

# Systems Advocacy

**Office of the  
Public Advocate**

Annual Report  
2010–2011

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The Honourable Paul Lucas MP  
Attorney-General, Minister for Local Government  
and Special Minister of State  
State Law Building  
50 Ann Street  
BRISBANE QLD 4000

31 October 2011

Dear Attorney

I am pleased to present the Public Advocate's Annual Report for the financial year ended 30 June 2011.

This report is made in accordance with the requirements of section 220 of the *Guardianship and Administration Act 2000*.

The report provides information on the key activities of the Office of the Public Advocate for 2010-11 and a statement of our financial and operational functions for the year.

Yours sincerely

A handwritten signature in black ink, appearing to read 'S. Brady', followed by a period.

Dr Susan Brady  
**Acting Public Advocate – Queensland**

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# The Office of the Public Advocate: our year in review

This has been a significant year for the Office. We have implemented our new evidence-based approach to statutory systems advocacy, as articulated in our *Systems Advocacy Framework 2010-2012*. It is vital that our Office operates in this way because without evidence we have limited credibility and influence with our stakeholders, and might not be investing our scarce resources appropriately and to greatest effect.

In this report we present new evidence and different ways of thinking about how to tackle systems issues (as discussed in the section 'Statutory systems advocacy in Queensland'). We have not included individual stories or complaints about services. Individual stories have a compelling place in advancing the rights and interests of vulnerable people in our communities and make a critical contribution to the development of rights' respecting policy and programs. We think that the facts and figures presented here also tell a story that cannot be ignored. The report is written to inform readers with a human rights, social justice and public policy interest in promoting a fair, just and inclusive society for our most vulnerable citizens.

We revisited our role to help us to understand how we might better meet our responsibilities. Our statutory role (as outlined in Section 209 of the *Guardianship and Administration Act 2000*) is to promote and protect the rights and interests of adults with impaired decision-making capacity. As part of this process, we talked with stakeholders and their comments are informative. A general perception has grown over the years, particularly across government, that systems advocacy is limited to guardianship interventions and people who access specialist services. We believe the intention of the Parliament is that all vulnerable Queenslanders with impaired decision-making capacity benefit from the promotion and protection of their human rights and interests.

With this in mind we needed to answer a fundamental question. How many Queenslanders have impaired decision-making capacity? In 2011, there are approximately 130,000 adult Queenslanders (one in 35 people) living with impaired decision-making capacity. A population of this size is hard to ignore. Consequently, we developed the concept of the 'potential population' for statutory systems advocacy because we needed to better understand the scope, demand and focus of our work in a contemporary social justice and service delivery landscape. This year we developed a reliable understanding of the characteristics and needs of the potential population and provide readers with an overview in the section Key Result Area 1 'Knowledge and Evidence'.

We also turned our attention to understanding the guardianship system in more detail by undertaking the Adult Guardian Client Profile Project. This is a piece of significant primary research and is the first of its kind in Australia (see Key Result Area 1 'Knowledge and Evidence'). It is a ten-year profile of people

subject to guardianship orders made to the Adult Guardian (from 2000 - 2010). We examined the administrative aspects of guardianship because we were interested in understanding its growth and trends as well as the circumstances that trigger applications and the key issues prompting guardianship orders. The findings are instructive.

We have suggested that guardianship in its current form is unsustainable. We estimate that the number of adults subject to orders made to the Adult Guardian may exceed 3,600 Queenslanders by 2020. In practical terms this means about a 110% growth over the next decade. We also warn that health and human service systems appear to be using guardianship as a service access and case management tool rather than a legal intervention of last resort. Further independent testing of this hypothesis is urgently required given the integral role guardianship has in Queensland's social care safety net.

We realised from our evidence-based investigations that comparatively little is known about the state of affairs for vulnerable people living with impaired decision-making capacity in Queensland and their families. What we do know is that things have not improved all that much for them. People continue to be excluded and experience very high levels of social and economic disadvantage and very low levels of participation in community life. We know too, that the experience of persistent exclusion and extreme levels of disadvantage perpetuate the risks of abuse, neglect and exploitation. Using an evidence-based lens we have focused our efforts on identifying and understanding causes rather than symptoms. The suite of work undertaken this year is the first step in that process.

As part of the commitment to expand our knowledge and evidence base we have identified opportunities to partner with key stakeholders such as academics, government agencies and community associations. We acknowledge the broad range of important research being undertaken externally and extend our appreciation to those who have entered into research partnerships with us and their contributions to the evidence base (for more details see sub-section 'Research collaboration and partnerships').

We recognise that the ultimate goal of government and our community is to prevent distress and crisis from arising in the first place. From a systems advocacy perspective, this means we must develop a better understanding of the relationship between impaired decision-making capacity, exclusion and disadvantage, and the impact on a person's ability to access goods and services. As a starting point our Office examined a range of indicators: social participation; support needs; education; employment; meaningful day activity; housing and health as priority areas for government attention. The findings demonstrate that across all indicators, people with impaired decision-making capacity experience an extreme degree of



exclusion from basic social and economic resources, and the goods and services available to most Queenslanders (see Key Result Area 3 'Advocacy and Inclusion' for details).

Here are examples of some of the statistics we want readers to consider:

- Many Queenslanders with impaired decision-making capacity experience extreme levels of social isolation. In 2011 over 34,000 adults go without any social or leisure activities. Even within their own homes, 5,800 had no social interaction, such as visits from friends and family. At the most disadvantaged end of the spectrum there are a vulnerable group of almost 3000 people who do not leave their homes and may have no social contact at all. This extreme isolation results in very poor physical and mental health outcomes, and compounds the risks of abuse exploitation and neglect.
- Nearly 54,000 Queenslanders with impaired decision-making capacity living in households do not have their support needs met. This means that they did not receive the assistance they needed to perform daily activities such as self care, meal preparation, domestic tasks or using transport.
- About 22,000 working age Queenslanders with impaired decision-making capacity had no meaningful day activity. This means they were not employed, not attending school or post-school education and not accessing a supervised day activity. We suspect there is a direct relationship between low levels of meaningful day activity and contact with the police, the criminal justice system and specialist forensic systems. Arguably, access to meaningful day activity for young people with impaired decision-making capacity is a critical prevention strategy and should be a human rights priority to promote improved life opportunities for them.

The over-arching message from the evidence is the critical and immediate need for all levels of government, across all sectors, to invest in a sustainable social system that embeds fair access to social, economic and civic resources for people with impaired decision-making capacity. We think a systemic focus on the foundation ethic of a 'fair go' is a constructive way to promote and protect rights and interests, and reduce the risks of abuse, neglect and exploitation.

Justice is a continuum and without a strong social justice platform it is unlikely that policy and service responses for vulnerable Queenslanders can be fair, non-discriminatory, non-segregated, and sustainable at a local community level.

We have presented facts and figures in this report to highlight that justice and a fair go for Queenslanders with impaired decision-making capacity is not limited to legal interventions like guardianship or access to specialist service systems but everyone's responsibility. We believe this responsibility extends across all levels of government and also demands vision and

commitment from non-government and private sectors alike.

The social and economic determinants for participation (for all people) mean that diverse sectors across governments can contribute significantly to improve and promote life opportunities and outcomes for people with impaired decision-making capacity and their families. If we are to address the seemingly intractable access inequalities, gaps and extreme levels of disadvantage across universal and mainstream service systems (like health, housing, education and employment), then a broad system-wide incorporation into whole-of-government planning is fundamental and overdue.

We trust this annual report has outlined our thinking as we explored the role and responsibilities of statutory systems advocacy in Queensland. We have defined our concept of statutory systems advocacy and the importance of an evidence-based approach to identifying and advancing priority systems issues.

We have taken the opportunity to share evidence because we want to make our priority systems issues explicit. We hope that sharing the evidence presented here will promote substantive debate across sectors and portfolios on ways to reduce discrimination, exclusion and disadvantage as well as ways to increase the participation opportunities and inclusion of all Queenslanders with impaired decision-making capacity, their families and support networks. Our new approach has confirmed for us the critical public policy need for evidence to inform government decision-making and planning.

Thank you to our many partners and stakeholders. We look forward to continued work with you to find enduring solutions to persistent exclusion and extreme disadvantage. We also thank Ms Dianne Pendergast, the previous Adult Guardian, and extend our appreciation for her support in co-sponsoring the Adult Guardian Client Profile Project.

Finally, I want to thank the dedicated small team in the Office for your outstanding work this year. The talent and endeavour of the research team warrant special mention – sincere thanks to Dr Kathleen Rousseaux, Avril Alley, Kath Dornbusch and James Clark.



Dr Susan Brady  
**Acting Public Advocate – Queensland**

# About the Office of the Public Advocate

The Office of the Public Advocate was established under Chapter 9 of the *Guardianship and Administration Act 2000* to undertake systems advocacy on behalf of adults with impaired decision-making capacity.

The Public Advocate is an independent statutory position appointed by Governor in Council in accordance with requirements of the *Guardianship and Administration Act 2000*. Staff may be appointed under the *Public Service Act 2008* to assist the Public Advocate to perform the functions under the *Guardianship and Administration Act 2000*.

Under section 209 of the *Guardianship and Administration Act 2000*, the functions of the Public Advocate are:

- (a) promoting and protecting the rights of adults with impaired capacity for a matter;
- (b) promoting the protection of adults from neglect, exploitation or abuse;
- (c) encouraging the development of programs to help the adults to reach the greatest practicable degree of autonomy;
- (d) promoting the provision of services and facilities for the adults;
- (e) monitoring and reviewing the delivery of services and facilities to the adults.

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## Our role

We promote and protect the rights, autonomy and participation of Queenslanders with impaired decision-making capacity in our community.

## Our vision

Our vision is to realise a just and inclusive society for all citizens.

## Our approach

We are committed to evidence-based systems advocacy that explores and extends our knowledge and influence on inclusive policy, programs and practices to promote improved life opportunities and outcomes for Queenslanders with impaired decision-making capacity.

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## Our values

### Creative influence:

We engage collaboratively with our stakeholders by building goodwill, sharing knowledge and expertise, and fostering trust and confidence in our work.

### Knowledge leadership:

We are committed to research and analysis that informs social policy debate to progress inclusive and sustainable responses for Queenslanders with impaired decision-making capacity.

### Professionalism and integrity:

We work with clear purpose and commitment to systems advocacy, within a culture where accountability and respect is paramount.

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## Queensland guardianship system – an overview

Few would disagree that the policy and service delivery landscape has shifted over the last ten years with marked changes to strategic social policy frameworks, legislation and regulation. The policy shifts have been toward greater recognition of the human rights of people with impaired decision-making capacity, and also an expansion in reporting and accountability requirements for the related service systems. These changes influence the delivery of guardianship in Queensland.

Accordingly, we think it is both timely and appropriate to provide an account of the reforms specific to people with impaired decision-making capacity and the function of statutory systems advocacy. The context in which we now work has changed our thinking about how best to deliver and apply our statutory systems advocacy functions. This is explored further in the next section on ‘Statutory systems advocacy in Queensland’.

### Guardianship introduced

In 2000, following a review by the Queensland Law Reform Commission into assisted and substitute decision-making, significant reforms were implemented in the guardianship system. The *Guardianship and Administration Act 2000* established a guardianship system for adults with impaired decision-making capacity, including a specialised and independent tribunal (the then Guardianship and Administration Tribunal) to make and review guardianship and administration orders.<sup>1</sup>

In short, these legislative reforms established two independent statutory roles to protect adults with impaired decision-making capacity from neglect, exploitation and abuse:

- (i) The Office of the Adult Guardian with functions including, investigating complaints about neglect, exploitation or abuse; being appointed as a guardian where there is no alternative; consenting to health care; seeking government or organisational assistance; and approving certain restrictive practices<sup>2</sup> by service providers.
- (ii) The Office of the Public Advocate with the function to undertake broader systems advocacy on behalf of all adults with impaired decision-making capacity.

The guardianship legislation recognises the rights of adults with impaired decision-making capacity to be involved in decisions

that affect their lives. It also recognises the importance of maintaining the involvement of family and support networks in decisions. The legislation aims to balance the rights of adults with impaired decision-making capacity to exercise autonomy in decision-making with their right to adequate and appropriate support for decision-making when required.

The legislation is premised on the notions that intervention should be the last resort and where it is required, the least intrusive and least restrictive alternatives should be pursued.

### Tribunal system reform

In late 2009, there was an administrative reform which impacted on the guardianship system. A new central tribunal was established for civil and administrative matters – the Queensland Civil and Administrative Tribunal (QCAT).

This reform resulted in the amalgamation of 18 tribunals and 23 jurisdictions in Queensland into the one tribunal. The Guardianship and Administration Tribunal was subsumed by this amalgamation resulting in guardianship matters being overseen by the QCAT Human Rights Division. The Human Rights Division also manages matters relating to anti-discrimination, children and education.

The QCAT annual report 2009-10 noted that guardianship matters form the largest component of its workload. A significant increase in guardianship matters was reported compared with previous years. QCAT attributes this to the ageing population and highlighted the need for formal arrangements, to protect the rights of individuals.<sup>3</sup>

### Guardianship appointments

The Queensland Civil and Administrative Tribunal appoints a guardian to make personal and health care decisions on behalf of a person with impaired decision-making capacity.<sup>4</sup> A family member, friend or relative may be appointed as a guardian (known as a private guardian).

As a last resort, the Queensland Civil and Administrative Tribunal may appoint the Adult Guardian instead of a private guardian. Circumstances in which this may occur include, for example, when there is serious conflict with a family or support network about the decision/s to be made; or where there is evidence that a person with impaired decision-making capacity is unable to care for themselves and has no family or friends to act as their guardian. The Adult Guardian may also be appointed in situations involving the abuse, neglect or exploitation of the person with impaired decision-making capacity.<sup>5</sup>

<sup>1</sup> The *Powers of Attorney Act 1998* and *Public Trustee Act 1978*, whilst also relevant to guardianship are not included in this synopsis.

<sup>2</sup> Under Section 123E in the *Disability Services Act 2006* (Qld) a restrictive practice is the containment or seclusion of an adult with intellectual disability, restriction of access of an adult with intellectual disability or the use of chemical, mechanical or physical restraint on an adult with intellectual disability. Legislative amendments which commenced in July 2008 aimed to reduce the use of restrictive practices and introduced regulations around their use. Queensland law now requires the development of a positive behaviour support plan before considering or gaining consent for the use of restrictive practices.

<sup>3</sup> Queensland Civil and Administrative Tribunal 2010, *Annual Report 2009-10*, The State of Queensland, Brisbane.

<sup>4</sup> Queensland Civil and Administrative Tribunal 2011, Department of Justice and Attorney-General, viewed 12 October 2011, <http://www.qcat.qld.gov.au/guardianship-for-adults-matters.htm>

<sup>5</sup> Office of the Adult Guardian 2010, Department of Justice and Attorney-General, viewed 12 October 2011, <http://www.justice.qld.gov.au/justice-services/guardianship/adult-guardian-role-of-the-adult-guardian>

## Queensland Law Reform Commission's review of guardianship laws (2010)

More recently, it is the Queensland Law Reform Commission's (QLRC) review of the guardianship laws (since introduction in 2000) which has implications for the future of our statutory systems advocacy work.

Of relevance to the QLRC guardianship review was an earlier review in 2009 of all Queensland boards, committees and statutory authorities. This was known as the Weller Review and was commissioned by the Queensland Government to 'reduce bureaucracy, and unnecessary red tape; improve the overall efficiency of government bodies; and maintain the integrity and security of necessary regulatory functions'.<sup>6</sup>

The Office of the Public Advocate was included in the Weller Review which recommended that:

- the function of the Public Advocate be transferred to the Adult Guardian; and
- the Public Advocate position be abolished.

The Department of Justice and Attorney-General's submission to the Weller Review noted that the separate functions did not facilitate access to the information and data needed to inform systems improvement. The department submitted that *'...by being separated from the experiences of the Adult Guardian, the Public Advocate does not have sufficient access to information to amass a systemic assessment based on objective data and meet its original objectives'*.<sup>7</sup>

The Weller Review in its findings observed that *'[I]f by reason of its separate structure the Public Advocate has not been able to access data and experience the necessary body of evidence to enable it to undertake its role effectively, then government and stakeholder ambitions for the role have been undersold by an organisational form ultimately that is not fit for purpose'*.<sup>8</sup>

In April 2009, the Queensland Government supported the Weller Review's recommendation in relation to the Office of the Public Advocate.<sup>9</sup> In November 2009, the QLRC's review of guardianship laws was requested by the then Attorney-General and Minister for Industrial Relations to consider this amalgamation and to *'report on issues to be taken into account to ensure that an independent systemic advocacy role will be maintained when the functions of the Public Advocate are transferred to the Adult Guardian'*.<sup>10</sup>

The QLRC has completed its review of the guardianship laws and released its report and recommendations in September 2010.

### Queensland Law Reform Commission's recommendations for systems advocacy

Table 1 presents the recommendations made by the QLRC in relation to the function of systems advocacy. The emphasis, in line with the terms of reference, is on ensuring the independent function of systems advocacy continues when it is amalgamated with the functions of the Adult Guardian.

In summary, the QLRC's recommendations propose an additional power for the Adult Guardian in performing the systems advocacy function, to access information held by relevant agencies (both personal and statistical). To support this power, a sanction is also recommended for non-compliance. The recommendations further propose that the Adult Guardian may report systems issues to the Minister at any time and that the amalgamation of systems advocacy is evaluated after a five year period.

<sup>6</sup> Webbe, S. and Weller, P. 2008, *A Public Interest Map: An Independent Review of Government Boards, Committees and Statutory Authorities, Part A Report*, Brisbane, Appendix A, p. 70.

<sup>7</sup> Webbe, S. and Weller, P. 2009, *Brokering Balance: A Public Interest Map for Government Bodies. An Independent Review of Queensland Government Boards, Committees and Statutory Authorities, Part B Report*, Brisbane, p.142.

<sup>8</sup> Webbe, S. and Weller, P. 2009, *Brokering Balance: A Public Interest Map for Government Bodies, An Independent Review of Queensland Government Boards, Committees and Statutory Authorities, Part B Report*, Brisbane, pp.142-143.

<sup>9</sup> Queensland Government 2009, *Government's Response to the Report: Brokering Balance: A Public Interest Map for Queensland Government Bodies, An Independent Review of Queensland Government Boards, Committees and Statutory Authorities, Part B Report*, Queensland Government, Brisbane.

