianship accounts for the increase in active caseload.

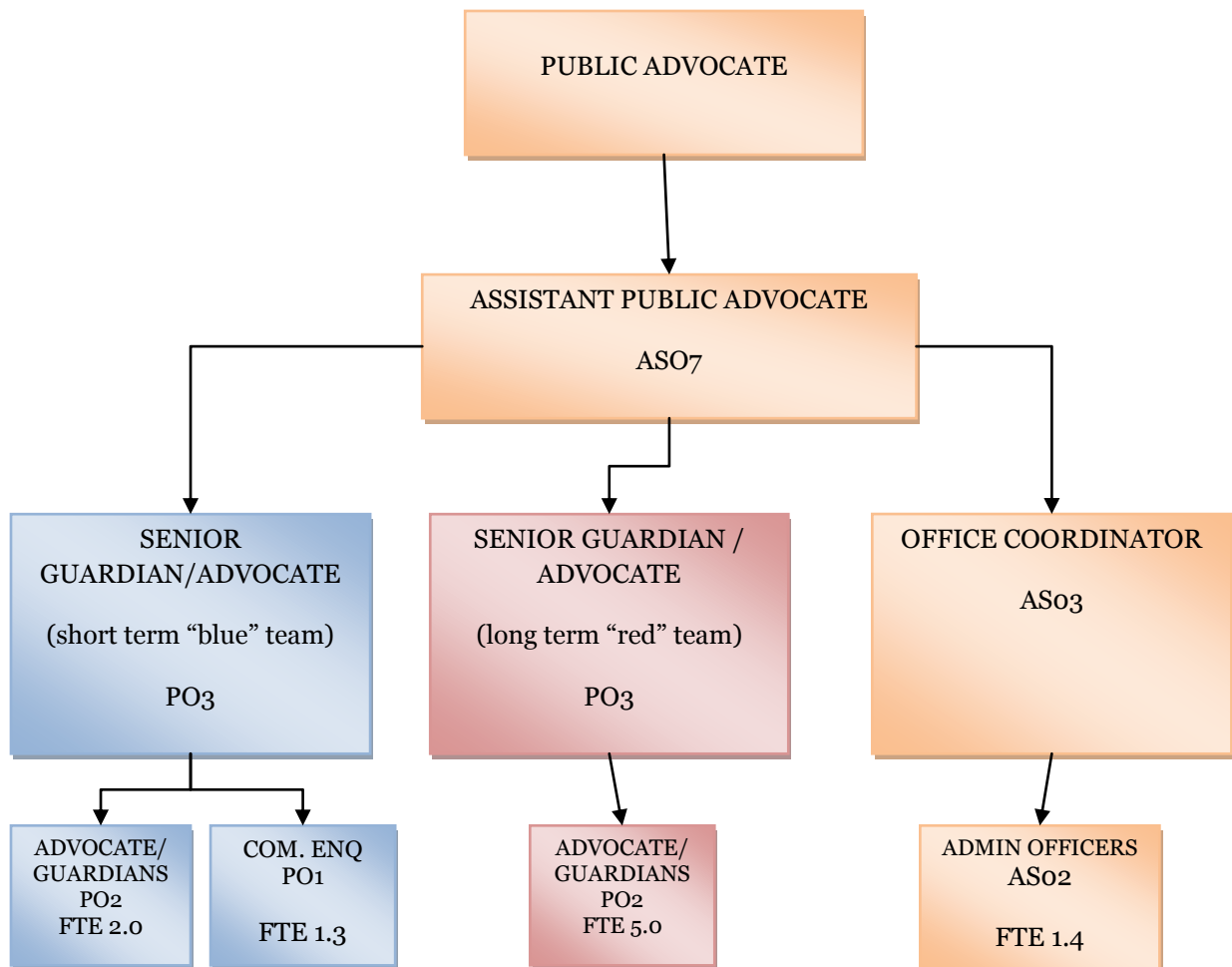
This graph does not reflect the time spent on each activity, as investigations for example, involve intensive time investment over a short period of time.

Proportion of work (by case numbers)



Employment and Human Resources

Funded positions as at 30 June 2009



Staff of the OPA 2008-2009

Funded staff establishment: 14.7 FTE

The following is a list of staff who have worked either full time or part time at the Office of the Public Advocate for some time during 2008-2009.

John Brayley	Public Advocate
Margaret Farr	Assistant Public Advocate until 30 March 2009 (long service leave)

Administration

Trish Bull	Office Coordinator
Cheryl Thomas	Administration Officer
Michelle Howse	Administration Officer
Di Chartres	Executive Project Officer (part time)
Debbie Buttress	Senior Project Officer

Advocacy, Guardianship, and Investigation

Julie-Anne Dowling	Acting Assistant Public Advocate from 30 March 2009 onwards
	Senior Advocate /Guardian Long Term Team (from December 2008)
	Advocate/Guardian
Elly Nitschke	Senior Advocate/Guardian Short Term Team
David Cripps	Acting Senior Advocate/Guardian Long Term Team 30 th March 2009 onwards
Karen Bowden	Advocate and Guardian
Maria Atkins	Advocate and Guardian
Bethany Jordan	Advocate and Guardian
Andrew Sarre	Advocate and Guardian