<sup>10</sup> Queensland Law Reform Commission 2006, *Terms of Reference: A review of the law in relation to the General Principles, the scope of substituted decision-making, the role of the support network, adequacy of investigative powers, health and special health matters, and other miscellaneous matters, under the Guardianship and Administration Act 2000 and the Powers of Attorney Act 1998*, Queensland Law Reform Commission, viewed 12 October 2011, <http://www qlrc.qld.gov.au/guardianship/reference.htm>

**Table 1. Queensland Law Reform Commission recommendations for systemic advocacy – guardianship review (2010)\***

<b>Reporting on systemic advocacy</b>	
Rec 24-1	The <i>Guardianship and Administration Act 2000</i> (Qld) should be amended to provide that the Adult Guardian's Annual Report must include information about: <ul style="list-style-type: none"> <li>a) the systemic advocacy that has been undertaken during the year;</li> <li>b) the expenditure on systemic advocacy; and</li> <li>c) the number of staff (expressed as full-time equivalents) who were engaged in undertaking systemic advocacy.</li> </ul>
Rec 24-2	The <i>Guardianship and Administration Act 2000</i> (Qld) should be amended to provide that: <ul style="list-style-type: none"> <li>c) the Adult Guardian may, at any time, prepare a report to the Minister on a systemic issue and give a copy of the report to the Minister; and</li> <li>d) the Minister must table a copy of the report in the Legislative Assembly within five sitting days after receiving the report.</li> </ul>
<b>Review by the Minister</b>	
Rec 24-3	The <i>Guardianship and Administration Act 2000</i> (Qld) should be amended to provide that: <ul style="list-style-type: none"> <li>d) within five years of the commencement of the provisions transferring the Public Advocate's functions and powers to the Adult Guardian, the Minister must review the systemic advocacy function of the Adult Guardian to ascertain whether an independent systemic advocacy role has been maintained; and</li> <li>e) as soon as practicable, but within one year after the end of the five year period, the Minister must table a report about the review in the Legislative Assembly.</li> </ul>
<b>Intervening in guardianship proceedings</b>	
Rec 24-4	Section 210(2) of the <i>Guardianship and Administration Act 2000</i> (Qld) should be amended to include a note that refers to the Tribunal's power under section 41(2) of the QCAT Act to give leave for a person to intervene in a proceeding.
<b>Power to require information and access to documents</b>	
Rec 24-5	The <i>Guardianship and Administration Act 2000</i> (Qld) should be amended to give the Adult Guardian, as systems advocate, the power to require from an agency, or a person who has the custody or control of information or documents, information and access to documents about: <ul style="list-style-type: none"> <li>a) a system being monitored or reviewed by the Adult Guardian;</li> <li>b) arrangements for a class of individuals; and</li> <li>c) policies and procedures that apply within an agency, service or facility.</li> </ul>
Rec 24-6	The provision that gives effect to Recommendation 24-5 should: <ul style="list-style-type: none"> <li>c) generally be modelled on section 183(1), (2)(a), (c), (3)–(5) of the <i>Guardianship and Administration Act 2000</i> (Qld); and</li> <li>d) provide that the Adult Guardian's power to require information or access to documents includes the power to require: <ul style="list-style-type: none"> <li>(iii) personal information about an adult if the provision of that information is necessary to comply with the Adult Guardian's notice; and</li> <li>(iv) statistical information that is in the custody or control of an agency or person.</li> </ul> </li> </ul>
<b>Sanctions</b>	
Rec 24-7	The provisions that give effect to Recommendations 24-5 and 24-6 should provide that the maximum penalty for non-compliance with the requirements of those provisions is 100 penalty units.

\* Queensland Law Reform Commission 2010, *A Review of Queensland's Guardianship Laws*, Report No. 67, Volume 4, Chapter 24, Queensland Law Reform Commission, Brisbane, pp. 227-258.

## Queensland Government response to the guardianship review recommendations

The Department of Justice and Attorney-General is leading the coordination of the Queensland Government's response to the recommendations made by the QLRC in relation to guardianship laws. During the year the Office of the Public Advocate has met with departmental officers on a number of occasions to discuss respective views on the recommendations made in relation to maintaining a separate and independent systems advocacy function.<sup>11</sup>

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### STOP PRESS:

On 11 October 2011, the Attorney-General, Minister for Local Government and Special Minister of State tabled the *Queensland Government initial response to the Queensland Law Reform Commission's Report: A Review of Queensland's Guardianship Laws*. The document is available from the Queensland Parliament website at <http://www.parliament.qld.gov.au/documents/tableOffice/TabledPapers/2011/5311T5556.pdf>

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Whilst guardianship reform is an important issue facing Queenslanders with impaired decision-making capacity it is important not to lose sight of our broad statutory responsibility to protect and promote the rights and interests of all Queenslanders with impaired decision-making capacity through systems advocacy. In practice this extends our focus to all systems which impact on people with impaired decision-making capacity for example – guardianship – health – disability – housing – education – transport – justice – corrections.

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<sup>11</sup> The Office has also been involved in broader discussions in relation to the other extensive areas of the guardianship review, including powers and functions in relation to the Adult Guardian, guardianship and administration appointments, Queensland Civil and Administrative Tribunal, as well as health care matters such as advance health directives.



## Statutory systems advocacy in Queensland

Our systems advocacy function operates within a statutory framework and provides an important layer of protection and promotion for the rights and autonomy of Queenslanders with impaired decision-making capacity.

Statutory systems advocacy may be described as advocacy delivered from within government, and with a legislative basis. It occupies a unique position of potential influence in the development of rights' respecting social policy, and is an important complement to public interest advocacy.

It is a strategy to influence government and non-government policy makers – when they make laws, policies and regulations, deliver goods and services, and make other decisions that affect citizen's lives.

Government delivered systems advocacy undertaken by public servants does not include direct action (taking issues to the streets) or lobbying in a public way against government decisions. Lobbying and direct action are strategies best used by non-government and private sector interests.

## Applying our statutory systems advocacy

Our systems advocacy work aims to make an impact at the strategic and structural level of government policy, programs and practices to ensure the rights and interests of all Queenslanders with impaired decision-making capacity are understood, promoted and safeguarded. Our role is outlined in the *Guardianship and Administration Act 2000*.

We place a strong emphasis on inclusion and participation and therefore we look at all aspects of life and do not limit our focus to specialist systems only. We think influencing systems or strategic policy includes examining the impact of policy on the delivery of services, programs and practices. The core focus of our systems advocacy is on substantive policy (strategic and systems focused) and not on procedural policy (operations and practice focused).

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**Knowledge and evidence is a critical component and a key foundation for our systems advocacy work. It speaks for itself, that we require knowledge and evidence about a systems issue before we can influence our stakeholders' opinions and positions.**

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## Influencing policy

The key objectives of our systems advocacy work is to influence government policy from the following perspectives: policy direction, policy reform, and policy implementation.<sup>12</sup>

Figure 1 illustrates the main areas of systems advocacy influence on policy change.

We believe government must have fair and just social policy before it can deliver inclusive and non-discriminatory services and programs. All our policy change activities are focused on improving life opportunities for Queenslanders with impaired decision-making capacity.

## Our strategy and business approach

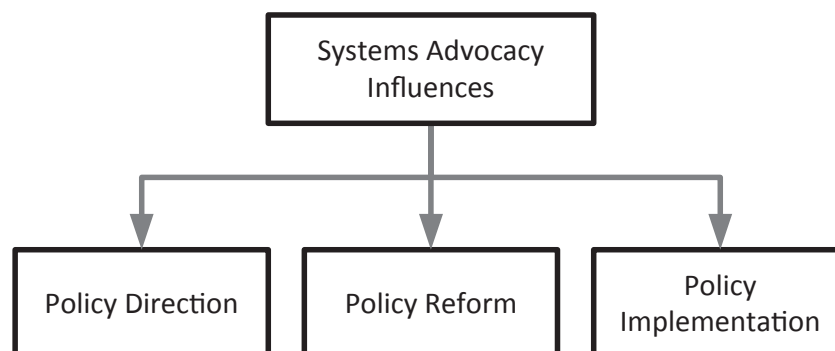
In 2009, the Weller Review made recommendations to the Queensland Government regarding which government boards and statutory bodies would be abolished, kept or changed. The Weller Review recommended the systems advocacy function of the Public Advocate be transferred to the Adult Guardian and the Public Advocate position be abolished. The Queensland government supported this recommendation.

The amalgamation of the functions of the Public Advocate with those of the Adult Guardian are planned to occur following the Queensland Government's response to the Queensland Law Reform Commission's review of the guardianship laws, including consideration of maintaining an independent systems advocacy function. Amendments to the *Guardianship and Administration Act 2000* in relation to systems advocacy will be required to

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<sup>12</sup> 'Policy direction' means we seek to influence government to develop policy where it is needed (identifying policy gaps). 'Policy reform' is a focus on influencing government to reform discriminatory, harmful or ineffective policy. 'Policy implementation' concerns influencing government to implement policy and to monitor and report on policy outcomes, including the promotion of continuous improvement and sustainability of fair and appropriate service responses.

**Figure 1. Systems Advocacy and Policy Influence**





implement both the Weller Review's recommendation and any additional changes arising from the Queensland Law Reform Commission's guardianship review (see earlier).

In the meantime, the Office of the Public Advocate is advancing a contemporary direction for systems advocacy supported by our *Systems Advocacy Framework 2010-12* (discussed in the next section). A key component of our strategic direction is the application of an evidence-based approach to systems advocacy. The United Nations Convention on the Rights of Persons with Disabilities (UNCPD) and the Australian Government's Social Inclusion Principles both promote a robust, evidence-based approach to inform the development of policy and service strategies for inclusion and participation:

- statistics and data collection (Article 31, UNCPD)<sup>13</sup>; and
- using evidence and integrated data to inform policy (Social Inclusion Principle 9).<sup>14</sup>

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**Our approach addresses the Weller Review's observations about the importance of accessing objective data and evidence to inform our systems advocacy priorities.**

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## Systems Advocacy Framework 2010-2012

The *Systems Advocacy Framework 2010-2012* (see Figure 2) is a key strategic document setting the direction for our Office. This year we have embedded and applied our contemporary approach to systems advocacy. The drivers informing our strategic direction include local, national and international developments.

The work of the Office contributes to the Department of Justice and Attorney-General's Strategic Plan 2010-14. In particular, the Office of the Public Advocate plays an important role in the objective to protect the rights and interests of Queenslanders with impaired decision-making capacity. Our work also contributes to the Queensland Government strategic objective of **'A Fair Queensland'** which supports safe and caring communities through services that deliver justice, protect vulnerable people, increase community and workplace safety and uphold rights.

Our work is influenced by the Australian Government's social inclusion agenda and efforts to embed the focus on equal human rights. This encompasses the Australian Government's National Disability Strategy, a 10-year national plan to improve the lives of people with disability, promote participation, and create a more inclusive society.

At the international level, our work contributes to Australia's commitment as a signatory to the UNCPD. The purpose of this significant Convention as stated in Article 1 is to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'. The types of rights articulated in the UNCPD include: awareness raising (Article 8), accessibility (Article 9), living independently and being included in the community (Article 19), personal mobility (Article 20), freedom of expression and opinion, and access to information (Article 21), and participation in political and civic life (Article 29).

The *Systems Advocacy Framework 2010-2012* provides a high level strategic summary of our approach to statutory systems advocacy and the four Key Result Areas for our activity over the next few years (refer to Figure 2):

- Key Result Area 1 – Knowledge and Evidence
- Key Result Area 2 – Communication and Influence
- Key Result Area 3 – Advocacy and Inclusion
- Key Result Area 4 – Business Processes.

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<sup>13</sup> United Nations 2007, Convention on the Rights of Persons with Disabilities, viewed on 12 October 2011, <http://www.un.org/esa/socdev/enable/rights/convtexte.htm>.

<sup>14</sup> Australian Government 2009, *Social Inclusion Principles for Australia*, Australian Government, Canberra.

Figure 2. Systems Advocacy Framework 2010-2012

## Vision

Our vision is to realise a just and inclusive society for all citizens.

## Our Role

We will promote and protect the rights, autonomy and participation of people with impaired decision-making capacity in our community.

## Our Approach

We are committed to evidence-based systems advocacy that explores and extends our knowledge and influence on inclusive policy, programs and practices to promote improved life opportunities and outcomes for people with impaired decision-making capacity.

## Priorities for Focus

Promotion and protection of rights and interests ↔ Inclusion and access to the goods and services available to all citizens ↔ Sustainable service systems that improve outcomes

## Key Result Areas (KRA)

### KRA 1 – Knowledge and Evidence

- Use an evidence-based approach to all research and information gathering activity
- Produce, integrate and translate knowledge for key audiences/stakeholders

### KRA 2 – Communication and Influence

- Provide accurate, reliable and timely information to stakeholders on priority systems advocacy matters
- Develop effective communication strategies to promote and protect rights and interests

### KRA 3 – Advocacy and Inclusion

- Promote and protect rights, interests and wellbeing
- Promote inclusive policy, programs and practice to improve social and economic participation
- Ensure government reform, policy and legislation considers and addresses rights and interests

### KRA 4 – Business Processes

- Operate transparently and with accountability
- Ensure effective business and risk processes

## Systems Advocacy Actions

- **Create and use knowledge** acquired through research and consultation
- Contribute to and advocate for policy and service environments that foster **rights promotion** in a sustainable and transparent way
- Encourage the **development of systems** that are inclusive, accessible and equitable
- **Communicate** about priority systems barriers

## Priority Population

We will focus our efforts on people with impaired decision-making capacity who experience the greatest exclusion and disadvantage.

## Priority Setting for Action

We are committed to engaging with government to advance inclusive policy and legislative reform.

In summary, our *Systems Advocacy Framework 2010-2012* provides a platform for influencing social policy through:

- an evidence-based approach to systems advocacy
- a focus on the structural barriers to rights protection and social and economic participation
- the contemporary application of legislation
- collaboration with government, coupled with statutory independence
- alignment with key levers for change – state, national and international.

We have also developed the Systems Advocacy Toolbox as a companion resource to provide practical guidance and support staff to deliver statutory systems advocacy. The Toolbox is also available to be shared with our stakeholders.

We have built on our framework, striving to refine our understanding and application of statutory systems advocacy in a contemporary social justice context. Our work has concentrated on the broad social, economic and justice issues affecting the lives of Queenslanders with impaired decision-making capacity. Our progress against the Systems Advocacy Framework is reported in this annual report, with a section dedicated to each Key Result Area.

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**Our approach is strategic and targeted, and aims to promote and protect the rights, autonomy and participation of people with impaired decision-making capacity. In practical terms, this means working hard to reduce the levels of discrimination and disadvantage experienced. We think that engaging with all levels of government to promote fair access to the goods and services available to all Queenslanders is an important contribution to rights promotion.**

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## Monitoring and evaluation of our systems advocacy outcomes and impacts

This year we have introduced new thinking about how to measure priority project outcomes and impact. We understand that while policy makers may implement new and improved strategic policy, or review and change old strategic policy, these changes usually take a long time to yield results that can be measured at the individual level.

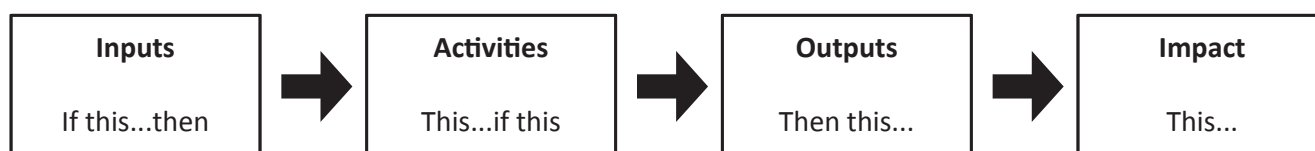
Unlike service and program reform, strategic or systems policy reform often happens in a political space far removed from where individual outcomes are delivered (at the service level). Accordingly, it is difficult to attribute improvements in people's lives to a specific systems advocacy project. For this reason we acknowledge that many factors may contribute to improvements and not just one, however this does not diminish the contribution of our systems advocacy activities.

We face some particular challenges in measuring strategic or systems policy implementation. It is relatively straight forward to identify if a new strategic policy has been created, or an old one changed, however it is harder to measure whether a policy is being implemented. For example, it is easier to learn that a new law or regulation is approved, but determining the extent to which it is appropriately enforced and its consequences, whether intended or unintended, is more difficult.

These difficulties in outcomes measurement mean we must be clear about how we approach the task of assessing our systems advocacy outcomes. Ensuring that we monitor and evaluate progress during key points in a project's life cycle assists us with measuring our priority project outcomes.

We have developed a LogFrame model to keep our work deliberate and outcome focussed. Figure 3 shows a simplified version of our LogFrame method.

**Figure 3. LogFrame Method**



Our approach recognises the difference between inputs, outputs and outcomes of any planned project we undertake. This type of logical approach is very important given our limited resources and small team. It makes us think through and justify our investments in priority projects. We also know that without describing how a series of activities can lead to short, medium, and long term outcomes, we can lose track of our purpose and goals. While this approach appears demanding and requires commitment, it tests our understanding of the systems issues brought to our attention during the year and helps us plan and build on our progress and outcomes over the next year.

## Statutory systems advocacy – our responsibilities

A general perception has grown over the years, particularly across government, that statutory systems advocacy is limited to guardianship interventions and a subset of the population who access specialist services. We believe that the intention of Parliament is that all adult Queenslanders with impaired decision-making capacity benefit from the promotion and protection of their human rights and interests.

Stakeholders have observed that specialist service responses are unable to meet all of the needs of people with impaired decision-making capacity. It is paramount that access to mainstream services is not impeded by siloed service responses and barriers. Early systems responses are more effective and enduring than crisis interventions.

Our research demonstrates that we have a vested interest in the delivery of all types of services (mainstream and specialist) to Queenslanders with impaired decision-making capacity. Our priorities for our systems advocacy work are:

- promotion and protection of rights and interests
- inclusion and access to the goods and services available to all citizens
- sustainable service systems that improve outcomes and life opportunities.

## Evidence-based approach to systems advocacy

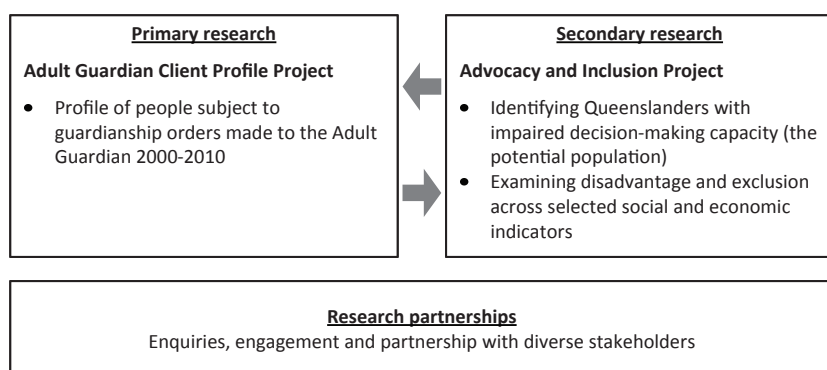
Our commitment to an evidence-based approach in our work is affirmed in our *Systems Advocacy Framework 2010-2012*. Our evidence is sourced from primary research and secondary data analysis, as well as through engagement and partnerships with key stakeholders (see Figure 4).

**During the year, the Office has continued to address the earlier Weller Review observations regarding access to information and data. We have worked hard to build a body of evidence to support our work and advance the rights and interests of Queenslanders living with impaired decision-making capacity.**

Through successful partnerships with the Office of the Adult Guardian and the Department of Communities (Disability and Community Care Services) we led the Adult Guardian Client Profile Project. We collected primary data to describe and analyse guardianship orders made to the Adult Guardian over the past 10 years (the profile does not include private guardianship appointments, such as family members). This project is detailed in Key Result Area 1 ‘Knowledge and Evidence’.

Our secondary data analysis has focussed on advocacy and inclusion issues. It has helped us establish how many Queenslanders are living with impaired decision-making capacity and to better understand their circumstances and disadvantages. This project is detailed in Key Result Area 3 ‘Advocacy and Inclusion’.

**Figure 4. Our approach to knowledge and evidence**



The evidence we present highlights that a necessary condition for people with impaired decision-making capacity to be ‘included’ is that governments and sectors embed the fundamentals of inclusion across all aspects of society. This relies, in large part, on the implementation of inclusive social policy frameworks and good governance structures supported by government, non-government and business sectors.

## Relationship between systems advocacy and individual advocacy

As we mentioned earlier, there has been some confusion about the distinction between systems advocacy and individual advocacy. It is important to understand our function of systems advocacy and why it is different to individual advocacy. These two functions are not mutually exclusive and there is a strong co-incidence of interests between them.

While we do not have a direct role in individual advocacy, individual matters provide practical examples and therefore can inform our systems advocacy work. Individual matters assist us in identifying areas of concern or barriers within systems which may be addressed through systems advocacy. We gather this information through our enquiry-related processes (discussed further under Key Result Area 3 ‘Advocacy and Inclusion’) and through research partnerships with key stakeholders (discussed further under Key Result Area 1 ‘Knowledge and Evidence’).

## The scope of statutory systems advocacy

Following the adoption of the *Systems Advocacy Framework 2010-2012* (see Figure 2) and our evidence-based approach to systems advocacy, we have focused on identifying and understanding the adults for whom we have a statutory

responsibility without limiting our frame of reference to guardianship and specialist services. We think this is an essential part of influencing the development of policies, programs and services that respect rights, promote inclusion and deliver improved opportunities for participation in social, economic and civic life for all Queenslanders with impaired decision-making capacity.

## The potential population for statutory systems advocacy

We developed the concept of a ‘potential population’ for statutory systems advocacy which grew from the need to better understand the scope, demand and focus for our work in a contemporary policy and service delivery landscape.

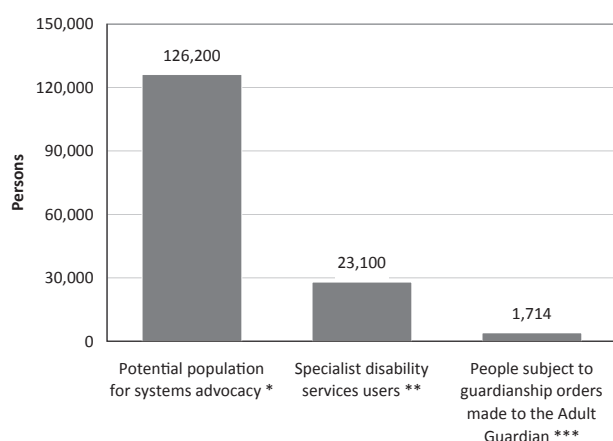
Specifically, and importantly, the potential population for statutory systems advocacy includes all vulnerable Queensland adults living with impaired decision-making capacity.

Our Office uses the Survey of Disability, Ageing and Carers to identify and profile the potential population. For this purpose, the potential population for our systems advocacy includes adults living in either private households or cared accommodation (e.g. a group home, health establishment or institutional setting) who need assistance to make decisions or think through problems due to a disability.<sup>15 16</sup>

<sup>15</sup> Australian Bureau of Statistics 2004, *Disability, Ageing and Carers, Australia: User Guide 2003*, Cat No. 4431.0.55.001, Australian Bureau of Statistics, Canberra.

<sup>16</sup> Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

**Figure 5. Comparison of the populations for systems advocacy: Potential population, specialist disability service users and guardianship orders made to the Adult Guardian**



\* Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

\*\* Australian Institute of Health and Welfare 2011, *Disability Support Services 2008-09, Report on Services Provided under the National Disability Agreement*, Cat No. DIS 59, Australian Institute of Health and Welfare, Canberra.

\*\*\* Adult Guardian Client Profile Project 2011.

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**The potential population for systems advocacy is therefore broad and inclusive and is not restricted to people who receive a government-funded or government-provided specialist service, or people in the guardianship system.**

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Figure 5 compares the three populations. What is immediately striking is the vast majority of Queenslanders with impaired decision-making capacity are outside the specialist disability and guardianship systems, with the gap demonstrating the, as yet, unrealised potential demand for services and supports.

The population comparison also highlights the critical need for improved access to mainstream services and early responses to need and crisis to reduce the risks of entry to expensive and resource intensive systems. Our evidence-based examination of these risks are explored in Key Result Area 1 'Knowledge and Evidence' and Key Result Area 3 'Advocacy and Inclusion' where we investigate the systems issues arising from the appalling levels of disadvantage and exclusion experienced by Queenslanders with impaired decision-making capacity.



## Key Result Area 1

### Knowledge and Evidence

It is vital that our Office operates from a knowledge and evidence base. Without evidence we have limited credibility and influence with our stakeholders, and we might not be investing our scarce resources appropriately and to greatest effect. We believe there is a critical public policy need for evidence to inform government decision-making and planning for people with impaired decision-making capacity.

We strive to ensure our evidence is relevant, accessible, and rigorous. Sharing knowledge and evidence is critical to advancing our systems advocacy priorities and promoting policy and program change.

We hope our knowledge-related activities will inform substantive debate and progress systems improvements for Queenslanders with impaired decision-making capacity.

## Our approach to knowledge and evidence

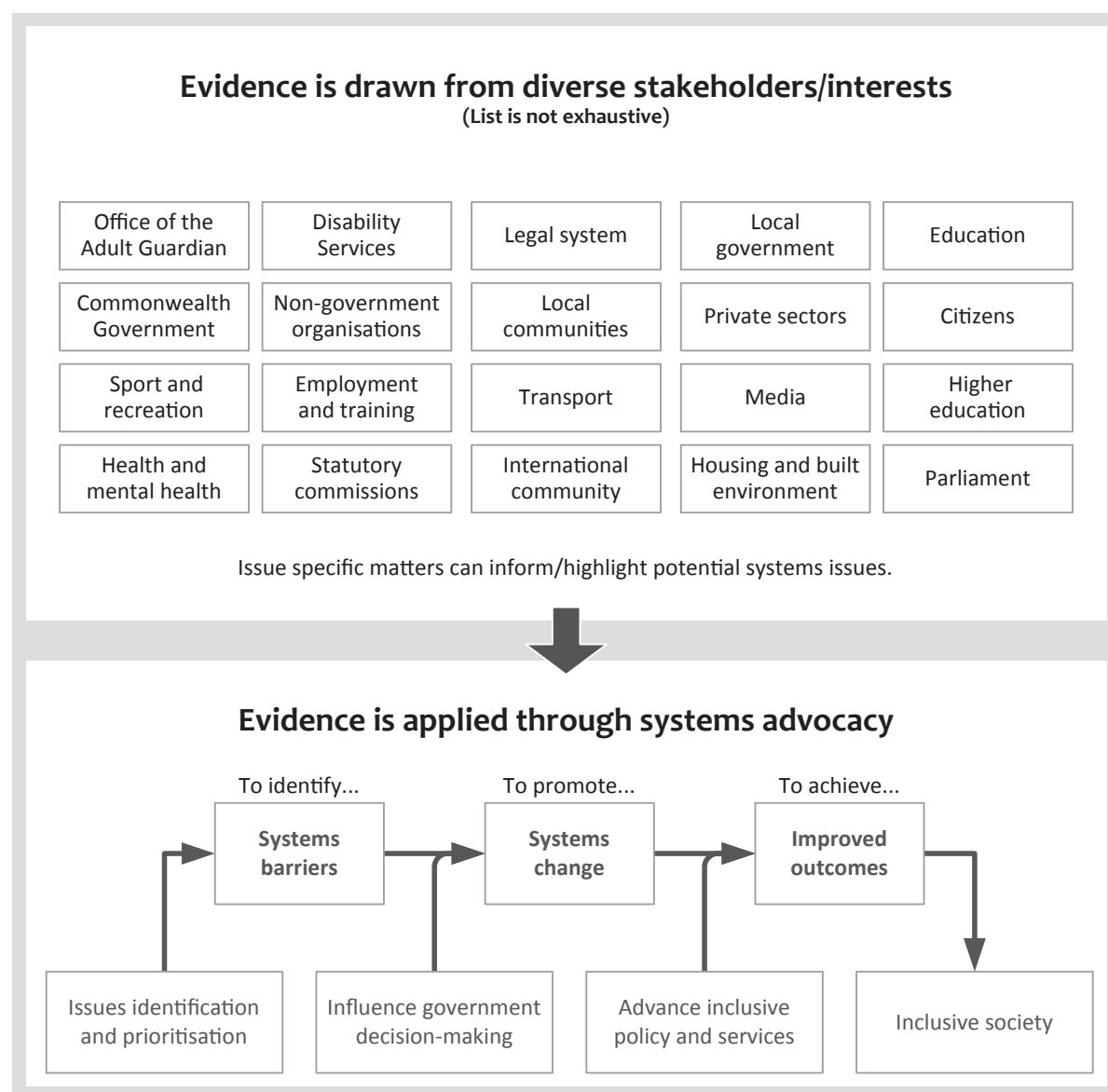
This year we have delivered on our key objective to apply an evidence-based approach to all our information gathering activity. We use our knowledge and share it to influence decision-making processes especially within government. Our evidence-based approach is strategic and promotes and protects the rights and interests of Queenslanders with impaired decision-making capacity.

We are committed to improving the broader social, economic and civic participation for all Queenslanders with impaired decision-making capacity, their families and support networks.

We cannot achieve this in isolation. Figure 6 illustrates how systems advocacy issues are informed by the knowledge and evidence held by our stakeholders. We use this evidence to identify our priorities and to advance our systems advocacy projects.

We are also committed to collaborating with external researchers and other stakeholders to test and explore new ideas and approaches to benefit people with impaired decision-making capacity and the broader community (see section ‘Research collaboration and partnerships’).

**Figure 6. A framework for evidence-based systems advocacy**





## Our research

This year we have undertaken both primary and secondary research activities to build our evidence base, selecting the most appropriate methodology for the objectives of each project.

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**Our research presents new evidence and new ways of thinking about the systems issues relating to Queenslanders with impaired decision-making capacity.**

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In our priority research project profiling clients of the Adult Guardian over a 10-year period, we used both primary and secondary data and a combination of qualitative and quantitative analysis (refer to 'Adult Guardian Client Profile Project'). This research project helped us better understand the trends in guardianship and the characteristics and needs of an important group of Queenslanders who are subject to guardianship orders made to the Adult Guardian. We hope the findings will help inform future directions in guardianship.

Our secondary research has developed a comprehensive understanding of our potential population for statutory systems advocacy (refer to next section). It provides us with demographic information on Queenslanders with impaired decision-making capacity and flags issues in relation to future risks and demands.

Our 'Advocacy and Inclusion' project presents an examination of disadvantage (using participation rates) for people with impaired decision-making capacity. The results are hard to ignore and necessitate structural change to promote fairer access to the goods and services available to most Queenslanders (refer to Key Result Area 3).

## Potential population for statutory systems advocacy

As part of our commitment to develop a contemporary evidence-based appreciation of the nature and scope of statutory systems advocacy, we undertook research using secondary data to profile the key characteristics of all Queenslanders with impaired decision-making capacity. The profile highlights individual vulnerability, and complexity of circumstances. Our research confirms the critical role of statutory systems advocacy in promoting fair access to supports and services, and protecting human rights and interests.

## Data statement

We use the Survey of Disability, Ageing and Carers (SDAC), published by the Australian Bureau of Statistics (ABS), to identify Queenslanders with impaired decision-making capacity. In the SDAC, a person with impaired decision-making capacity is defined as a person who needs assistance to make decisions or think through problems due to a disability.

Our secondary research into the potential population is primarily based on the 2003 SDAC Basic Confidentialised Unit Record File (CURF).<sup>1</sup> We have also utilised the Population Projections for Australia, published by the ABS.<sup>2</sup>

We have calculated population estimates using the 2003 SDAC CURF. Age standardised estimates for 2011 are constructed using the ABS Series B Population Projections for Queensland. The estimates and associated percentages in this report can not be reproduced without accessing the 2003 SDAC CURF.

When considering SDAC estimates it is also important to note that:

- the estimates are not exact counts.
- each estimate has been rounded and carries an error margin.
- the responses to the SDAC are self-reported by either the respondent or their proxy and intend to represent the views of the individual.<sup>3 4</sup>
- where the respondent lived in cared accommodation, for example, in a group home, health establishment or institutional setting, the responses were collected from a nominated contact officer for the establishment.

For further information about the publications, refer to the ABS website at [www.abs.gov.au](http://www.abs.gov.au)

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<sup>1</sup> Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

<sup>2</sup> Australian Bureau of Statistics 2008, *Population Projections, Australia, 2006 to 2101*, Series B, Cat No. 3222.0, Australian Bureau of Statistics, Canberra.

<sup>3</sup> Australian Bureau of Statistics 2004, *Disability, Ageing and Carers, Australia: User Guide 2003*, Cat No. 4431.0.55.001, Australian Bureau of Statistics, Canberra.

<sup>4</sup> Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

## Our potential population

As mentioned earlier, the potential population for systems advocacy includes all vulnerable Queensland adults living with impaired decision-making capacity. A person's capacity to make decisions may be impaired for a range of reasons, for example, dementia, intellectual disability, acquired brain injury or mental illness.

We use the Survey of Disability, Ageing and Carers to identify and profile the potential population. For this purpose, the potential population for our systems advocacy includes adults (living in either private households or cared accommodation, for example, in a group home, health establishment or institutional setting) who need assistance to make decisions or think through problems due to a disability.<sup>17 18</sup>

### Size and growth

The exact size of the potential population is not known as it is difficult to determine the number of Queenslanders who may need assistance with making decisions. However, we think that the Survey of Disability Ageing and Carers and population projection data from the Australian Bureau of Statistics can be used to reliably estimate the size of our potential population.

In 2011, there are an estimated 129,800 adults (one in 35 people) with impaired decision-making capacity in Queensland. By 2020, the potential population is estimated to increase to approximately 164,000 adults (one in 33 people) and the growth will continue (see Figure 7).<sup>19</sup>

<sup>17</sup> Australian Bureau of Statistics 2004, *Disability, Ageing and Carers, Australia: User Guide, 2003*, Cat No. 4431.0.55.001, Australian Bureau of Statistics, Canberra.

<sup>18</sup> Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

<sup>19</sup> Potential population figures are based on 2003 data from the Survey of Disability, Ageing and Carers and population projections released by the Australian Bureau of Statistics.

The expected increase in the prevalence of impaired decision-making capacity in the Queensland population is attributed, in part, to an ageing population. An aging population means an increase in the age-related conditions which can impair a person's decision-making capacity (such as dementia and stroke). Technical advances in medical treatment in areas such as traumatic brain injury and degenerative diseases are also a factor.

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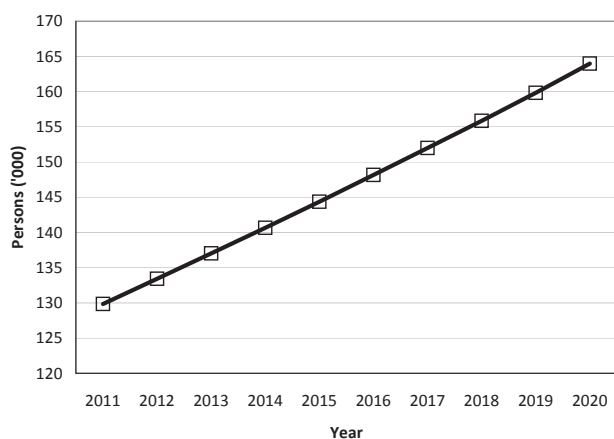
**The number of Queenslanders with impaired decision-making capacity is expected to grow over the next 20 years, along with the potential population for systems advocacy. The demand for supports and services (mainstream and specialist) and guardianship and administration services will increase, with this growth in the population.**

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### Age

The majority of Queenslanders with impaired decision-making capacity are over 50 years of age (Figure 8). People aged 80 years or older account for the largest single age group (26%) in the potential population. The peak in the oldest age group is primarily attributable to the increased prevalence of age-related conditions which can specifically impair a person's decision-making capacity.

**Figure 7. Growth in the potential population**



Sources: Projected figures are based on data from the following sources: 1) Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra; 2) Australian Bureau of Statistics 2008, *Population Projections, Australia, 2006 to 2101*, Series B, Cat No. 3222.0, Australian Bureau of Statistics, Canberra.

Note: The growth in population assumes that the 2003 age standardised prevalence rates remain constant over time.