Margi Keville	Advocate and Guardian
Elicia White	Advocate and Guardian
Barbara Robertson	Advocate and Guardian
Mylee Edwards	Advocate and Guardian
Chris Northcott	Advocate and Guardian
Tarnia White	Acting Advocate and Guardian
	Community Enquiry Officer
Jenny Fox	Community Enquiry Officer
Rosemary Hillard	Community Enquiry Officer
Passant Ibrahim	Student – Final Placement

Rotary Research Project

Ellie Rosenfeld	Rotary Senior Research Officer
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Occupational health, safety and injury management

OPA was guided by the policies and best practice principles of the Attorney General's Department in relation to occupational health and safety and injury management. Practical assistance was provided by the AGD on request, and OPA uses the Department's Workplace Health and Safety Division when required. OPA participate in the AGD policy reviews and audits.

OPA has an elected, trained OHS representative and First Aid Officer. OHS matters are routinely discussed in OPA staff meetings.

There were no work related claims during this reporting period.

Loss of work time through sick leave was 7.8 days per FTE this year, 5.7 days in sick leave, 1.7 days in family carer leave and 0.4 days in special leave with pay.

OPA was assisted by the temporary placement of government redeployees during 2008-2009 as well as student placements.

Student Placements

In 2008 the Office of the Public Advocate offered a field education placement to a Flinders University Masters of Social Work student. Passant Ibrahim completed a successful 70 day placement during which time she assisted with guardianship work and participated in the wider work of the Office.

She conducted a Client Satisfaction Survey that was designed and completed with assistance from Dr Keith Miller, Flinders University. Feedback was generally positive with 65% of respondents rating their overall satisfaction with OPA's service as very good or excellent.

In late 2008, final year University of Adelaide law student Catherine Stubberfield worked at this Office part time. Catherine worked on the development of a Community Guardian model based on the Victorian program. She focused on the legal and risk management aspects of the proposal, and received support and oversight from our advising lawyer in the Crown Solicitors Office while doing this work.

Both Passant and Catherine were able to accompany the Public Advocate and Assistant Public Advocate to a meeting with the Attorney General and present key findings from their work.

References

Attorney General's Department New South Wales (2008) Capacity Toolkit, Government of New South Wales, Sydney

http://www.lawlink.nsw.gov.au/lawlink/diversityservices/LL_DiversitySrvces.nsf/pages/diversity_services_capacity_toolkit Accessed August 5 2009.

Australian Bureau of Statistics (2004) Persons with a disability, Disability Status by Main Health Condition- South Australia – 2003,

<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02003?OpenDocument> Accessed 25th September 2009

Australian Bureau of Statistics (2009) Noticeboard: Survey of Disability, Ageing and Carers 2009

<http://www.abs.gov.au/Websitedbs/c311215.nsf/20564c23f3183fdaca25672100813ef1/4302cod294e39e93ca2572f300149cff!OpenDocument> Accessed 25th September 2009.

Australian Institute of Health and Welfare (2003) Disability prevalence and trends, AIHW Canberra.

Australian Institute of Health and Welfare (2008) Disability in Australia: trends in prevalence, education, employment and community living, Bulletin 61, AIHW Canberra.

Australian Institute of Health and Welfare (2008) Disability Support Services 2006-07, AIHW Canberra.

Australian Institute of Health and Welfare (2009) Disabilities in Australia: multiple disabilities and need of assistance, AIHW Canberra.

Buchanan A and Brock D (1990) Deciding for others: The Ethics of Surrogate Decision Making, Cambridge University Press, Cambridge.

Calcedo-Barba A, Garcia-Solano Fernando, Fraguas D and Chapela E (2007) On measuring capacity, *Current Opinion in Psychiatry* 20:501-506.

Carney T and Tait D (1997) The Adult Guardianship Experiment, Tribunals and Popular Justice, The Federation Press, Sydney.

Chenoweth L, and Clements N (2009) Final Report Funding and Service Options for People with Disabilities, Griffith University.

Council of Australian Governments (2008) National Disability Agreement Fact Sheet, November 2008 http://www.coag.gov.au/coag_meeting_outcomes/2008-11-29/docs/20081129_national_disability_agreement_factsheet.pdf Accessed 24 September 2009.

Department of Families and Communities (2007) Annual Report 2006-2007 http://www.familiesandcommunities.sa.gov.au/DesktopModules/SAHT_DNN2_Documents/Download/633896597741707648/DFC%20Annual%20Report%2006-07.pdf Accessed 26th September 2009.

Department of Families and Communities (2008) Disability SA Eligibility and Access Guidelines <http://www.sacentral.sa.gov.au/subject/Community+Support/Disability/Corporate+and+business+information/Disability+SA+eligibility+and+referrals/Disability+SA+eligibility> Accessed 26 September 2009.

Department of Human Services (2005) Responding to Allegations of Physical or Sexual Assault – Departmental Instruction, Department of Human Services, Melbourne (downloadable on the web at www.dhs.vic.gov.au)

Churchill R, Owen G, Singh S, Hotopf M (2007) International experiences of using community treatment orders, Department of Health, UK

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_072730 Accessed 7th September 2008

Currie C (2005) SAMHSA's Commitment to Eliminating the Use of Seclusion and Restraint, Psychiatric Services, 56:1139-1140, <http://www.ps.psychiatryonline.org/cgi/reprint/56/9/1139> Accessed 9th September 2008.

Department of Health (2000) No Secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse, Home Office and Department of Health, London, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008486

Department of Health (2009a) Adult Community Mental Health Services (Metropolitan Regions) Integrated Model of Care 3 August 2009, Mental Health Operations Unit, Operations Division, Department of Health. www.health.sa.gov.au

Department of Health (2009b) Draft South Australia's Mental Health and Wellbeing Policy, Mental Health Policy Unit, Policy and Intergovernmental Relations Division, Department of Health. www.health.sa.gov.au

Engleman N, Jobes D, Berman A and Langbein L (1998) Clinicians' Decision Making About Involuntary Commitment, Psychiatric Services 49:941-945.

Gardner J, Saunders D and Schwass W (2009) Review of the Mental Health Act 2009 – Community Consultation Report July 2009, Government of Victoria.

Glendinning C, Challis D, Fernandez Jose-Luis et al (2008) Evaluation of the Individual Budgets Pilot Programme – Summary Report, Social Policy Research Unit, University of York, www.york.ac.uk/spru Accessed 4th October 2009.

Gout H (2009) Forcible Restraint: Hospital Patients With Nowhere to Go, Independent Weekly Newspaper, May 2009, <http://www.independentweekly.com.au/news/local/news/general/hospital-patients-with-nowhere-to-go/1527002.aspx> Accessed 6th October 2009

Julia Farr Association (2009) Briefing: family members causing harm to their loved ones living with disability http://www.juliafarr.org.au/doc_library.asp?category=52

Kisley S, Campbell LA, Preston N (2005) Compulsory community and involuntary outpatient treatment for people with severe mental disorders, Cochrane Collaboration Systematic Reviews, <http://mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD004408/pdf fs.html> Accessed 7th September 2008

Laragy C (2008) Australian research on individualised funding for people with intellectual disability: new opportunities or unacceptable risks, http://www.juliafarr.org.au/doc_library.asp Accessed 4th October 2009.

Large M, Ryan C, Nielssen O and Hayes R (2008) The danger of dangerousness: why we must remove the dangerousness criterion from our mental health acts. Journal of Medical Ethics 34:877-881.

Marshall M and Lockwood A (1998) Assertive community treatment for people with severe mental disorders, Cochrane Systematic Reviews, Issue 2 <http://mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD001089/frame.html> Accessed 9th September 2008.

Marshall M and Rathbone J (2006) Early Intervention for Psychosis (Review) Published in the Cochrane Library 2009 <http://www.mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD004718/pdf fs.html> Accessed 5th October 2009.

National Health Performance Committee (2001) National Health Performance Framework Report, Queensland Health, Brisbane

http://www.health.qld.gov.au/nathlthrpt/performance_framework/11381_doc.pdf Accessed 24 September 2009.

National Health and Hospitals Reform Commission (2008) Beyond the Blame Game: Accountability and performance benchmarks for the next Australian Health Care Agreements, NHHRC, Canberra http://www.health.qld.gov.au/nathlthrpt/performance_framework/11381_doc.pdf Accessed 24 September 2009

National People with Disabilities and Carer Council (2009) Shut Out: The Experience of People with Disabilities and the Families in Australia, Commonwealth of Australia, Canberra http://www.fahcsia.gov.au/sa/disability/pubs/policy/community_consult/Documents/NDS_report.pdf Accessed 25th September 2009

Office of the Public Advocate (2008) Submission to the Legislative Council Select Committee on Glenside Hospital, http://www.opa.sa.gov.au/documents/09_Publications/Papers/Presentations/Glenside%20Hospital%20Document%20-%20Index%20Hyperlink%20-%20Final%20-%20December%2020.pdf Accessed 24 December 2008.

Office of the Public Guardian (2009) A Guide to Supervision of Deputies, OPG Publication 507, <http://www.publicguardian.gov.uk/docs/opg507-june09-web.pdf> Accessed 3rd October 2009.

Parliament of Australia (2009) Who Cares...? Report on the inquiry into better support for carers, House of Representatives Standing Committee on Family, Community, Housing and Youth, Commonwealth of Australia, 2009. <http://www.aph.gov.au/house/committee/fchy/carers/report/fullreport.pdf>

Productivity Commission (2009) Review of Government Services, Chapter 14 Services for People with a Disability <http://www.pc.gov.au/gsp/reports/rogs/2009> Accessed 26th September 2009

Ruhrmann S, Schultze-Lutter F and Klosterkötter J (2009) Intervention in the at-risk state to prevent transition to psychosis, *Current Opinion in Psychiatry* 22:177-183.

Sattar S, Pinals D, Din A and Applebaum P (2006) The Psychiatry Resident as a Variable in Involuntary Commitment Decisions, *Academic Psychiatry*, 30: 191-195.

Social Inclusion Board (2007) Stepping Up: A Social Inclusion Action Plan for Mental Health Reform 2007-2012, Social Inclusion Board, Adelaide.