Of note, the age profile of the potential population features a decline in the 50 to 79 years age range. This may be due to the shorter life expectancy of people with a life-long disability. While the life expectancy of people with life-long disability has been increasing, it continues to be shorter than the life expectancy of the general population.<sup>20</sup>

## Disability and supports

We use six broad categories to describe the disability experienced by people with impaired decision-making capacity: intellectual disability (including autism), dementia (including stroke), psychiatric disability (including mental illness), neurological, acquired brain injury and other. These categories are based on 'disability type' and 'condition' data in the Survey of Disability, Ageing and Carers and largely align with the Disability Services National Minimum Data Set.<sup>21</sup> They are not clinical definitions, but broad classifications of disability.

As shown in Figure 9, the most common disabilities in the potential population are psychiatric disability (49%), intellectual disability (27%) and dementia (25%). The data suggests that psychiatric disability (including mental illness) attaches to other disabilities.

Further analysis shows that the majority of the potential population (65%) have a profound or severe core activity limitation (in communication, self care and/or mobility).<sup>22</sup> This

means that as well as having impaired decision-making capacity, people require assistance to undertake, or are not able to undertake, core activities in ordinary daily life. The rest, about one-third (35%), perform core daily activities with difficulties or with assistance from aids or equipment.

## Issues

**Our secondary research on the potential population for statutory systems advocacy has provided valuable insights into the number and characteristics of Queenslanders with impaired decision-making capacity. The profile highlights vulnerability, not only due to impaired decision-making capacity, but also due to other disabilities and complex support needs. These circumstances also increase the risk of abuse, neglect and exploitation.**

We estimate that the potential population will increase from 130,000 in 2010 to approximately 164,000 Queenslanders in 2020. The expected growth in the potential population will have significant implications for the delivery of mainstream and specialist services, and guardianship and administration services, in Queensland.

Statutory systems advocacy will become increasingly necessary to ensure the rights and interests of the growing potential population are promoted and safeguarded. We will continue to promote the inclusion and participation of Queenslanders with impaired decision-making capacity to government and non-government decision-makers.

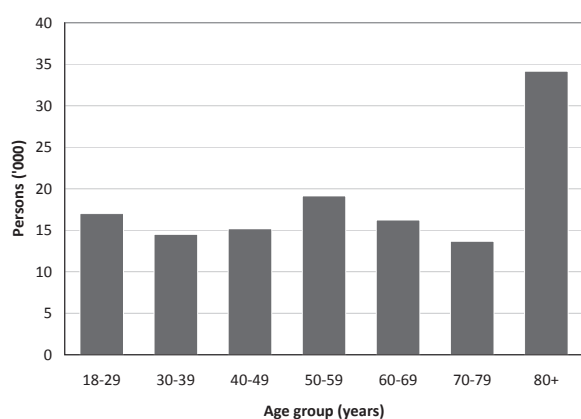
Further evidence on the characteristics and circumstances of Queenslanders with impaired decision-making capacity can be found in Key Result Area 3.

<sup>20</sup> Department of Families, Housing, Community Services and Indigenous Affairs 2010, *Ageing and Australian Disability Enterprises*, Occasional Paper No 27, Department of Families, Housing, Community Services and Indigenous Affairs, Canberra.

<sup>21</sup> The Disability Services National Minimum Data Set (DS NMDS) is a collection of data items that are collected in all Australian jurisdictions via an agreed method of collection and transmission. The purpose of the DS NMDS is to facilitate the annual collation of nationally comparable data about services funded under the National Disability Agreement, and to obtain reliable, consistent data with minimal load on the disability services sector.

<sup>22</sup> In Queensland, specialist disability services are provided for people with a profound or severe limitation in one or more core activities.

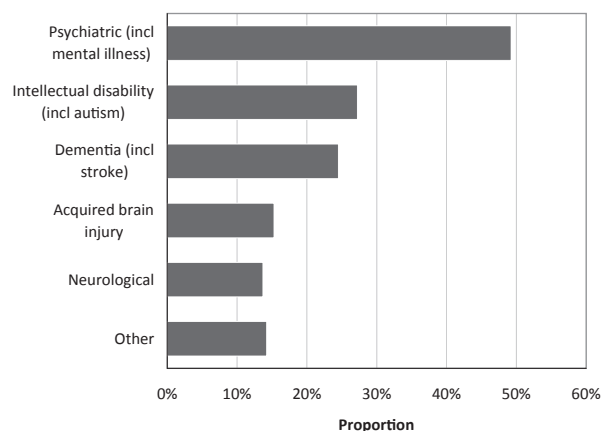
**Figure 8. Age profile of the potential population**



Source: Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.o.30.002, Australian Bureau of Statistics, Canberra.

Note: The 18-29 year age group spans 12 years unlike the other age groups which span 10 years.

**Figure 9. Disability in the potential population**



Source: Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.o.30.002, Australian Bureau of Statistics, Canberra.

Note: The sum of percentages exceeds 100% as people may have multiple disabilities and be counted in more than one category.

## Adult Guardian Client Profile Project

The Adult Guardian Client Profile Project is a piece of significant primary research undertaken by our Office over the last year. This project, a joint venture, sponsored by the Office of Adult Guardian, is a ten year profile of people subject to guardianship orders made to the Adult Guardian. Other types of guardianship, for example, the appointment of family members, are not included in the project.

Our Office will use the findings to support an evidenced-based approach to systems issues relating to the legal intervention of guardianship. A sound evidence base will provide an improved understanding of this population's needs and disadvantages to better inform future priorities and strengthen advocacy for Queenslanders subject to guardianship orders.

## Data Statement

The Adult Guardian client profile involved the collation of three datasets, namely the Adult Guardian client database, the shared clients database and sample case files.

Guardianship data was extracted from the Adult Guardian client database to form a dataset of all guardianship orders and clients between 2000 and 2010. The Adult Guardian client data presented in this report is current as at November 2010, when it was extracted from the Adult Guardian data system. The Office of the Adult Guardian maintains an active data system to manage its clients, meaning that information about guardianship orders and clients is continually updated. The figures we present are indicative as their accuracy is dependent on the quality and completeness of client information in the Adult Guardian data system.

The shared client database was formed by linking data from the Adult Guardian client database with specialist disability data from the Department of Communities, known as the Disability Services National Minimum Data Set (DS NMDS). Along with the conditions accompanying the data collected for the DS NMDS, our shared client data only represents the shared clients of the Adult Guardian and Department of Communities (not all Adult Guardian clients).

At the time of the analysis, the most recently available DS NMDS data was from the 2008-09 Queensland collection. The 2009-10 data was preliminary at the time of our analysis and consequently unavailable for use. Further information about the DS NMDS can be found on the Australian Institute of Health and Welfare website at <http://www.aihw.gov.au/disability-services-nmgs-collection>

The references to clients in the subsequent sections refer to 'shared clients', who are adults for whom the Adult Guardian has been appointed at least once between 2000 and 2010, and who also received a funded specialist disability service in 2008-09. The figures and findings relating to Adult Guardian clients are therefore extrapolations and may be subject to a margin of error.

We gathered data from a random sample Adult Guardian case files. The reliability of case file data was tested and found to be representative of the Adult Guardian client base.

All client data used to create the Adult Guardian client profile (i.e. the DS NMDS and the Adult Guardian client database and case files) was de-identified to maintain client confidentiality. Individuals cannot be identified in any of the data sources.

When considering the guardianship projections in this report, it is important to note that the projections are estimates and not exact counts. They have been rounded and are therefore subject to a margin of error.

## Partnership and innovation

**The Adult Guardian Client Profile Project explores ten years of Adult Guardian data and identifies socio-demographic characteristics and needs, outlines trends in guardianship in Queensland and highlights systems issues.**

The project only examines information about people subject to guardianship orders made to the Adult Guardian.

This project is of interest to guardianship jurisdictions in other states and territories. It is the first time research of this kind has been undertaken in Queensland (or nationally as far as we can establish) and demonstrates the benefits and possibilities of information-sharing between agencies with shared clients.

### Data sources and collection

As illustrated in Figure 10, the research methodology for the Adult Guardian Client Profile Project incorporated a detailed examination of:

- the Adult Guardian client database
- a shared client dataset integrating the Adult Guardian client database and the Department of Communities' National Minimum Data Set (see 'Data linkage' section below for further information)
- a representative sample of Adult Guardian client case files.

The Adult Guardian client database provided broad information on all guardianship clients over the ten year period 2000 to 2010. Examination of the shared client dataset and the representative sample of case files provided rich client data and built a reliable evidence base to develop our understanding of the characteristics and needs of guardianship clients.

We strongly support data sharing between agencies to promote evidence-based policy and service delivery improvements for mutual clients.

**There is a need to profile Adult Guardian clients to identify systems issues and safeguard the human rights and interests of Queenslanders with impaired decision-making capacity and their families subject to guardianship interventions.**

### Data linkage

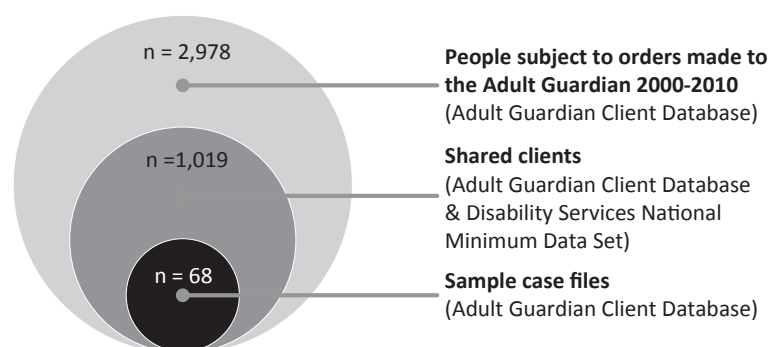
We undertook a data linkage process to fill an information and data gap concerning the Adult Guardian database. We collaborated with the Department of Communities (Disability and Community Care Services) to integrate de-identified client data of the Adult Guardian with specialist disability data, known as the Disability Services National Minimum Data Set (DS NMDS). The result of the data linkage process was a new dataset of shared clients for research purposes.

At the time of data collection, the Adult Guardian client database was shallow in terms of person-level information. The DS NMDS provided a deeper understanding of shared clients.

**This research has highlighted the critical importance of a reliable client database. A well designed and maintained database can provide valuable client information. It can also assist with meeting organisational requirements of transparency and accountability.**

We achieved an effective data matching rate of 59%, providing 1,019 de-identified records of shared clients. Some records were excluded from the data matching process as they did not contain

**Figure 10. Data sources for the Adult Guardian Client Profile Project**



Source: Adult Guardian Client Profile Project 2011.



the data required for the linking process, some Adult Guardian clients were deceased, while others were over the age of 65 years and therefore outside the service provision parameters of the Department of Communities (Disability and Community Care Services).

## Case file data

The data gathering process included the collection of quantitative and qualitative data from a sample of Adult Guardian case files. We undertook this process to further expand on the data made available through the shared client dataset.

A data collection tool was developed to gather information that would describe the socio-demographic profile of Adult Guardian clients, including age, gender, disability, support needs, carer status, communication, employment, indigenous status and associated risks. The tool also collected information on the growth, trends and administrative aspects of applications made to the Queensland Civil and Administrative Tribunal, including triggers for applications, guardianship applicants, and the key issues for guardianship orders. We were also able to compare some aspects of this socio-economic profile with that of the broader population of people with impaired decision-making capacity (refer to Key Result Area 3).

We randomly selected a sample of 75 client case files. The unavailability of some case files meant that a total of 68 cases were examined. We tested the sample case file data to determine if it was exemplar of the Adult Guardian client base and concluded that the sample was representative. This means that the findings can be applied to the overall guardianship population where the Adult Guardian is appointed as the guardian.

## Guardianship orders made to the Adult Guardian from 2000 to 2010

### Snapshot of findings

A final report on the Adult Guardian Client Profile is in progress, however the data collection and analysis was completed this year. A snapshot of our findings is provided below. It explores both administrative aspects (trends in guardianship) and the profile of adults subject to guardianship orders made to the Adult Guardian.

As seen in Figure 11, over the ten year period from 2000 to 2010, the Queensland Civil and Administrative Tribunal (previously the Guardianship and Administration Tribunal) appointed the Adult Guardian for a total of 2,978 adults between 2000 and 2010. In late 2010, there were 1,714 active guardianship orders with the Adult Guardian.

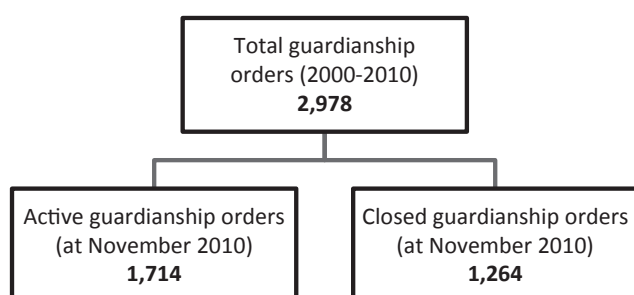
Over the ten years, only 1,264 (42%) of the total number were closed. Further analysis identified that 381 (30%) of closed cases were due to the death of the client and not a scheduled review or revocation of an order. From 2000 to 2010, there were 883 revoked (or 30% of the total number of orders).

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**These findings suggest a low level of revocation of orders and therefore a high level of retention of orders made to the Adult Guardian. Further research is required to determine the reasons for rates of retention of orders given the principled requirement of last resort and the least restrictive alternative in all the circumstances.**

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**Figure 11. Number of guardianship orders made to the Adult Guardian (2000–2010)**



Source: Adult Guardian Client Profile Project 2011, Adult Guardian Client Database, n=2,978.

Since the establishment of the *Guardianship and Administration Act 2000*, the number of people subject to first-time guardianship orders made to the Adult Guardian has increased from 13 people during 2000 to an estimated 722 during 2010 (see Figure 12). This increase represents the number of first-time appointments made to the Adult Guardian and does not include reviewed and continued appointments.

Figure 13 shows the projected number of new clients entering the guardianship system each year, from 2011 to 2020. Please note that Queenslanders already in the guardianship system are not included. This means the total number of people in the system is much higher.

The last three years have seen an exponential increase in the number of first-time guardianship appointments made to the Adult Guardian (see Figure 12). This increase may be attributable, in part, to the introduction of the restrictive practices amendments to the *Disability Services Act 2006* (Qld) which came into effect in 2008. It is anticipated that the increase in first time guardianship appointments made to the Adult Guardian for restrictive practices will decelerate over time as the backlog of first-time appointments is addressed and less restrictive responses are promoted.

**The trends and demand for guardianship in this new area of regulation (restrictive practices) should be independently monitored and results, including outcomes for the individuals subject to restrictive practices, reported annually.**

We estimate that in the year 2020, there could be approximately 1,200 new people who become subject to guardianship orders made to the Adult Guardian (see Figure 13).<sup>23</sup>

<sup>23</sup> The calculation of the number of first-time guardianship orders made to the Adult Guardian is based on the Adult Guardian client database. It assumes that there will be a rate of growth consistent with the pre-2008 trend and that guardianship appointments of restrictive practices will not make a significant contribution beyond 2008-2009.

There is a concerning disparity between the projected growth of new people subject to a guardianship order made to the Adult Guardian for the first time and the projected growth of the Queensland population.

**Over the next ten years, the adult population of Queensland is expected to grow by 2.1%<sup>24</sup> annually while the number of people who become subject to guardianship orders made to the Adult Guardian for the first time is projected to grow by almost 6.6% each year.**

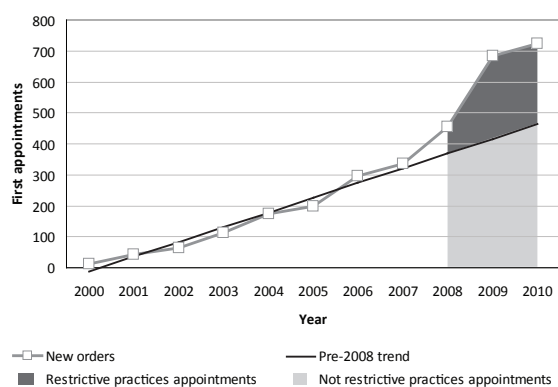
It is important to note that these figures only include adults who will become subject to guardianship orders to the Adult Guardian for the first time. The total number of adults in a given year will also include people who remain subject to orders made in previous years.

Further analysis shows that in 2010, the average duration of a guardianship order was approximately 38 months per person. This means that based on current trends, the projected number of all adults subject to guardianship orders made to the Adult Guardian in 2020 may exceed 3,600 Queenslanders.

**The exponential growth in the population of people with impaired decision-making capacity suggests an associated growth in legal interventions like guardianship. Guardianship in its current form is unsustainable.**

<sup>24</sup> Australian Bureau of Statistics 2008, *Population Projections, Australia, 2006 to 2101*, Series B, Cat No. 3222.0, Australian Bureau of Statistics, Canberra.

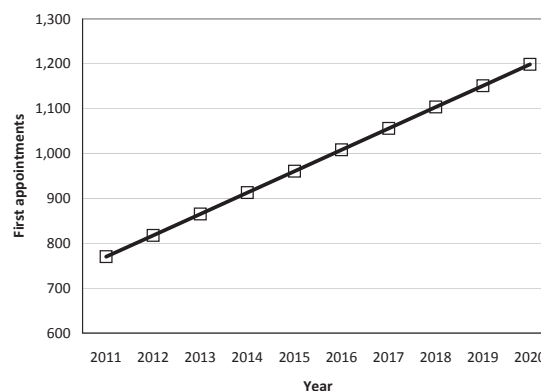
**Figure 12. Growth in first-time guardianship orders made to the Adult Guardian (2000-2010)**



Source: Adult Guardian Client Profile Project 2011, Adult Guardian Client Database, n=2,978.

Notes: The number of guardianship orders for 2010 was extrapolated using the ten months of data available for 2010. The number of guardianship orders is based on people's first order made to the Adult Guardian. It does not include reviewed or continued guardianship orders made to the Adult Guardian.

**Figure 13. Projected growth in the number of first-time guardianship orders made to the Adult Guardian**



Source: Adult Guardian Client Profile Project 2011, Adult Guardian Client Database, n=2,978.

Notes: The projected number of first-time appointments made to the Adult Guardian was calculated from a linear regression using first-time appointment data for 2000-2010.

## Administrative aspects of guardianship

We examined the administrative aspects of guardianship orders made to the Adult Guardian.<sup>25</sup> We were interested in understanding the circumstances that trigger applications and the key issues prompting the guardianship orders.