Stainton T (2008) Individualised Funding: An International Review of Approaches, Outcomes and Challenges, Prepared for the Roundtable on Intellectual Disability Policy: Implementing Individualised Funding, La Trobe University October 24, 2008 http://www.juliafarr.org.au/doc_viewer.asp?RID=807 Accessed 4th October 2009.

United Kingdom Government (2005) Mental Capacity Act 2005 http://www.opsi.gov.uk/acts/acts2005/pdf/ukpga_20050009_en.pdf Accessed 29 July 2009.

United Nations Enable (2009) Convention on the Rights of Persons with Disabilities <http://www.un.org/disabilities/default.asp?navid=12&pid=150> Accessed 21st September 2009.

United Nations Enable (2008) Chapter Six: From provisions to practice: implementing the Convention; Legal Capacity and Supported Decision Making <http://www.un.org/disabilities/default.asp?id=242> Accessed 21st September 2009

Victorian Council for Civil Liberties (2009) Dignity, autonomy, privacy: disability reforms <http://www.libertyvictoria.org/node/107> Accessed 29th September 2009

Victorian Law Reform Commission (2009) Review of Guardianship Law and Practises <http://www.lawreform.vic.gov.au/wps/wcm/connect/Law+Reform/Home/Current+Projects/Guardianship/LAWREFORM+++Guardianship+++Home> Accessed 29th September 2009.

Williams R (2007) Individualised Funding – A summary review of its nature and impact and key elements for success, Julia Farr Association, Adelaide
http://www.juliafarr.org.au/individualised_funding.asp Accessed 4th October 2009

XYZ v State Trustees Ltd [2006] VSC 444 (22 November 2006)
<http://www.austlii.edu.au/au/cases/vic/VSC/2006/444.html> Accessed 29th September 2009

Appendix A: Background on Assessing Performance of Human Service Systems (see Annual Report Part A “Program Review”)

The Program Review function gives scope for the Public Advocate to review programs designed to meet the needs of people who have a mental incapacity — including support services, professional care, accommodation and housing, work rehabilitation, and community participation. These services are funded by Commonwealth, State and Local government, and operated by government, the non-government not-for-profit sector, or private sector for-profit providers. Causes of incapacity include intellectual disability, brain injury, mental illness, neurological disease and dementia.

There is future scope for in-depth reviews of the performance of specific programs within each sector, and conducting more in-depth reviews of overall programs using internal government department data.

In this section of the Report, overall performance of the key State Government sectors of Disability, Mental Health, and Adult Protection is commented on.

In undertaking this task, it is useful to put the review in a framework. Where possible, review discussion is evidence based. The key sources of evidence that have been used are: (1) the scientific evidence base on what constitutes best practice, and delivers good outcomes; (2) data where available; and (3) the lived experience of consumers and carers who use the system. All three sources are complementary, and none is more important than the other.

Much of this discussion focuses on access to services, continuity of services, and whether consumers experience them as appropriate. However, these are just three components of performance.

Therefore, it is worth firstly briefly considering recognised performance frameworks used in both health and disability services. Australia’s National Health Performance Framework contains concepts that are applicable to general health, mental health and disability services. The framework is reproduced in Figure 1 (National Health Performance Committee, 2001).

The ultimate outcomes for healthy South Australians, including vulnerable adults, are broad measures of physical, mental and social wellbeing, and opportunities to participate and be active. These outcomes are not only determined by the performance of service systems, but broad societal factors.



Figure 1: National Health Systems Performance Framework

There are nine key performance factors that are listed in the framework — effectiveness, responsiveness, continuity, appropriateness, accessibility, capability, efficiency, safety and sustainability. All are important, and because of their fundamental nature, measures of access, continuity and appropriateness none can be considered a necessary first base.

For people who have a mental incapacity access includes the ability to obtain early intervention services, as well as gain entry to more intensive services when required. Appropriateness applies to support and rehabilitation services as well as to clinical care.