### Guardianship triggers

Our examination of case files revealed that the circumstances behind applications for guardianship where the Adult Guardian is appointed can be varied. The application process for guardianship is often activated by multiple triggers.

Seeking access to services was the single most common circumstance for an application for guardianship made to the Adult Guardian (Figure 14). Abuse, neglect, exploitation and family conflict, either singly or together, provided a set of circumstances which also prompted the application process. Self-harm and/or neglect, often reflected in the adult's poor health and wellbeing, also commonly prompted an application.

More recently, the use of restrictive practices was the trigger for a number of orders to the Adult Guardian. While the number is small in the sample case files it is much larger in the shared clients analysis (refer to 'Data sources and collection'). When reviewing this data it is important to note that the approval of a guardian for restrictive practices has been a mandatory legislative requirement since 2008. As a guardian for restrictive practices, legislation requires the Adult Guardian to consent to the positive behaviour support plans for individuals for whom it acts. This includes the initial positive behaviour support plan and revised plans resulting from an annual review of the use of

restrictive practices. Meeting these regulatory demands may be resource intensive for service providers and the Office of the Adult Guardian.

**These findings suggest that mandatory administrative requirements are drivers rather than 'last resort' need arising from risks of abuse, exploitation and neglect. Arguably this creep in scope falls outside of Parliament's original intention for legal interventions such as guardianship.**

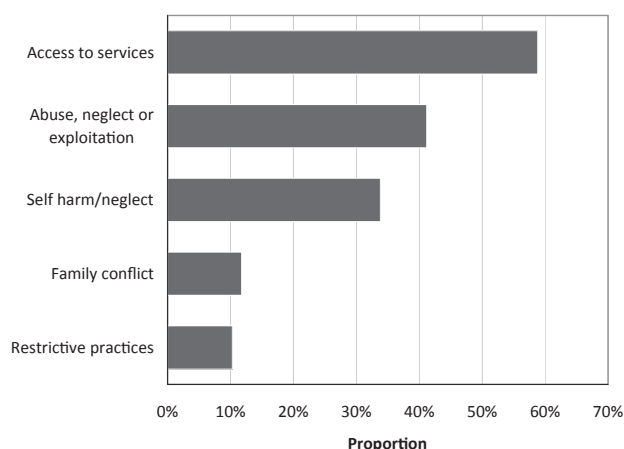
### Guardianship applicants

Family members, friends, professionals or anyone who has a genuine and continuing interest in the welfare of a person with impaired decision-making capacity can apply for a guardian to be appointed. The person with impaired decision-making capacity can also apply on their own behalf.

Figure 15 shows that the large majority (74%) of applications are made by providers in health care or service settings, including government and non-government service providers. This is consistent with the application triggers, which show that applications are regularly heard by the Queensland Civil and Administrative Tribunal because of issues such as the need to access services (refer to Figure 14).

<sup>25</sup> The findings presented in this section are based on a detailed analysis of a representative sample of 68 Adult Guardian case files.

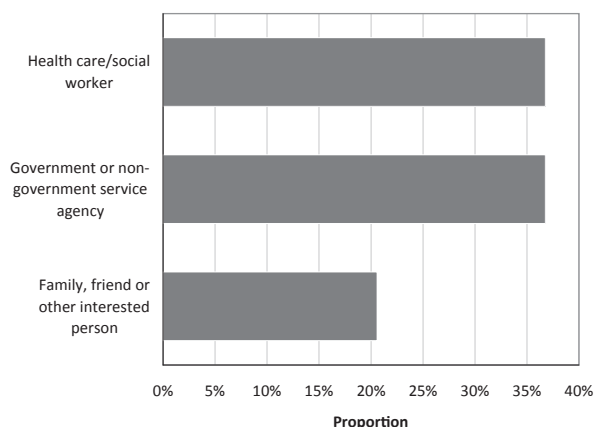
**Figure 14. Main triggers for guardianship orders made to the Adult Guardian**



Source: Adult Guardian Client Profile Project 2011, Sample Case Files, n= 68.

Note: A guardianship application may have more than one trigger.

**Figure 15. Applicants of guardianship orders made to the Adult Guardian**



Source: Adult Guardian Client Profile Project 2011, Sample Case Files, n= 68.

In practical terms this means that service providers are making applications for decisions regarding service provision. Arguably these findings suggest that the legal intervention of guardianship is being used as a case management or brokerage tool by service providers. This may stem from resource constrained and risk adverse service delivery cultures wanting to shift case management accountability and liability from the service system to the legal system.

**Using guardianship as a case management tool continues to occur despite the policy language of seamless and coordinated service delivery, and effective case management.**

Greater attention should be given to building service cultures of collaboration, including the implementation of a set of basic standards on communication, referral, and case management responsibility. These standards should be met before an application for guardianship is decided. This would safeguard the integrity of the last resort principle.

Family and friends were the applicants for only 21% of guardianship orders made to the Adult Guardian. The Adult Guardian dataset does not provide an insight into why families account for this small proportion of applicants. The small proportion of families and friends making an application for guardianship may be the result of families having a low level of awareness about, or confidence in, the guardianship system. Further investigation of this issue is needed.

**We encourage the application of the principle of maintenance of existing family relationships and support networks unless it is proved on the balance of probabilities that doing so would result in the abuse, neglect or exploitation of the person with impaired decision-making capacity.**

Further research is required on guardianship outcomes for the person with impaired decision-making capacity and the level of risk posed to the person if family remain involved as decision-makers. Alternative dispute resolution, supported decision-making or other options like community guardianship should also be considered as they could potentially reduce the need for guardianship appointments to the Adult Guardian.

## Guardianship order issues

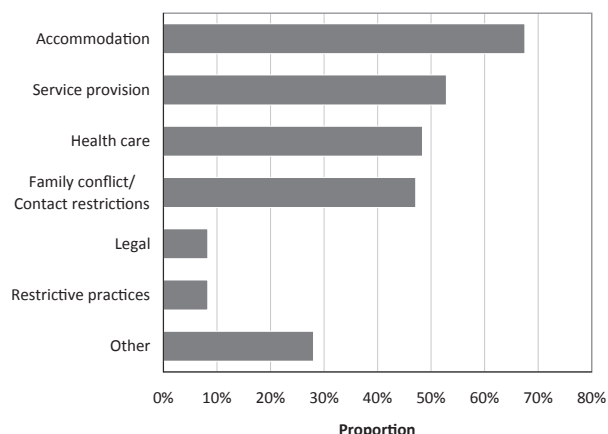
The most frequent issues for which guardianship is sought were access to safe and appropriate accommodation; support services; and health care (Figure 16). The appointment of the Adult Guardian sometimes occurred as a result of family conflict and/or issues relating to who may be in contact with the person with impaired decision-making capacity. Contact issues usually arise where there are alleged risks of abuse, neglect or exploitation.

As highlighted earlier, accommodation is a key issue for which the Adult Guardian is appointed. Our analysis of case files included identifying changes in accommodation type from the time the guardianship order was made.

Figure 17 shows the change in the proportion of clients living in various types of accommodation, from the time of the guardianship order. Over one quarter (28%) of people were residing in hospital at the time of the order. This proportion reduced to 7% following the guardianship appointment. The proportion of clients in residential aged care increased significantly after the guardianship appointment (from 4% to 26%).

The findings lead us to hypothesise that appointments made to the Adult Guardian may be used as a part of the hospital discharge planning process.

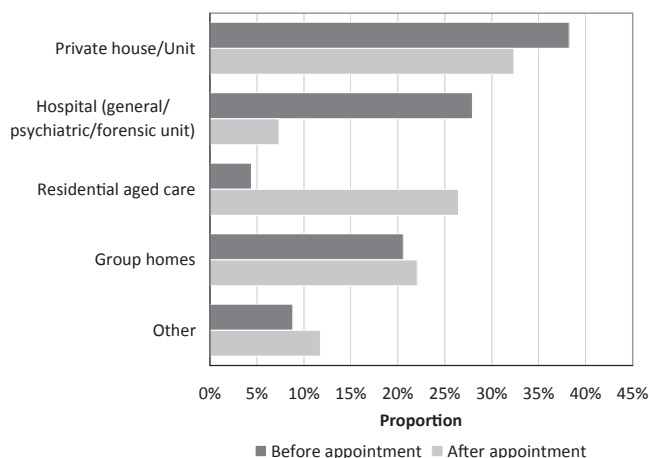
**Figure 16. Key issues for guardianship orders made to the Adult Guardian**



Source: Adult Guardian Client Profile Project 2011, Sample Case Files, n= 68.

Note: An order may relate to more than one issue, therefore the categories are not mutually exclusive. The 'other' category includes orders relating to directions, education, training and employment, day to day issues, licensing and permits and personal matters not elsewhere classified.

**Figure 17. Accommodation used by people subject to guardianship orders made to the Adult Guardian**



Source: Adult Guardian Client Profile Project 2011, Sample Case Files, n= 68.

Note: The 'other' category includes boarding houses, hostels, shelters and types of accommodation not elsewhere classified.

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**Health care workers may be using the guardianship system to expedite the discharge of some hospital patients who may, for example, be inappropriately placed in acute beds.**

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There was little change in the proportion of people residing in group homes from the time of the guardianship order. This may indicate that people are less likely to be moved in or out of group home accommodation as a result of a decision made by a guardian, however they may be moved from one group home to another.

The findings show that the majority of accommodation decisions made by the Adult Guardian involve moving people from private homes and hospital settings into aged care facilities. A less common decision might be moving a person from a hospital setting to a group home, hostel or other accommodation. As noted earlier, service providers may be using the guardianship system to activate changes in accommodation or service provision. The resources to facilitate such decisions are significant, and as such, raise concerns about the appropriateness and efficiency of using guardianship for this type of case management or conflict resolution.

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**Guardianship is a critical component of the social care safety net and should be used as an intervention of last resort. It should not be used as a case management tool or a mechanism to shift liabilities for client outcomes from the provider to the guardian (that is, from the service system to the legal system).**

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We should not forget that a guardian can only consent to services that are available – in other words, the choice of service options is limited to availability and dependent on clients meeting service eligibility criteria.

Further examination of the processes and outcomes of guardianship is needed to identify opportunities for innovation but most importantly to enhance the sustainability of the guardianship system into the future.

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**An investigation of the costs and benefits of statutory individual advocacy and dispute resolution options is required. Alternative and more contemporary guardianship models like community guardianship and supported decision-making should also be examined.**

**The development of best practice case management guidelines, practice standards and guiding principles that safeguard 'last resort' tests before an application is lodged or heard would be beneficial and in keeping with the original intention of Parliament for guardianship.**

**What is clear from our research is that the service system is using the legal system for service access and other case management responses. Further testing of this hypothesis is urgently required.**

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## Profile of Adult Guardian clients

The references to clients in the following sections refer to 'shared clients', who are adults for whom the Adult Guardian has been appointed at least once between 2000 and 2010, and who also received a funded specialist disability service in 2008-09.<sup>26</sup>

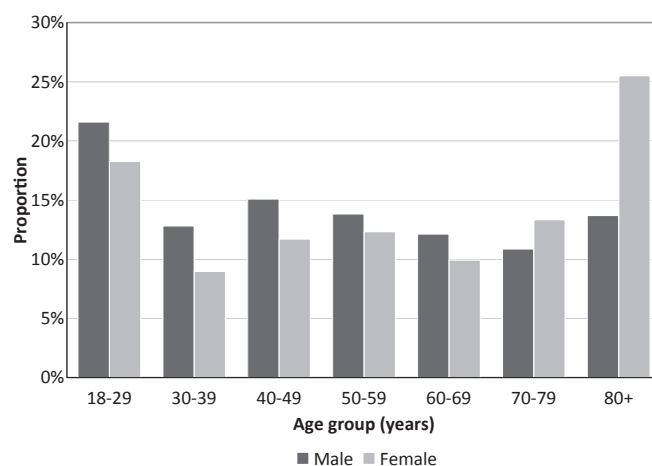
### Age and gender profile

The age profile of Adult Guardian clients (at the time of their first appointment) is broadly characterised by three noticeable

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<sup>26</sup> Refer to the section 'Data linkage' for information about the methodology and database of shared clients.

**Figure 18. Age-gender profile (at the time of their first appointment) of people subject to guardianship orders made to the Adult Guardian**



Source: Adult Guardian Client Profile Project 2011, Adult Guardian Client Database, n=2,886 (92 missing values).

Note: The 18-29 year age group spans 12 years of data unlike the other age groups which span 10 years.

peaks: young adults, the middle aged and elders (with a skew towards females). These peaks, seen in Figure 18, suggest a strong relationship to life transitions. Changes in familial circumstances during these transition periods may be associated with entry into the guardianship system.

For young adults with impaired decision-making capacity, the move to independent living away from the family home may trigger the application for a guardianship order. Also among the younger cohorts are those young people who have moved from guardianship within the child protection system into the formal guardianship system for adults.

Queenslanders with impaired decision-making capacity may be particularly vulnerable in middle age. This cohort is likely to include adults with impaired decision-making capacity (usually life-long) who are cared for by parents, who are themselves reaching advanced ages. This ‘ageing carers’ phenomenon is an important underlying factor contributing to the entry into the guardianship system of middle-aged adults.

The peak in the older age groups is primarily attributable to the increased prevalence of age-related conditions which can specifically impair a person’s decision-making capacity. The need for guardianship may also stem from a weakened informal support network, for example through the death of a spouse, older adult children and/or friends.

Early responses and prevention research suggests that strong case management models may be particularly relevant for people in crisis, people with newly acquired disability, new carers, and for people facing life stage transitions.<sup>27 28</sup>

<sup>27</sup> Australian Institute of Health and Welfare 2007, *Disability in Australia: Acquired Brain Injury*, Bulletin No. 55, Cat No. AUS 96, Australian Institute of Health and Welfare, Canberra.

<sup>28</sup> Australian Institute of Health and Welfare 2008, *Disability in Australia: Intellectual Disability*, Bulletin No. 67, Cat No. AUS 110, Australian Institute of Health and Welfare, Canberra.

**If guardianship appointments are inextricably linked to life transition issues then demand will be exponential and the current system is unlikely to be sustainable.**

It will be critical to promote public confidence in the efficacy of enduring instruments, like the enduring power of attorney and advance health directives. The revocation of enduring instruments must be of last resort. The public will have less confidence in the efficacy or endurance of such instruments unless there are strict revocation standards.

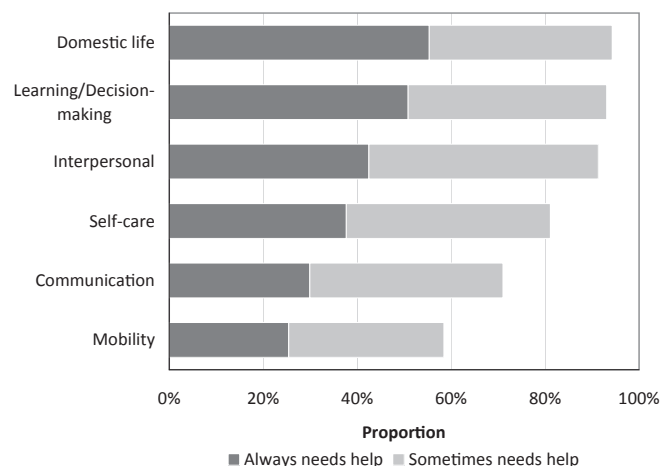
The age-gender profile also shows an unbalanced gender ratio with males accounting for 55% of clients (see Figure 18). This means that more males than females have entered the guardianship system. Despite lower numbers, the pattern of female age distribution is similar to the male age distribution.

## Disability and support needs

Adult Guardian clients are, by legislative definition, people who have a disability that impairs their decision-making capacity. Intellectual disability was the most prevalent primary disability (62%), followed by psychiatric disability (13%) and acquired brain injury (8%).

Our analysis revealed that the majority of clients require support with activities relating to independent and daily living (Figure 19). Almost all clients (94%) require assistance with daily domestic life and a large majority (81%) require assistance with self-care activities. The large proportion of clients who sometimes or always require assistance with general interpersonal interactions (91%) and communication (71%) suggests complex life circumstances and vulnerability.

**Figure 19. Support needs of people subject to guardianship orders made to the Adult Guardian**



Source: Adult Guardian Client Profile Project 2011, Shared Clients, n=1,019.



Our secondary research shows that 42% of adult Queenslanders with impaired decision-making capacity are not having their support needs met (as discussed in Key Result Area 3). This means they are not receiving the level of assistance they require for daily and independent living.

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**It is noteworthy that lack of access to needed support services is a common experience for most people with impaired decision-making capacity and not limited to people subject to guardianship orders to the Adult Guardian.**

**To have a better understanding of unmet need, we think that access to mainstream and specialist services and supports for people with impaired decision-making capacity must be independently monitored and reported. Agreed targets must be set and progress measured regularly. Reporting should cover the state of affairs now (baseline) and over time (trends). This will provide valuable information to identify risk and plan for future demand.**

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## Carer support

We acknowledge that not all people have or need a carer. For those who do, families and unpaid carers provide the majority of care. For many, quality of life is dependent on the commitment of families and support networks to fill the gaps in the service system.<sup>29</sup>

Research has identified that primary carers aged 18- 50 years have poor mental health outcomes with very high rates of clinical depression, anxiety and family breakdown.<sup>30</sup> This age group represents a productive time of life and highlights the consequences of low levels of economic participation and poverty, including the loss over time of personal support networks and social connectedness.

### Without informal carer

The majority (69%) of clients did not have an informal carer.<sup>31</sup> Many of those without an informal carer lived in cared accommodation, such as group homes and hostels (57%), and fewer in private homes (35%). It is likely that people living in cared accommodation may not have close family or friends to provide them with decision-making support.

We identified that clients without an informal carer tended to be older than those who had an informal carer. For example, 68% of people without an informal carer were aged 35 years or more, whereas 59% of those with an informal carer were younger than 35 years. It is reasonable to assume that older clients may not

have had an informal carer because family, for example parents, were likely to be aged and unable to provide the level of care and support needed.

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**The absence of an informal carer, or having an ageing carer, appears to be a driver for guardianship for a large proportion of clients. Our findings suggest that without an informal support network, people with impaired decision-making capacity are highly vulnerable to entering the guardianship system.**

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### With an informal carer

Less than one-third (31%) of clients had an informal carer and many of them lived in private homes (71%), either with or without their informal carer. In most cases the informal carer was the person's mother (44%). The majority of carers (64%) were aged 45 years or over suggesting that the ageing carers phenomenon is present. The ageing generation of carers is cause for concern in terms of sustaining the informal support network.