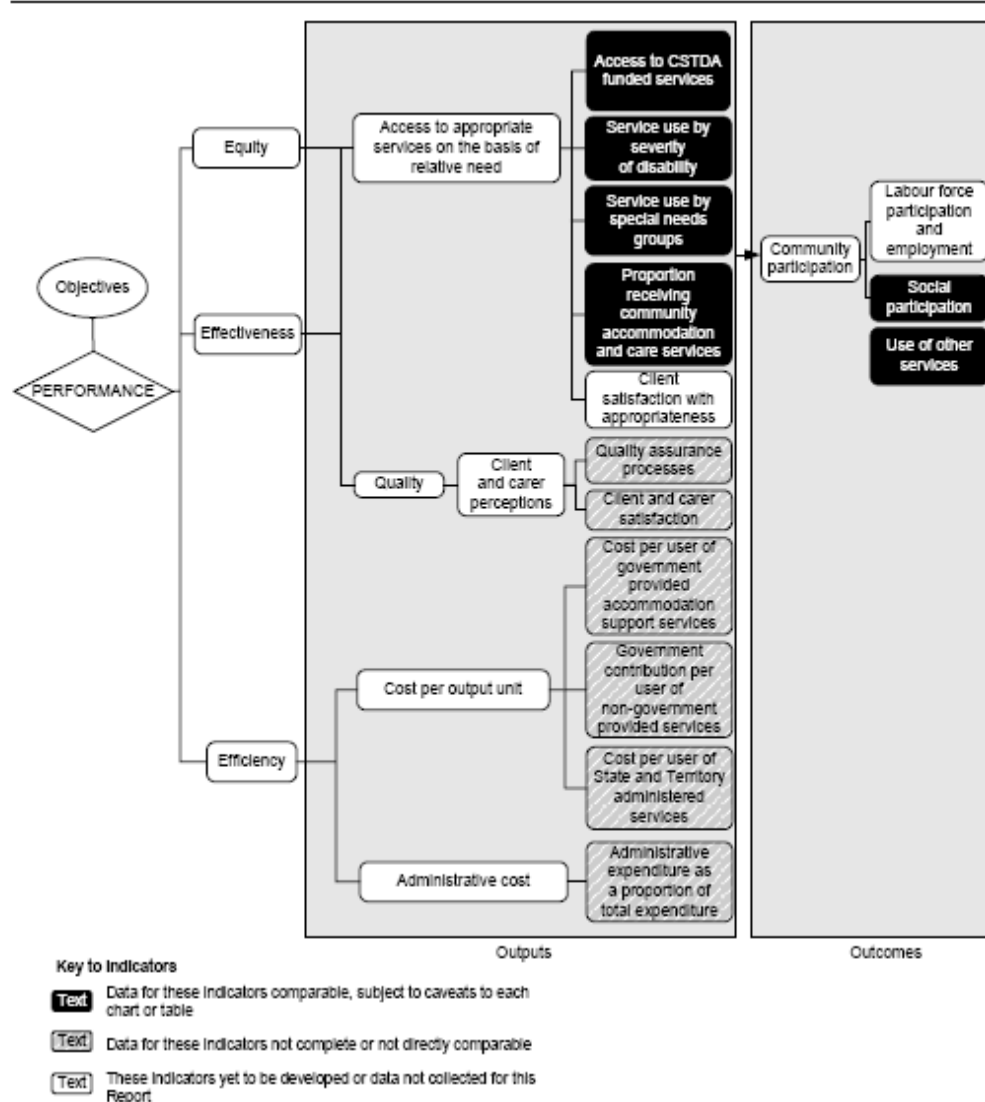
This emphasis on access and continuity is reflected in recent Australian reviews. For example, the National Health and Hospitals Reform Commission in its 2008 publication “Beyond the Blame Game” (NHHRC, 2008) lists performance benchmarks or “tracking indicators” for “redesigning the care for those with chronic and complex conditions” and “recognising the health needs of the whole person”. The emphasis is on measures of access, continuity and coordination. Amongst their carefully selected benchmarks are many that apply to people who have a mental incapacity, and include the waiting time for aged care assessment, waiting time for sub-acute care, waiting time for patients with psychosis seen by a community mental health professional within seven days after hospital, waiting time for access to public dental services, waiting time for admission to a supported mental health place in the community and patients’ experience of being treated with dignity.

Nationally, performance data that describe disability services have traditionally been collected to support advocacy and have emphasised access and need. For example, the Australian Institute of Health and Welfare in 2003 listed common purposes of collecting “minimum data set snapshot data” as: supporting budget submissions for increased funding or changing funding emphasis; supporting planning for future service delivery; resisting proposals to increase service-user contributions; providing national comparisons; and

indicating that certain groups of people are not accessing services as much as could be expected. The new National Disability Agreement of November 2008 aims for key reforms amongst others, of improved access to disability care, a renewed focus on early intervention and nationally consistent assessment processes and quality assurance (Council of Australian Governments Fact Sheet, 2008)

The Report of Government Services (2009) defines the following interrelationship between indicators with a focus on effectiveness, efficiency and equity of access. Data presented in the next section on disability services are consistent with this framework.

Figure 14.9 Performance indicators for services for people with a disability



Appendix B: The population who may require a disability service in South Australia (see Annual Report Part A “Program Review”)

In determining unmet need, it is first necessary to consider the prevalence of disabling conditions in the community and then compare this with the number of people who are receiving services.

The key data source for community prevalence is the Australian Bureau of Statistics (ABS) surveys of Disability Ageing and Carers, the two most recent completed surveys undertaken in 1998 and 2003. A new Australia-wide survey was due to be commenced in April 2009 (ABS, 2009)⁵.

A formal unmet need analysis would require work with the original datasets to determine community prevalence in South Australia for specific disabilities. However, to estimate broadly community prevalence, existing reports of the ABS and the Australian Institute of Health and Welfare (AIHW) have been used.

Each of these reports has grouped the causes of disability differently, so they need to be considered collectively to gain an impression of the number of people who might require a service. The reports consider disability broadly and do not differentiate between the service divisions of disability services, mental health, health and aged care. Nevertheless, some comparisons can be made — particularly for the groups with a specific disability such as an intellectual disability or brain injury, who have profound or severe functional limitations.

A 2003 AIHW publication used data from the 1998 survey to estimate the prevalence of people within main disability groups in Australia. These data are described in Table 1.

Disability Group	Percentage of total population	Severe or Profound Core Activity Limitation – Percentage of total population
Intellectual	2.7%	0.6%
Psychiatric	4.1%	0.7%
Acquired Brain Injury	1.1%	0.1%
Sensory/Speech	7.5%	0.5%
Physical/Diverse	16.2%	4.3%

Table 1. Analysis of main disability groups in Australia in 1998 (AIHW, 2003)

Table 1 is useful because of the recognisable groupings of people who have a disability associated with specific conditions.

⁵ To sample the Australian population, the ABS surveyors visit private homes, hotels, motels, boarding houses, hospitals, nursing homes and disability accommodation etc., and ask a set of standard questions. In the last completed survey in 2003, 14,300 dwellings were visited along with 550 establishments providing care. By doing this an estimate can be made of prevalence of disorders across the entire community, including people who may not be known to services. There is an error rate in this approach, which can be greater for less common conditions.

Specific South Australian data were published in 2004 by ABS using data from the 2003 survey. Table 2 describes the number of South Australians with a reported disability, plus the sub-set of those who have a profound or severe core activity limitation⁶. It is expected that a person with a severe and profound restriction should be receiving services.

Cause of disability	Number of South Australians with reported disability	Number of South Australians with a profound or severe core-activity limitation
Dementia, psychosis and mood disorders	18,700	10,000
Intellectual and developmental disorders	16,400	5,700
Other mental and behavioural disorders	11,000	5,700
Neurotic, stress related and somatoform disorders	12,900	3,100
[Physical conditions	303,000	80,700

Table 2: 2003 South Australian Data Describing Intellectual, Psychiatric and Behavioural Disorders– ABS (2004)

Unfortunately, this ABS analysis does not group underlying conditions in a way that is helpful for planning. For example, dementia and psychiatric illness are linked together in a single group. However, the number of people with an intellectual and development disorder who have a profound or severe impairment should be comparable in magnitude to the number of people receiving services.

In August 2008, the Australian Institute of Health and Welfare (AIHW) released an analysis of trends in disability in Australia that demonstrated increases in some groups. A table derived from their data illustrates increases in the number of people identified needing assistance for autism and for schizophrenia (Table 3).

These trends correlate with the experience of service providers for greater demand for dementia care due to an ageing population, increasing demand for services for people with autism spectrum disorders, and increasing demand for psychiatric disability services, as well as clinical mental health services.

⁶ The ABS use categories of profound core activity restriction (when a person is unable to do or always needs help with a core activity task), or a severe core activity restriction (includes sometimes needing help, or has difficulty being understood by family and friends, or can communicate more easily using sign language or other non-spoken forms of communication). Core activities comprise self care (such as bathing, dressing, eating), mobility, and communication (AIHW, 2008).

Condition	1998 Severe or profound disability SA Estimate	2003 Severe or profound disability SA Estimate	Change 1993-2003
Autism	918	1835	100%
Depression	5550	10515	89%
Schizophrenia	1354	1798	32%
Dementia	7045	7311	4%
ADHD	2405	2479	3%
Multiple sclerosis	784	511	-34.7%
(estimates have a standard error of 25-50% and need to be used with caution)			

Table 3: South Australian estimate based on AIHW (2008) Australia Wide Data Analysis of Change in Disability Prevalence for Selected Conditions. For the purpose of this discussion an estimate of South Australian numbers has been determined by using the original AIHW figure for Australia and calculating 7.4% of that total, to reflect this state's population.

Consideration of multiple disabilities

A 2009 report from the AIHW Disability Series, further analyses the 2003 data to describe the impact of multiple disability (AIHW, 2009). Previous analysis has tended to categorise people into groups, whereas this paper determined that over a half of all Australians with a disability had a combination of two or more intellectual, psychiatric, sensory/speech, acquired brain injury and physical disabilities.

People who have multiple disabilities are more likely to have a profound or severe impairment in their activities.

This has implications for both service review and analysing unmet need. Disability providers will either need to have the expertise to manage a range of disabilities, or have effective partnerships with other agencies that can provide services and expertise that they cannot. Sound and effective links are required with health services, given the prevalence of both mental illness and physical conditions.

Unmet need cannot only be considered by determining whether a person is receiving services for what is considered to be a primary disability, but also whether all the needs associated with that disability are met, and if services for co-morbid disabilities are provided.

Age Group	Prevalence of Multiple Disabilities	Top three most Frequent combinations for people with more than one disabilities	SA Estimate prevalence
Under 15	49%	Intellectual and psychiatric	2020
		Intellectual and physical	1436
		Intellectual and sensory/speech	1347
15-64 years	45%	Psychiatric and physical	17, 989
		Acquired brain injury and physical	6386
		Psychiatric, sensory/speech and physical	4373
65 years and over	62%	Psychiatric and physical	5543
		Psychiatric, sensory/speech and physical	5165
		Intellectual, psychiatric, sensory/speech and physical diverse	4877

Table 4: SA Estimates of Multiple Disability based on 2003 Australian Wide Data - AIHW (2009) Report on Multiple Disability

Appendix C Formal Matters Raised with the Minister (Section 22 (3) Report)

If calling please ask for
John Brayley

Telephone
8269 7575

5 May 2009

The Honourable Jennifer Rankine
Minister for Disabilities
45 Pirie Street
ADELAIDE SA 5000

Dear Minister Rankine

Re PEOPLE REQUIRING DETENTION IN HOSPITAL WHILE AWAITING DISABILITY SA SERVICES

Thank you for the opportunity to meet today.