Our analysis of the data did reveal that 90 young Queenslanders (aged less than 25 years) with impaired decision-making capacity had informal carers and that in 53% of cases the carer was a parent. The Adult Guardian dataset does not provide an insight into why these young people are subject to a guardianship order made to the Adult Guardian when it is reported that their parents provide informal care. This finding requires further investigation.

Guardianship should be of last resort. It is essential that legal interventions, like guardianship, seek to promote and maintain existing family relationships, whilst upholding the principle of the least restrictive alternative in all circumstances.

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**Investment in providing appropriate and sustainable supports to maintain family and informal support networks is a critical factor in managing the demand for guardianship services.**

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<sup>29</sup> National People with Disabilities and Carer Council 2009, *Shut Out: The Experience of People with Disabilities and Their Families in Australia*, Commonwealth of Australia, Canberra.

<sup>30</sup> Australian Institute of Health and Welfare 2008, *Disability in Australia: Trends in Prevalence, Education, Employment and Community Living*, Bulletin No.61, Cat No. AUS 103, Australian Institute of Health and Welfare, Canberra.

<sup>31</sup> An informal carer is a person such as a family member, friend or neighbour who provides regular and sustained care and assistance to the person requiring support. Paid or voluntary carers whose services are arranged by a formal service organisation are not informal carers.

## Communication

Figure 20 shows that the majority (65%) of clients used spoken language as their most effective means of communication. Nearly one-third (28%) have little or no effective communication while another 4% communicate through means other than the spoken word, such as gestures. About 14% of clients needed an interpreter to assist with non-spoken communication.

Research and related literature on ‘challenging’ behaviour and the use of restrictive practices highlights the strong relationship between a person’s communication capacity, the ability of others to understand them, and associated frustration levels. Clear communication is a critical factor in being understood and expressing choices. Not being understood can lead to frustration and despair, and may contribute to the development of anti-social behaviour, a break down in services and isolation. Early response programs to improve communication and address behaviours must be a priority for people who experience difficulties with communication.

As noted above, the resource intensive nature of the administration of restrictive practices makes it imperative that investment in prevention models is seen as a priority and advanced

## Employment

The majority (78%) of clients are not employed, not actively looking for work or are unable to work. Of those who were able, willing and available to work, 75% were not successful in obtaining employment.

**People with impaired decision-making capacity continue to face discrimination and disadvantage in attempts to secure employment or meaningful day activity.**

The data shows that employment disadvantage is a common experience for people with impaired decision-making capacity who are willing and able to work, and that the majority are unable to access employment opportunities (refer to Key Result Area 3). It also highlights the gap in policy and programs to secure employment or meaningful day activity for clients who are able and willing to participate in the economic and social opportunities available to most Queenslanders.

## Indigenous clients

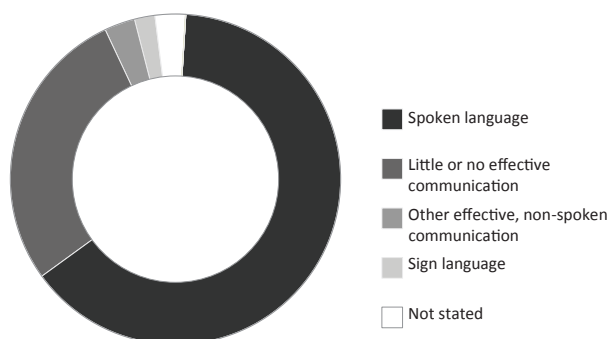
People of Aboriginal and Torres Strait Island backgrounds accounted for a much larger proportion (12%) of clients, than the representation of Indigenous people in the broader population of Queenslanders with a disability who access specialist disability services (6%).<sup>32</sup>

Our analysis revealed that almost 46% of Indigenous clients are younger than 30 years, compared to 30% of non-Indigenous clients (see Figure 21). There are a number of factors that may contribute to the younger profile of Indigenous clients. The over-representation of young Indigenous Queenslanders in the child protection system may be a contributing factor.<sup>33</sup> Young Indigenous people with a disability, who have been subject

<sup>32</sup> Australian Institute of Health and Welfare 2011, *Disability Support Services 2008-09: Report on Services Provided under the Commonwealth/State Disability Agreement and the National Disability Agreement*, Table A2.12, Cat No. DIS 58, Australian Institute of Health and Welfare, Canberra.

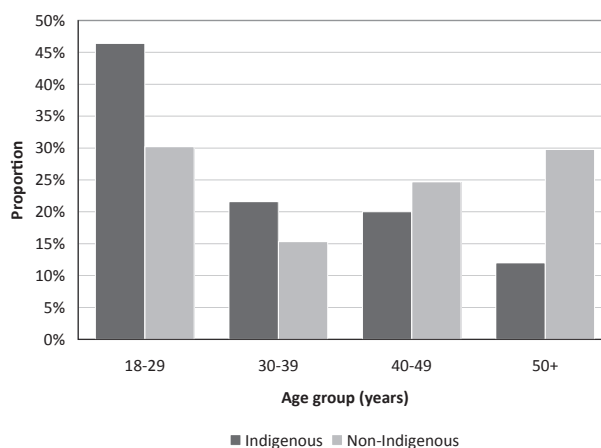
<sup>33</sup> Australian Institute of Health and Welfare 2011, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander People: An Overview 2011b*, Cat No. AIHW 42, Australian Institute of Health and Welfare 2011, Canberra.

**Figure 20. Communication method of people subject to guardianship orders made to the Adult Guardian**



Source: Adult Guardian Client Profile Project 2011, Shared Clients, n=1,019.

**Figure 21. Age profile of Indigenous and non-Indigenous people subject to guardianship orders made to the Adult Guardian**



Source: Adult Guardian Client Profile Project 2011, Shared Clients, n = 1,019.

Note: The 18-29 years age group includes 12 years of data.



to child guardianship, may move into the adult guardianship system on turning 18 years of age. Another factor may be the relatively high prevalence rate of young Indigenous people with developmental conditions causing disability. Mental illness, substance and alcohol abuse and acquired brain injury may also contribute to an increased risk of impaired decision-making capacity in this population.<sup>34</sup>

The almost complete absence of older Indigenous people in the guardianship system is most likely to be influenced by the shorter life expectancy of Indigenous Queenslanders. For example, the estimated life expectancy of Indigenous Australians is 59 years for males and 65 years for females. This is 16-17 years less than the general Australian population.<sup>35</sup>

The over-representation of indigenous people in the guardianship system (particularly very young adults) is of great concern. This finding highlights the critical importance of investing in cultural awareness, appropriate communication tools and alternative case management processes in the guardianship system. Every effort must be made to encourage and maintain family and community involvement in decision-making.

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**Indigenous Queenslanders in the age group 20-40 years are at high risk of entry into the guardianship system.**

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## Issues

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**Appointing the Adult Guardian as a last resort is integral to Queensland's social care safety net. The findings suggest that the Adult Guardian may not always be a last resort appointment, particularly in matters relating to accommodation and access to support services, where family members or other support networks exist.**

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Using guardianship as a case management tool to access services is occurring despite the current policy language of seamless service integration and coordinated case management. This may stem from under-resourced, often fragmented, complex and risk adverse service cultures. It is inappropriate, inefficient and unsustainable to use the legal intervention of guardianship in this way. Arguably, this approach falls outside Parliament's original intention and undermines guardianship's integrity as a mechanism of social justice and rights protection.

The guardianship system may benefit from promoting, across sectors, a mutual understanding of the goals of shared and core case management responsibility, including role and liability clarification. It may be useful to have clear guidelines for dispute resolution and crisis management when multiple agencies are involved in complex individual matters.

It also appears that some of the decisions to re-appoint the Adult Guardian are inconsistent with the principle of last resort. The data shows there is a low level of revocation of orders made to the Adult Guardian, resulting in a high proportion of orders that are continued. A further examination to better understand the dynamics of review and revocation processes is needed.

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**We have suggested that guardianship in its current form is unsustainable, not only as a case management tool, but because of the expected growth in guardianship appointments. We estimate that the number of people subject to guardianship orders made to the Adult Guardian may exceed 3,600 Queenslanders in 2020.**

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Queensland's ageing population will have a significant impact on the demand for guardianship orders made to the Adult Guardian. There will be an increase in the age-related conditions which can impair a person's decision-making capacity; weakened informal support networks of older Queenslanders; and the inability of ageing carers to continue providing care and support.

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**Investment in providing appropriate and sustainable supports to maintain family and informal support networks should be a priority, not only to uphold the principle of last resort, but as a demand management strategy. We know that for a large proportion of people, the absence of an informal carer, or having an ageing carer, can be a driver for entry into the guardianship system.**

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The Adult Guardian client profile has provided new insights into the Queensland guardianship system and the circumstances of Queenslanders subject to guardianship orders made to the Adult Guardian. Our research has identified systems issues and highlighted the need for further investigation.

We think the Queensland guardianship system should be monitored against an agreed set of performance criteria. Progress towards the achievement of performance criteria should be reported and widely disseminated.

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<sup>34</sup> Australian Institute of Health and Welfare 2011, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander People: An Overview 2011*, Ca. No. AIHW 42, Australian Institute of Health and Welfare 2011, Canberra.

<sup>35</sup> Australian Bureau of Statistics 2010, *Deaths, Australia*, Cat No. 3302.0, Australian Bureau of Statistics, Canberra.

## Research collaboration and partnerships

We are committed to expanding our knowledge and evidence base to inform and influence policy, programs and practices to improve life opportunities and outcomes for Queenslanders with impaired decision-making capacity.

To support and extend our evidence-based approach, we have partnered with academics, government agencies and community associations on primary research projects. Our collaboration has focussed on current research activities and forward programs of research. This engagement aims to align the work of the Office with the work of other agencies to maximise the opportunity to build a broad and robust evidence base to effectively promote best practice and the rights and interests of people with impaired decision-making capacity. It also ensures research is complementary and avoids duplication of effort and better targeting of scarce resources.

## Research collaboration

This year we have been privileged to work and partner with researchers from academia, government and non-government on innovative primary research and applied research projects. We are committed to progressing these types of projects as they provide critical and contemporary evidence to better understand the systems barriers excluding people with impaired decision-making capacity from the social, economic and civic resources available to most Queenslanders.

We believe that a collaborative approach to building knowledge and evidence can produce enduring outcomes. Over the past year we have purposefully and actively engaged with a number of government agencies and data custodians to identify knowledge gaps, advance research opportunities and share information and data.

We are proud of the significant partnership formed with the Office of the Adult Guardian and the Department of Communities for the Adult Guardian Client Profile Project. The opportunity to work collaboratively and develop new evidence and deliver new insights into the Adult Guardian client base was embraced by the agencies. Our integration of de-identified client data from the Office of the Adult Guardian and the Department of Communities advanced our understanding of the shared client base across the two human services agencies.

The methodology employed to integrate the datasets, and its associated requirements, benefits and limitations, was also shared with the Office of Economic and Statistical Research and other Queensland Government departments through the Statistical Liaison Officers Network. An understanding of how to successfully apply the data integration methodology may assist other government agencies to advance their understanding of clients, who are common to multiple government agencies.

A positive relationship has been developed with the Queensland office of the Australian Bureau of Statistics. Discussions focussed on our current and future work program and future engagement opportunities.

This year, in conjunction with the Office of Economic and Statistical Research's Statistical Liaison Officer Network, we identified an evidence gap on elder abuse. We advocated the need to identify existing administrative sources and collection points and methods to deliver comprehensive data on key indicators relating to elder abuse. We also continued to advocate for data on adults with impaired decision-making capacity proceeding through the criminal justice system at all stages, from arrest and criminal proceedings through to corrections.

## Research partnerships

We congratulate our research partners on their commitment to the promotion and protection of the rights and interests of people with impaired decision-making capacity and look forward to continuing research collaborations.

### Research partnership Indigenous Queenslanders and the guardianship system

*Lead investigators: Professor Jayne Clapton and Ms Natalie Clements, School of Human Services and Social Work, Griffith University.*

*Key partners: Central Queensland University, James Cook University and the Office of the Public Advocate.*

This year, we have continued our research partnership with Griffith University, Central Queensland University and James Cook University to explore the notion of 'impaired capacity' in relation to Indigenous people, and the interaction which Indigenous people and communities have with the guardianship system. The partnership embarked on a small-scale exploratory research project to gather evidence on issues that require consideration and attention to assist Queensland's guardianship system to improve outcomes for Indigenous Queenslanders with impaired decision-making capacity.

The research was designed to gain insights into the views, impressions and experiences of Indigenous people, their communities and communities and other stakeholders about guardianship. Data was collected from a small sample of people in particular locations. The findings do not necessarily represent those of the wider Indigenous community in Queensland, nor do they provide definitive conclusions. The findings, do however, highlight issues to be considered in future planning and program responses for indigenous Queenslanders with impaired decision-making capacity, especially as it relates to legal interventions, such as guardianship.

The key insights from the research reinforced findings from previous studies and highlighted cultural considerations, policy issues and inadequacies in Queensland's guardianship system as it relates to Indigenous Queenslanders. These issues appear to stem from the mismatch between the Queensland guardianship model and the cultural practices of Indigenous Queenslanders.

The incompatibilities between the policies and practices of the guardianship system and Indigenous values and culture are fundamental. The guardianship model is based on western, individualistic practices, whereas Indigenous culture is founded on collective customs. This means the guardianship system is being applied to Indigenous Queenslanders in ways that may

not be addressing their needs and interests within the context of their culture. The evidence clearly suggests the need for a broader and more culturally-appropriate range of decision-making alternatives for Indigenous Queenslanders.

Supported decision-making is an approach that may be more compatible with Indigenous culture. If designed appropriately and in partnership with Indigenous communities, supported decision-making may be a more natural and culturally acceptable way to support Indigenous Queenslanders with impaired decision-making capacity.

Supported decision-making, or other early interventions, could provide autonomy and more choice for Indigenous people and communities, reduce government intervention and lead to better outcomes for Indigenous Queenslanders with impaired decision-making capacity. It may also help address the over-representation of young Indigenous Queenslanders in the guardianship system.

We support steps to improve case management and conflict resolution at the local level. This may allow for more informed and earlier service responses for Indigenous Queenslanders with impaired decision-making capacity.

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**The findings highlight Indigenous Queenslanders are not well served by the guardianship system. Improved case management, earlier service responses, conflict resolution at a local level and improved consultation about 'what works' is overdue.**

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There is an urgent need for consultation with Indigenous people about guardianship and 'what works' in their communities. Their input into assessment tools and processes, communication mechanisms and service responses is vital to ensure a culturally appropriate, practical and sustainable approach.

#### **Our research - Indigenous people subject to guardianship orders**

We have expanded on the above research by describing the characteristics of Indigenous Queenslanders subject to guardianship orders made to the Adult Guardian. Our research has confirmed that the age profile of Indigenous people is noticeably different from that of non-Indigenous people. Indigenous people subject to guardianship orders tend to be younger and almost completely absent in the older age groups.

During the year, we have received anecdotal reports from stakeholders suggesting the guardianship system is being used as a 'social management' mechanism for some Indigenous Queenslanders. In particular, our attention has been drawn to issues in regional areas, including involuntary 'detention' for alcohol rehabilitation, and the use of guardianship as a facilitator for these types of interventions. Further research is required, particularly the identification of culturally appropriate

responses for Indigenous people and options which are the least restrictive possible in all the circumstances.

### **Research partnership Withholding and withdrawing life-sustaining treatment from adults lacking capacity: Enhancing medical decision-making through doctors' compliance with the law**

*Lead investigators: Professor Lindy Willmott and Dr Ben White, Faculty of Law, Queensland University of Technology*

*Key Partners: Guardianship Tribunal (New South Wales), The New South Wales Trustee and Guardian, Office of the Adult Guardian (Queensland), Office of the Public Advocate (Queensland), Office of the Public Advocate (Victoria), Queensland Civil and Administrative Tribunal, Southern Cross University, Victorian Civil and Administrative Tribunal, and the University of Queensland.*

This three year research project is partially funded by an Australian Research Council Grant. The final report is expected in late 2012.

We have partnered with the Queensland University of Technology and guardianship, administration and advocacy agencies in New South Wales and Victoria on research into the law regarding end-of-life decision-making in three jurisdictions – Queensland, Victoria and New South Wales.

People with impaired decision-making capacity for whom end-of-life decision-making is under consideration are very vulnerable. The researchers estimate that over 13,000 adults with impaired decision-making capacity die each year in Queensland, Victoria and New South Wales following decisions not to provide medical treatment. The research proposes that while decisions to withhold and withdraw life-sustaining treatment are a necessary and legitimate part of medical practice, the extent to which these decisions are consistent with legislative intent is unknown.<sup>36</sup>

The research investigates the level of knowledge of medical professionals about the law and makes recommendations for reform. It will identify strategies to assist medical professionals improve their understanding of the legal requirements of end-of-life decision-making.

The aim of the research is to produce better outcomes for patients and their family and friends to enhance clinical practice through promoting compliance with the law, and reduce health expenditure incurred because of defensive medicine and legal compliance costs.<sup>37</sup>

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<sup>36</sup> Queensland University of Technology 2011, Queensland University of Technology, viewed 22 July 2011, <http://www.ljrc.law.qut.edu.au/research/projects/endoflife/>

<sup>37</sup> Queensland University of Technology 2011, Queensland University of Technology, viewed 22 July 2011, <http://www.ljrc.law.qut.edu.au/research/projects/endoflife/>

In 2010-11, three articles based on this research were published in the Journal of Law and Medicine. The articles focused on the role of medical professionals in decisions to withhold or withdraw life-sustaining treatment.