I now write to you about one of the matters discussed, in accordance with the provisions of Section 22 (1) and (3) of the Guardianship and Administration Act 1993. Under Section 22 the Public Advocate may raise matters with the Minister and the Attorney General.

The context of this letter is a situation where people with a disability can wait in hospital for many months for supported accommodation, well past the time that they clinically require hospital care.

My particular concern relates to a number of instances where it has been necessary for the Public Advocate to apply for and invoke special powers to place and detain patients (Section 32 (a) (b) of the Guardianship and Administration Act) to keep people in hospital. In some instances people have needed physical restraint while waiting to leave hospital under the provisions of Section 32(c).

In these cases the powers have been used principally because the person is still in hospital and confined to a hospital room. It is likely that in many instances security guards and restraint teams would not be needed if the person were in their preferred community accommodation with disability supports.

I have written a second confidential letter which gives examples of cases from recent weeks. While clinical problems such as agitation may be caused by a person's underlying illness, it is reasonable to conclude that it escalates further when they wish to return home but are unable to do so, are living in a hospital room, and are not in a more calming spacious residential environment.

This causes avoidable harm to the individual (in particular if the placement of security guards and physical restraint is needed) and is an infringement on an individual's rights.

PROMOTING THE RIGHTS AND INTERESTS OF PEOPLE WITH A MENTAL INCAPACITY



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I note that when extreme situations occur Disability SA staff do their very best to find solutions, but even when this happens stays in hospital are prolonged.

In these situations a Guardian has little option. If Section 32 directions are revoked the person may be at greater immediate risk if they leave hospital without services. For this reason continuing the orders is safer than cancelling them in most situations given the system constraints. The preferred option however would be early placement with proper supports.

The purpose for this letter is to raise this problem so that solutions can be put in place, rather than suggesting a particular plan. Nevertheless I make the following comments about potential design solutions.

First, in human service "modernisation" and "reform" within large organisations it is common to set redesign targets for how quickly assessments are made and decisions about eligibility completed. A target timeframe would allow consumers to mentally plan ahead how long it will take rather than experience sequential delays.

Second, the option of short term accommodation and support should be available. This would resolve the current situation where there is an extra delay caused through requests for detailed definitive decision about long term eligibility. For people who have had a brain injury their situation may improve significantly over the first 6 -12 months. With a fast short term allocation the person would receive assistance to support immediate rehabilitation, but their longer term needs may be considerably less.

Third, demarcation disputes between funders and providers need to be eliminated. Whether the service is provided by Disability Services, Domiciliary Care or Mental Health it is still the Government that ultimately funds the service. There is no value to the consumer in waiting in hospital so services can ensure that the correct provider picks up the tab. Having multiple queues for similar services creates more inefficiency and delay. Disability services provided by either Disability SA or Health should be jointly allocated on need.

I would be grateful if you could respond to the matter I have raised with respect to patients who are detained while waiting for accommodation and support services, as well as commenting on solutions.

Yours sincerely


John Brayley
PUBLIC ADVOCATE

Copy for information: Attorney General

Hon Jennifer Rankine MP

OPA No. 4268	OO
Serv 13/7/09	Epi 8619



Government
of South Australia

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and Communities
Minister for the Northern
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Minister.Rankine@saugov.sa.gov.au

09MDI/0219T

Dr John Brayley
Public Advocate
PO Box 213
PROSPECT SA 5082

Dear Dr Brayley

Thank you for your correspondence regarding the issue of people with a disability awaiting discharge from hospital settings.

This situation is of obvious concern to both the Minister for Health, Hon John Hill MP and myself. We have requested that our respective departments work together on this issue to determine if we can provide more appropriate responses to those affected. As you are aware, the issues you have raised are complex to resolve and present ongoing challenges to both the acute health and disability sectors.

I am advised that in the vast majority of cases where people are awaiting hospital discharge, a person's eligibility for Disability SA services has already been determined. While some people who remain in hospital will require a blended health and disability service outside of an acute setting, the question of eligibility for services is not usually the cause of the extended hospital stay. Rather, the cause of the delay is more likely to be due to the high demand on funded supported accommodation placements or the high demand on services to support people in their homes.

Disability SA does run a 'fast track' system for determining eligibility in certain situations. I am advised that in two cases you mention

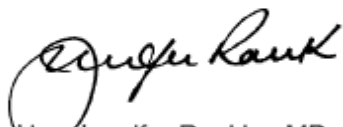
it is uncertain as to whether they are eligible for ongoing Disability SA services. Nonetheless, in these two cases, Disability SA is providing case management support until eligibility can be determined.

All clients who require urgent accommodation, whether they are awaiting hospital discharge or living in the community, are referred to the Disability SA Accommodation Placement Panel once eligibility is determined. The panel meets regularly and priority is given to those in most urgent need. Factors such as a person's deteriorating mental state and personal risk, are taken into consideration when determining the priority of the response. It is also important to remember that from a prioritisation point of view, people at risk of harm in the community are sometimes a greater priority than those who are in a secure care environment.

Unfortunately, Disability SA does not have the resources to provide ongoing support services to those who fall outside its client base. I do not believe that this is a matter of demarcation disputes between government departments, but rather a matter of determining funding priorities within a complex and high-demand service area.

Thank you again for raising your concerns with me about this important matter.

Yours sincerely



Hon Jennifer Rankine MP
MINISTER FOR DISABILITY

2 / 7 / 2009

Appendix D: Summary of the Role, Structure and Function of the Office

The Public Advocate is established under Division 3 of the *Guardianship and Administration Act 1993*.

The general legislative functions defined under Section 21 of the Act are:

“21—General functions of Public Advocate

- (1) The functions of the Public Advocate are—
 - (a) to keep under review, within both the public and the private sector, all programmes designed to meet the needs of mentally incapacitated persons;
 - (b) to identify any areas of unmet needs, or inappropriately met needs, of mentally incapacitated persons and to recommend to the Minister the development of programmes for meeting those needs or the improvement of existing programmes;
 - (c) to speak for and promote the rights and interests of any class of mentally incapacitated persons or of mentally incapacitated persons generally;
 - (d) to speak for and negotiate on behalf of any mentally incapacitated person in the resolution of any problem faced by that person arising out of his or her mental incapacity;
 - (e) to give support to and promote the interests of carers of mentally incapacitated persons;
 - (f) to give advice on the powers that may be exercised under this Act in relation to mentally incapacitated persons, on the operation of this Act generally and on appropriate alternatives to taking action under this Act;
 - (g) to monitor the administration of this Act and, if he or she thinks fit, make recommendations to the Minister for legislative change;
 - (h) to perform such other functions as are assigned to the Public Advocate by or under this Act or any other Act.
- (3) The annual report furnished by the Public Advocate under this Act must include a summary of any matters raised by the Public Advocate under subsection (1).

Other legislated functions include:

- To act as guardian of last resort when appointed by the Guardianship Board;
- To investigate matters where a person who has a mental incapacity is at risk of abuse, exploitation or neglect (including self-neglect).

In addition, the Office of the Public Advocate:

- Provides advice and information about the Guardianship and Administration Act 1993, the Mental Health Act 1993 and the Consent to Medical Treatment and Palliative Care Act 1995 in a variety of formats.

Legislative authority

The Office of the Public Advocate (OPA) takes its legislative authority from the *Guardianship and Administration Act 1993* and the *Mental Health Act 1993*.

The Office of the Public Advocate is also bound to comply with legislation that relates to the management and accountability requirements of the Government, including:

- *Equal Opportunity Act 1984*
- *Occupational Health, Safety and Welfare Act 1986*
- *Public Sector Management Act 1995*
- *Sex Discrimination Act 1984*
- *Workers Rehabilitation and Compensation Act 1986*.

Organisation of the agency

The Public Advocate is an independent statutory official accountable to the South Australian Parliament. The Public Advocate is not subject to the control or direction of the Minister. The Public Advocate is supported by a team of public servants.

Relationship to other agencies

The Office of the Public Advocate was funded by the Attorney General's Department 2007–2008.

The funded staff positions of the Office of the Public Advocate as at 30 June 2008 are reflected in the organisational chart in the Employment and Human Resources section.

Appendix E: Summary of key definitions and principles

Mental incapacity

The *Guardianship and Administration Act 1993* defines mental incapacity as:

“...the inability of a person to look after his or her own health, safety or welfare or to manage his or her own affairs, as a result of –

- (a) any damage to, or any illness, disorder, imperfect or delayed development, impairment or deterioration, of the brain or mind; or*
- (b) any physical illness or condition that renders the person unable to communicate his or her intentions or wishes in any manner whatsoever.”*

Principles of the Guardianship and Administration Act

The Office of the Public Advocate practises in accordance with the *Principles of the Guardianship and Administration Act 1993*.

The principles are as follows:

“Where a guardian appointed under this Act, an administrator, the Public Advocate, the Board or any court or other person, body or authority makes any decision or order in relation to a person or a person’s estate pursuant to this Act or pursuant to powers conferred by or under this Act-

- *Consideration (and this will be the paramount consideration) must be given to what would, in the opinion of the decision maker, be the wishes of the person in the matter if he or she were not mentally incapacitated, but only so far as there is reasonably ascertainable evidence on which to base such an opinion.*

This is often called the substituted judgment principle. It does not mean making decisions in the best interests of people. It requires decision makers to put themselves “in the shoes of the person”.

- *The present wishes of the person should, unless it is not possible or reasonably practicable to do so, be sought in respect of the matter and consideration must be given to those wishes.*

This principle ensures that the views of people with mental incapacity are taken into account in any decisions made.

- *Consideration must, in the case of the making or affirming of a guardianship or administration order, be given to the adequacy of existing informal arrangements for the care of the person or the management of his or her financial affairs and the desirability of not disturbing those arrangements.*

This principle allows and encourages families, friends and/or community networks to take responsibility for the health and welfare of people with mental incapacity without unnecessary government intervention.

- *The decision or order made must be the one that is the least restrictive of the person's rights and personal autonomy as is consistent with his or her proper care and protection."*

This principle ensures that, out of all the alternatives available, the one that is chosen places the fewest limits on the person's autonomy.