The researchers have identified the following key issues:

- It is important that medical professionals understand the law regarding end-of-life decision-making. A lack of knowledge can lead to a lack of compliance with the law, which may have adverse consequences for all people involved.
- There are significant knowledge gaps among medical professionals regarding the law relating to end-of-life decision-making. The limited available information suggests that the knowledge of medical professionals in this area is also limited.
- The current state of the law is likely to impede the knowledge of medical professionals because the law regarding end-of-life decision-making is complex and sometimes inconsistent. In addition, the legal interpretation of the law can be in conflict with good medical practice. This issue is further complicated by some judicial and other interpretations of the law which have created unusual outcomes and precedents.<sup>38</sup>

The series of articles presented two main conclusions:

- Law reform is needed. This is not only due to the current difficulty interpreting the law, but also to design a legal framework to enable a group of legally untrained people (i.e. medical professionals) to understand and apply the law.
- Improved education of medical professionals is needed. End-of-life decisions are important and medical professionals should be supported in understanding and applying the law.<sup>39</sup>

We support the researchers' conclusions for law reform that results in legislation that is able to be understood and can be applied, and promotes best practice in the medical management of end-of-life decision-making. It is critical that medical professionals understand the law regarding end-of-life decision-making. A clearer legal framework and improved information is essential to achieve this. We think that an over-prescribed or highly regulated approach may not meet the needs of patients or the medical practitioners who care for them.

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**Refining legislation and improving the education of medical professionals are two valuable strategies, however they should also be supported by a broader community awareness campaign to improve take-up rates for enduring instruments such as advance health care directives.**

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Over the past year, we have actively promoted the need for accessible information about the benefits of advance health care planning, including palliative care. With a growth in the number of people with impaired decision-making capacity due to ageing, acquired disabilities and other conditions it is essential that Queenslanders are encouraged to plan for their futures. More generally, we think individuals should be encouraged to make their own decisions about consenting or refusing future health treatments including medical, surgical, dental and other treatments.

It is important that strategies to involve families and carers at an early stage in health care planning are promoted. This will assist in understanding wishes for future medical treatments and potentially avoid confusion and/or conflict at a later date when medical treatment is required. We strongly support a broad-based public awareness campaign to this effect.

## **Research partnership Precarious social inclusion: Chronic homelessness and impaired decision-making capacity**

*Lead investigators: Associate Professor Jayne Clapton and Professor Lesley Chenoweth, School of Human Services and Social Work, Griffith University; Professor Colleen Cartwright, Faculty Arts and Sciences, Southern Cross University; Associate Professor Malcolm Parker, School of Medicine, University of Queensland.*

*Key Partners: Micah Projects Inc., Office of the Adult Guardian and Office of the Public Advocate.*

We partnered with Griffith University and Micah Projects Inc. to develop an application for an Australian Research Council Linkage grant for research into chronic homelessness and impaired decision-making capacity. While the Australian Research Council Linkage application was unsuccessful, a grant was secured through the National Homelessness Research Projects grant scheme funded by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

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<sup>38</sup> White, B., Willmott, L., Trowse, P., Parker, M. and Cartwright, C. 2011, *The Legal Role of Medical Professionals to Withhold or Withdraw Life-Sustaining Treatment: Part 1 (New South Wales)*, Journal of Law and Medicine, Vol 18, No 3, pp. 498-522.

<sup>39</sup> White, B., Willmott, L., Trowse, P., Parker, M. and Cartwright, C. 2011, *The Legal Role of Medical Professionals to Withhold or Withdraw Life-Sustaining Treatment: Part 1 (New South Wales)*, Journal of Law and Medicine, Vol 18, No 3, pp. 498-522.



While not an official consortium, the Office of the Public Advocate, the Office of the Adult Guardian, Griffith University and Micah Projects Inc. have continued to take a lead collaborative role to progress this and other research into chronic homelessness and people with impaired decision-making capacity. This existing partnership provides a solid foundation for the effective translation of research findings into practice across different service systems.

The research supported by the FaHCSIA grant is investigating the shortfalls and precariousness in human service delivery for people with impaired decision-making capacity who are chronically homeless and who continue to experience marginalisation and social exclusion. The research addresses critical practice issues and highlights new approaches to delivering social policy and human services. Social inclusion for this vulnerable group of people will be promoted by addressing identified research questions from the National Homelessness Research Agenda.

The data collection phase of the project is well underway. The literature review and focus groups have been completed. The online survey and policy and legislative scan are progressing well.

While still a work in progress, a number of key systems issues have been identified, for example:

- There is a lack of integration between housing, homelessness, disability, mental health and substance misuse agencies to coordinate services for people with impaired decision-making capacity who are chronically homeless.
- There is a lack of flexibility in service delivery for individual needs and circumstances e.g. outreach versus centre-based services.
- The current referral systems are complex and referral criteria are confusing.
- The current quality systems are failing to ensure high quality outcomes for service users.
- There are gaps in funding to support Queenslanders with impaired decision-making capacity.
- Current eligibility criteria are a barrier to providing housing and support for Queenslanders with impaired decision-making capacity. For example, some people who have temporary accommodation are not considered homeless and therefore cannot access certain homelessness programs.

- The successful delivery of services to Indigenous people is impeded by the delivery of programs by government organisations staffed with non-Indigenous people.

The findings from the Adult Guardian Client Profile Project have revealed that the predominant reason for the appointment of a guardian is for accommodation decisions (refer to Key Result Area 1).

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**There is an urgent need for improved and integrated services to ensure more appropriate and sustainable housing support for people with impaired decision-making capacity. The current system is inflexible, disjointed and inadequate.**

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## **Research partnership**

### **Feeling safe, Acting safe: Self protection strategies of people with intellectual disability**

*Lead investigators: Professor Lesley Chenoweth and Dr. Sally Robinson, School of Human Services and Social Work, Griffith University.*

*Key partners: Office of the Adult Guardian and Office of the Public Advocate.*

This research project is exploring the ways in which people with an intellectual disability keep themselves safe in the places where they live, and the extent to which they are able to draw upon strategies to protect themselves from potential harm.

The researchers are currently working with people with an intellectual disability and their carers on the fieldwork component of the project. The inclusive methodology involves collecting information directly from people with an intellectual disability and involving them in the analysis of material.

We support the participatory methodology employed by Griffith University for this research. While there can be many challenges associated with directly involving people with an intellectual disability in the conduct of research (as opposed to simply gathering information about them), it provides the opportunity to empower individuals and, in a small way, provide an avenue for inclusion.

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**We think that participatory research projects are innovative and incorporate a rights respecting methodology which can help bridge the gap between vulnerable groups in the community, researchers, policy makers and service providers.**

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## **Our ongoing commitment**

This year we have been privileged to work and partner with researchers from academia, government and non-government on innovative primary research and applied research projects. We are committed to progressing these types of projects as they provide critical and contemporary evidence to better understand the systems barriers excluding people with impaired decision-making capacity from the social, economic and civic resources available to most Queenslanders.

Whilst the findings are often disturbing and also compelling, they provide an evidence base to be shared. We will continue to share and target our knowledge and evidence to promote dialogue with cross sector interests to progressively build inclusive policy and rights respecting service models that better meet the needs of people with impaired decision-making capacity, their families and support networks.

Our priority systems issues will include the vulnerability of elders; the use of enduring instruments; young people entering the guardianship system, with a focus on indigenous people; restrictive practices regulation and associated issues; and exploring new ways to support contemporary and sustainable models for guardianship.





## Key Result Area 2

### Communication and Influence

Our approach to communication and influence rests on a mix of knowledge production, information sharing and engagement strategies that support our statutory role in delivering systems advocacy. Communicating with influence is in large part about how we develop, deliver, and reinforce our systems advocacy messages and is critical to our success.

Our key objectives are to provide accurate, reliable and timely information to stakeholders on priority systems advocacy matters, and to develop effective communication strategies to promote and protect the rights and interests of Queenslanders with impaired decision-making capacity.

A core feature of our communications planning is ensuring that high quality, evidence-based and consistent information is readily available to all our stakeholders (government, non-government and the public), through a variety of means or products.

## Building effective communication and influence

This year we have invested in building effective communication and influence for our systems advocacy work to advance the right and interests of people with impaired decision-making capacity. In practical terms this means delivering consistent and targeted messages that promote understanding and take-up of inclusive policy and practice across all levels of government. Our engagement practices must have a broader reach than specialist service systems and include mainstream and private sectors as well.

The history of the exclusion of people with a disability has shown that fragmented policy and service approaches to meeting needs has not delivered improved life opportunities. Consequently, things have not changed that much for marginalised groups over the past twenty years.<sup>40</sup> We believe targeted effort is needed to build strong government relations across a broad range of portfolios to promote integrated and sustainable service responses to better meet the different needs of Queenslanders with impaired decision-making capacity.

### Communication plan

An effective communication plan is vital to the work of any business area. This is particularly important at a time of transition, as faced by our Office, and the application of our new strategic direction. The Office collaborated with Communication Services within the Department of Justice and Attorney-General to develop a communication plan which will contribute to meeting our business needs and strategic objectives into the future.

The Systems Advocacy Communication Plan is aligned with the *Systems Advocacy Framework 2010-2012* to support delivering our new, contemporary direction for statutory systems advocacy. The key objectives of our communication plan are:

- Increase public awareness of the contemporary systems advocacy approach the Office has adopted.
- Encourage government agencies to engage with the Office as a key partner in the policy formation process in all areas of public policy which impact on adults with impaired decision-making capacity.
- Encourage government agencies to access and incorporate our research findings and expertise into the development of policies, programs, and the delivery of services that will benefit people with impaired decision-making capacity, their families and carers.

We recognise that the progress of these objectives will require a long-term investment. The Office is in the early phase of implementing its new strategic direction toward an evidence-based approach to statutory systems advocacy. It will take time, expertise and successful outcomes to consolidate our statutory role as systems advocate for Queenslanders with impaired decision-making capacity.

### Communicating our business approach

A broad range of key messages have been articulated in our communication plan. These include:

#### What we do

- Deliver statutory systems advocacy to promote improved life opportunities and outcomes for people with impaired decision-making capacity.
- Encourage and contribute to the development of systems that are inclusive, accessible and equitable.
- Aim to make a positive impact at the strategic and structural level of government policy.
- The *Guardianship and Administration Act 2000* provides the legal authority for our work.

#### Why we do it

- Our vision is to realise a just and inclusive society for all citizens.
- We are committed to promoting and protecting the rights and interests of people with impaired decision-making capacity.

#### How we do it

- Engage collaboratively with our stakeholders by building goodwill, sharing knowledge and expertise, and fostering trust and confidence in our work.
- Undertake research and analysis (evidence-based approach) that informs social policy debate to progress inclusive and sustainable responses for people with impaired decision-making capacity.
- Work with a clear purpose and commitment to a workplace culture where accountability and respect is paramount.

Of significance to our communication plan outcomes, is the development of two key pieces of collateral – our Service Statement and a public brochure:

- The Service Statement describes to our key stakeholders the new strategic direction for statutory systems advocacy and the intention to build collaborative relationships with our stakeholders and other interested parties.

<sup>40</sup> For further information see Australian Social Inclusion Board at [www.socialinclusion.gov.au/Resources/](http://www.socialinclusion.gov.au/Resources/)

- The brochure provides information suitable for the public and outlines our work; the importance of statutory systems advocacy and explaining the boundaries of our work.

### **Strategies for effective consultation**

There are no prescribed statutory requirements for our systems advocacy to involve stakeholder consultation and engagement. However, it is implied given our rights protection and promotion functions. Common sense also suggests that effective systems advocacy will only be achieved when there is communication and engagement with key stakeholders on issues of mutual interest.

We determine, on an issue by issue basis, the scope and reach of our consultations. We are committed to proactive and targeted consultation however inevitably there are urgent systems issues and situations that require reactive and assertive engagement with government and other stakeholders.

A range of consultation mechanisms and strategies, tailored to a range of systems advocacy matters, provides coherence and consistency to our communication and consultation practices.

Our consultation is inclusive, planned and targeted for maximum effect. It is flexible to accommodate crisis situations.

Messages are a critical element in delivering our systems advocacy. How we develop, deliver and reiterate our messages are crucial to our systems advocacy success.

Messages inevitably need to be revised as we learn more about a systems policy issue and what appeals to or engages key decision makers and other relevant stakeholders.

### **Key elements in delivering our messages**

This year we have reviewed how systems advocacy messages have been delivered. As a result of the review we have committed to:

- Developing clear and compelling messages: A message explains what we are proposing, why it is worth doing, and the positive impacts of our systems advocacy proposal.
- Delivering messages effectively: Ensuring that decision-makers and other stakeholders understand our message and trust the integrity of our message.
- Reinforcing messages: Delivering a message once is generally not sufficient for the information to be fully absorbed. We must have a strategy to reinforce our message. This also provides an opportunity to respond to concerns expressed by decision-makers and other stakeholders.

Finally, we have committed to communicating our systems advocacy messages through key stages of our systems advocacy projects. Developing messages is a continuous strategy throughout the life of our systems advocacy projects.

## **Communicating and sharing knowledge and evidence**

We recognise the importance of communicating and sharing knowledge and evidence in meaningful and accessible ways with our stakeholders. We communicate and share our knowledge and evidence base of research to generate debate about how best to promote inclusive and sustainable policies, programs and practices that improve life opportunities for Queenslanders with impaired decision-making capacity.

Our systems advocacy projects communicate clear messages about priority systems barriers that we have identified from our evidence-based approach to research and information gathering. Importantly the success of our communication and influence will depend upon how well we produce, integrate and translate knowledge for our key stakeholders.

In 2010-11, we shared knowledge and evidence with stakeholders in a variety of publications including Fact Sheets and Research News bulletins. Publications from this year's research are progressing. The information will be published and made available on the Office of the Public Advocate website when finalised.

Over the next year we will continue to translate new knowledge and evidence as it becomes available and will expand our series of Fact Sheets, bulletins and other research and evidence-based publications to share with our stakeholders.

## **Communications mix (accessible products are audience appropriate)**

This year we have spent some time developing our products. This is an important component of our overall communications strategy and aims to raise awareness and inform our key stakeholders of the progress and outcomes of our systems advocacy projects. This is also a key element of a transparent and accountable agency.

Our communications mix is informed by our key strategic processes of knowledge production (building knowledge and evidence), knowledge transfer (translating knowledge and evidence to suit the stakeholder) and knowledge take-up (utilisation of knowledge and evidence).

Our communications strategy uses a range of products and forums that are audience appropriate. This includes fact sheets, research reports, and presentations, delivered through both electronic mediums and direct interactions, such as meetings and forums.

## **Publications branding**

New publications branding was developed for the Office of the Public Advocate in late 2010. With the new strategic direction for the Office, it was considered timely to refresh the publications branding. The key criteria for design considerations included the creation of a contemporary design to promote our 'statutory systems advocacy' function rather than the Office of the Public Advocate as an entity. The Office did not seek to create a new logo. We were also mindful that the new design would be transferable, taking into account the Queensland Government's decision to transition the function of systems advocacy to the Office of the Adult Guardian.

We worked with Communication Services within the Department of Justice and Attorney-General to develop the branding concept. The new publications branding meets Queensland Government guidelines and is complementary to the branding used by the Department of Justice and Attorney-General.

A range of publication templates featuring the new branding have been developed. These provide a consistent visual presence for the products developed by the Office in both hard form and online via the website. The publication templates enable the Office to complete its design and production in-house where practicable. This capability will be a distinct advantage as our research and evidence capacity grows and expands.

## **Website redevelopment**

Websites are an essential tool for knowledge transfer and is now a primary and common information source for most citizens. Online information must be timely, accessible and have currency. The website is the central communications point for our policy, guidelines and practice, priority issues, and our knowledge products.

The website structure and content was also revised in 2010-11 to reflect the new strategic direction of our work and aims to provide clear information about the role of systems advocacy to stakeholders and the general community. The new branding element has been incorporated as a transition panel on the web page which hosts the systems advocacy information.

Our website hosts research and evidence pieces produced by the Office, with a primary objective to maintain up-to-date electronic publications on contemporary, topical and relevant systems issues. To improve usability and navigation, the website has been restructured by grouping publications under the product headings of fact sheets, policy, reports, and annual reports.

Each publication listing is displayed alphabetically and accompanied by the date of the publication. Older publications, presentations and speeches have been archived and remain available upon request.

The redevelopment of our website is consistent with our commitment to sharing evidence and knowledge with our government and non-government stakeholders, academics, researchers, students and the broader community.

## **Feedback**

Our Office welcomes feedback from all stakeholders, including the public. We use this information to identify opportunities to improve our work.

We may be contacted through a range of mediums, including telephone and via email to our electronic mailbox.

Feedback is encouraged on all our publications. A reader survey is provided for this purpose. The survey is accessible online and is also distributed with hard copy publications.

## **Our ongoing commitment**

We will continue to refine and target our communication efforts to ensure that the key messages are reaching the appropriate audiences.

We will continue to investigate ways to improve and expand on our products to ensure that the issues facing people with impaired decision-making capacity are promoted and understood.

Our aim is to inform social policy debate and contribute to systems advocacy in our communities to advance the rights, interests, inclusion, and participation of Queenslanders with impaired decision-making capacity.

## Key Result Area 3

### Advocacy and Inclusion

Our systems advocacy work is about influencing policy change.

This year we committed to examining the levels of social and economic exclusion and disadvantage experienced by Queenslanders with impaired decision-making capacity using both primary and secondary data sources. The findings highlight the scale and severity of the disadvantage and cannot be ignored. The situation compels a statutory systems advocacy response to be advanced across all levels of government and sectors to address discrimination, disadvantage and exclusion.

## The exclusion and disadvantage experienced by Queenslanders with impaired decision-making capacity

The evidence presented below confirms that the level of disadvantage across a range of social and economic indicators is unacceptably high. For many people with impaired decision-making capacity, quality of life is significantly reduced and the risks of abuse, neglect and exploitation are increased.

Across most of the indicators, people with impaired decision-making capacity experience an extreme degree of exclusion from the social and economic resources available to most Queenslanders. This degree of exclusion can arise when multiple, persistent disadvantages are experienced for example, barriers to fair access to goods and services across key areas such as education, employment, housing and health care.



## Data statement

The following secondary data sources, published by the Australian Bureau of Statistics (ABS), are used in this section:

- Survey of Disability, Ageing and Carers (SDAC) Basic Confidentialised Unit Record File (CURF).<sup>1</sup>
- Population Projections for Australia.<sup>2</sup>

### Survey of Disability, Ageing and Carers

We use the SDAC to identify Queenslanders with impaired decision-making capacity. In the SDAC, a person with impaired decision-making capacity is defined as a person who needs assistance to make decisions or think through problems due to a disability. The SDAC identifies whether a person lives in a household or in cared accommodation (i.e. a group home, health establishment or institutional setting).

### Population estimates

Our population estimates are based on 2003 SDAC data. Age standardised estimates for 2011 are constructed using the ABS Series B Population Projections for Queensland.

We use the SDAC CURF to calculate the population estimates presented in this report. These estimates cover a range of social and economic indicators including social participation, support needs, education, employment, meaningful day activity, housing and health. The estimates and associated percentages in this report can not be reproduced without accessing the 2003 SDAC CURF.

### When considering SDAC estimates it is important to note that:

- the estimates are not exact counts.
- each estimate has been rounded and carries an error margin.
- the responses to the SDAC are self-reported by either the respondent or their proxy and intend to represent the views of the individual.<sup>3 4</sup>
- where the respondent lived in cared accommodation, for example, in a group home, health establishment or institutional setting, the responses were collected from a nominated contact officer for the establishment.

For further information about the publications, refer to the ABS website at [www.abs.gov.au](http://www.abs.gov.au)

<sup>1</sup> Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

<sup>2</sup> Australian Bureau of Statistics 2008, *Population Projections, Australia, 2006 to 2101*, Series B, Cat No. 3222.0, Australian Bureau of Statistics, Canberra.

<sup>3</sup> Australian Bureau of Statistics 2004, *Disability, Ageing and Carers, Australia: User Guide 2003*, Cat No. 4431.0.55.001, Australian Bureau of Statistics, Canberra.

<sup>4</sup> Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

## Disability in Queensland

Of the 3.5 million adults in Queensland in 2011, one in 27 (129,800 adults) has impaired decision-making capacity.

Of these Queenslanders, only 1.3% (1,714 people) are subject to guardianship orders made to the Adult Guardian, representing a very small proportion of Queenslanders with impaired decision-making capacity (see Figure 22).

Queenslanders with impaired decision-making capacity are not a homogenous group. Within the population there are younger Queenslanders who have life-long impaired decision-making capacity, middle-aged Queenslanders who have acquired impaired decision-making capacity and older Queenslanders for whom impaired decision-making capacity is age-related. These individuals vary not only by age but also in needs, expectations and life situations. This requires a range of policy solutions to provide the services and support to meet diverse individual needs.

**We are alarmed there are large numbers of adult Queenslanders living with impaired decision-making capacity – estimated to be approximately 129,800 in 2011, and growing. As this figure is hard to ignore, we have responded by developing a robust understanding of the characteristics and needs of this potential population for statutory systems advocacy in Queensland.**

We know that social and economic disadvantage may cause or exacerbate disability.<sup>41</sup> We also know that the majority of Queenslanders with impaired decision-making capacity and their families are among the most disadvantaged people in our community.<sup>42 43 44 45 46</sup>

In this section, we examine the indicators of: social participation; support needs; education; employment; meaningful day activity; housing and accommodation; and health as priority areas for government attention.

41 Lustig, D. C. and Strauser, D. R. 2007, *Causal Relationships Between Poverty and Disability*, Rehabilitation Counselling Bulletin 50(4), pp. 194-2002.

42 Australian Bureau of Statistics 2004, *Disability Ageing and Carers Australia: Summary of Findings 2003*, Cat No. 4430.0, Australian Bureau of Statistics, Canberra.

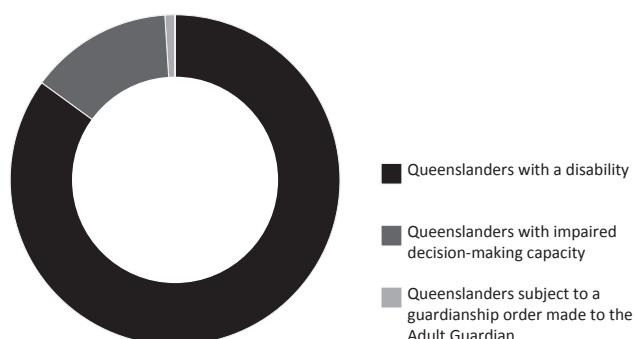
43 Australian Bureau of Statistics 2004, *Labour Force, Australia*, Cat No.4901.0, Australian Bureau of Statistics, Canberra.

44 Australian Bureau of Statistics 2008, *Population by Age and Sex, Australian States and Territories*, Cat No.3201.0, Australian Bureau of Statistics, Canberra.

45 Australian Institute of Health and Welfare 2009, *Disability Support Services 2007-08 National Data on Services Provided Under the Commonwealth State/Territory Disability Agreement*, Cat No. DIS 56, Australian Institute of Health and Welfare, Canberra.

46 Australian Institute of Health and Welfare 2009, *The Geography of Disability and Economic Disadvantage in Australian Capital Cities*, Cat No. DIS 54, Australian Institute of Health and Welfare, Canberra.

**Figure 22. 2011: Queenslanders with disability**



Sources: 1) Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra; 2) Adult Guardian Client Profile Project 2011, Adult Guardian Client Database, n=2,978.

## Social participation

Appalling levels of isolation are faced by many Queenslanders with impaired decision-making capacity (see Table 2). In 2011, over 52,200 vulnerable adult Queenslanders are effectively unable to leave their homes as often as they would like to participate in basic social activities. Nearly 34,200 of these adult Queenslanders go without any culture or leisure activities. Even within their own homes, 5,800 had no social interaction, such as visits from friends and family.

At the most disadvantaged end of the spectrum, there are a vulnerable group of almost 3,000 people who do not leave their homes and may have no social contact at all. This extreme isolation compounds the risk of abuse, neglect and exploitation as well as increasing the very poor outcomes for physical and mental health and wellbeing.

**Table 2. Social participation rates for adult Queenslanders with impaired decision-making capacity living in private households (2011)**

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**129,800 (Approx.)**

Queenslanders with impaired decision-making capacity

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**40%**

52,200 cannot leave their home as often as they would like

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**26%**

34,200 go without any culture or leisure activities

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**10%**

13,400 go without any social participation away from their home

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**4%**

5,800 have had no social contact in their own homes within the previous three months

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**2%**

3,000 do not leave their home at all

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Source: Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

Note: The above categories are not mutually exclusive and do not include people with impaired decision-making capacity who live in cared accommodation, for example in a group home, health establishment or institutional setting.

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We know that access to social resources enables the development of strong social networks, social connectedness, and social participation. Without appropriate policy and service responses people with impaired decision-making capacity and their families face poor quality of life and diminished life opportunities, as demonstrated by the disturbingly high rates of social isolation.

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**People at risk of extreme social isolation need to be identified early as the social care interventions will be less costly, easier to design and deliver and more likely to succeed.**

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Access to transport is an integral part of social and economic participation, including work and recreation. Over 61,600 adult Queenslanders with impaired decision-making capacity need assistance with transport.<sup>47</sup>

Barriers to accessible transport can reduce the ability of individuals, their families and support network to participate in the life of the community and to attend cultural, artistic, sports and other recreational activities. Research shows that transport is costly, fragmented, and uncoordinated between the public and private sectors. Concession and subsidised travel is available but inadequate and few programs provide on demand or door to door transport services. These transport barriers significantly reduce opportunities for participation.<sup>48</sup>

The following ideas should be considered to address transport barriers:

- a review of the Disability Standards for Accessible Public Transport
- a campaign to promote compliance with the *Disability Discrimination Act 1992* (Cth)
- transport affordability as a priority for government
- the expansion of the fleet of accessible taxis
- accessible transport operating at times and over routes that enable people to participate in community events.

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<sup>47</sup> Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

<sup>48</sup> National People with Disabilities and Carer Council 2009, *Shut Out: The Experience of People with Disabilities and Their Families in Australia*, National People with Disabilities and Carer Council, Canberra.

## Support needs

In 2011, over 53,900 adult Queenslanders with impaired decision-making capacity living in private households did not have their support needs met (see Table 3). This means that these vulnerable Queenslanders did not receive the assistance they needed to perform basic daily activities such as self care, meal preparation, domestic tasks and using transport. This includes almost 1,900 adults who did not receive any support at all. These circumstances may trigger crisis interventions like guardianship.

Our analysis shows that people with impaired decision-making capacity access more providers of support services than people with other types of disability.<sup>49</sup> Around 7,600 Queenslanders with impaired decision-making capacity accessed services from three different sectors and still do not have their support needs met. This means they are navigating service systems provided by government, non-government and private organisations.

<sup>49</sup> Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

**Table 3. Support needs of adult Queenslanders with impaired decision-making capacity living in private households (2011)**

**53,900 (Approx.)**

Queenslanders with impaired decision-making capacity do not have their support needs met

**20%**

**10,600** receive support only from informal sources and do not have their support needs met

**16%**

**8,600** receive support from one sector and do not have their support needs met

**47%**

**25,200** receive support from two sectors and do not have their support needs met

**14%**

**7,600** receive support from three sectors and do not have their support needs met

**3%**

**1,900** do not receive any support at all

Source: Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, 2003, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

Note: The three sectors are: government, non-government and private. The figures above do not include people with impaired decision-making capacity who live in cared accommodation, for example in a group home, health establishment or institutional setting. The degree to which a person's support needs were met was based on the SDAC variable "Extent to which need for assistance met".

People are required to access different service systems, for example, aged care services; specialist disability services; and community mental health services. In addition to accessing social care services, individuals and their families may also be accessing services in the health, mental health and palliative care sectors, as well as other services provided through education, employment, housing, transport, and income support.

Figure 23 illustrates the support from various sectors accessed by Queenslanders with impaired decision-making capacity who do not have their support needs met. Of those people:

- 1 in 2 have needs that can not be met by two sectors
- 1 in 5 have access to an informal carer only
- 1 in 29 do not receive any support and their need goes completely unmet.

This evidence confirms the level of unmet need for specialist services.<sup>50</sup> Unmet need, together with the fragmented and complex mainstream service system ‘maze’ can lead to high levels of frustration, anxiety and burn out for individuals and their families as they attempt to identify, secure and manage support.<sup>51</sup>

The service maze may also be a driver for a sizeable proportion of guardianship orders made to the Adult Guardian. It also suggests why the service sector is using the legal intervention of guardianship as a case management tool to activate changes in accommodation arrangements or service provision (refer to Key Result Area 1 for further information).

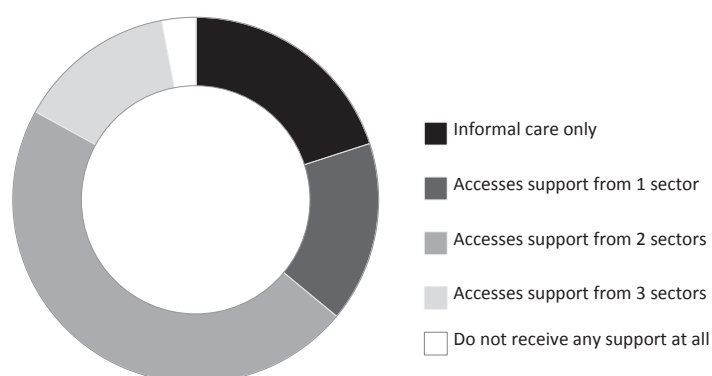
The current combination of specialist interventions and access to mainstream services is failing to meet the support needs of Queenslanders with impaired decision-making capacity and their families.

Given the level of unmet need, we think that specialist systems must proactively leverage and complement the existing mainstream systems such as health, housing, transport and education to reduce the impact of disadvantage and exclusion faced by people with impaired decision-making capacity.

<sup>50</sup> Australian Institute of Health and Welfare 2007, *Current and Future Demand for Specialist Disability Services*, Cat No. DIS 50, Australian Institute of Health and Welfare, Canberra.

<sup>51</sup> The Parliament of the Commonwealth 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, April 2009, Commonwealth of Australia, Canberra.

**Figure 23. Support provided to Queenslanders with impaired decision-making capacity who do not have their support needs met**



Source: Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.o.30.002, Australian Bureau of Statistics, Canberra.

We also acknowledge that the complexity of service systems derives from a number of administrative factors including the multiple portfolio and program areas across all levels of government that are involved in the funding and administration of social care; the separate service systems which provide assistance; and the involvement of government, not-for-profit non-government organisations and for-profit businesses in the delivery of human services. However, systems change can occur, and with collaboration, the adequacy of all of these services (individually and collectively), can improve the quality of life of people with impaired decision-making capacity and their families.

Even after individuals and families identify services they are faced with multiple program layers adding to the complexity of securing a service. Services also have different eligibility criteria and assessment processes for access to programs. As we reported in Key Result Area 1, individual crisis is further exacerbated by the lack of integrated case management and made even worse by services failing to accept core case management responsibility for complex individual matters. This is not surprising, given the frustrating and time consuming hurdles created by the service maze.



## Education

The level of educational attainment for individuals is a key socioeconomic indicator. Higher educational attainment leads to improved access to social resources including improved employment opportunities.

Our analysis of educational attainment for young people with impaired decision-making capacity (15-34 years) shows that in 2011, approximately 9,100 young people had not attained the minimum level of education (completed Year 10) required by the *Education (General Provisions) Act 2006* (see Table 4). More than half (4,600) of these young Queenslanders had never attended school or only reached Year 8. As these young Queenslanders

were all over the age of 15, it is not unreasonable to expect that they should have attended school and attained at least a Year 8 level of education.

**Table 4. Educational attainment for young Queenslanders with impaired decision-making capacity living in private households (2011)**

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**29,300 (Approx.)**

Young Queenslanders (15-34 years) have impaired decision-making capacity

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**31%**

**9,100** young Queenslanders (15-34 years) with impaired decision-making capacity have an educational attainment below the required legal minimum standard

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Source: Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

Note: The above figures do not include people with impaired decision-making capacity who live in cared accommodation, for example in a group home, health establishment or institutional setting. The *Education (General Provisions) Act 2006* requires that young people continue their schooling until they are 16 years old or have completed year 10, whichever happens first; and to continue in education and training for a further period for the purpose of achieving a senior certificate, certificate III or certificate IV.

Figure 24 illustrates the level of education attained by young Queenslanders with impaired decision-making capacity. Of those Queenslanders:

- 3 in 5 have not completed high school
- 1 in 6 only reached year 8 or never attended school
- 1 in 5 have completed post-school education (e.g. TAFE certificate, university degree etc).

Young people with impaired decision-making capacity must be included in mainstream education that prioritises educational attainment as an outcome for them.

Poor links between state administered school programs and Commonwealth administered disability employment services often result in fragmented transition arrangements from school to adult life for young people with disability.<sup>52</sup>

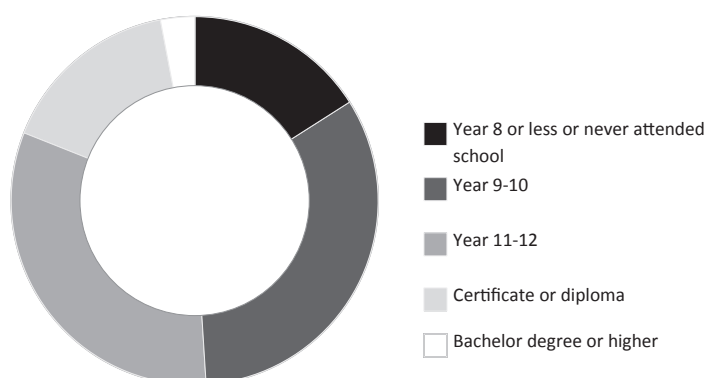
All levels of government must address the current level of educational disadvantage through responses that include:

- making educational attainment a priority for young Queenslanders with impaired decision-making capacity
- annual reporting on participation rates and educational attainment
- managing life transitions from education to employment and into stable independent living
- access to meaningful day activities, where employment options are not appropriate
- providing effective skills training and support to enhance autonomy and independence.

For young Queenslanders, access to education promotes independence, reduces boredom and frustration, maximises individual potential and is a fundamental human right which must be upheld and safeguarded. Through participation in education, young Queenslanders with impaired decision-making capacity experience not only an important element of social inclusion, but also the opportunity to enter life transitions such as progression to post-school employment, or education, or other meaningful day activity.

<sup>52</sup> Australian Human Rights and Equal Opportunity Commission 2005, *Issues facing people with disability*, Issues Paper 2, National Inquiry into Employment and Disability at [http://www.humanrights.gov.au/disability\\_rights/employment\\_inquiry/papers/issues2.htm](http://www.humanrights.gov.au/disability_rights/employment_inquiry/papers/issues2.htm)

**Figure 24. Highest level of educational attainment by young Queenslanders with impaired decision-making capacity**



Source: Australian Bureau of Statistics 2005, *Basic Confidentialised Unit Record File: Survey of Disability Ageing and Carers 2003 (Reissue)*, Cat No. 4430.0.30.002, ABS, Canberra.

## Employment

Employment opportunity is a pathway to addressing social and economic disadvantage. Employment of people with impaired decision-making capacity can reduce financial stress and increase resilience.

Many people with impaired decision-making capacity do not have the opportunity to participate in employment. Only 17,000 (34%) of working age people with impaired decision-making capacity who live in private households, are employed (see Table 5). A further 3,800 (8%) are unemployed and seeking employment.

**Table 5. Employment opportunity for working age Queenslanders with impaired decision-making capacity living in private households (2011)**

**50,600 (Approx.)**

Queenslanders of working age (15-64 years) with impaired decision-making capacity<sup>1</sup>

**59%**

**29,800** working age Queenslanders with impaired decision-making capacity were not employed or seeking employment<sup>1</sup>

**24%**

**12,400** working age Queenslanders with impaired decision-making capacity are employed more than 15 hours per week <sup>1</sup>

**9%**

**4,600** working age Queenslanders with impaired decision-making capacity are under-employed (1-15 hours per week) <sup>1</sup>

**8%**

**3,800** working age Queenslanders with impaired decision-making capacity are unemployed and looking for work<sup>1</sup>

**5%**

**82** working age Queenslanders subject guardianship orders made to the Adult Guardian are employed<sup>2</sup>

Source:

<sup>1</sup> Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra; Adult Guardian Client Profile Project 2011, Shared Clients, n=1,019.

Note: More than one denominator was used in the calculation of these percentages. The figures do not include people with impaired decision-making capacity who live in cared accommodation, for example in a group home, health establishment or institutional setting. People not participating in the labour force are described as not employed or seeking employment. In these figures, being employed does not refer to the use of employment services such as open or supported employment.

Source:

<sup>2</sup> Guardian Client Profile Project 2011, Sample Case Files, n= 68.

Note: The number of people subject to guardianship orders made to the Adult Guardian who are employed is an estimate based on the sample case files in the Adult Guardian Client Profile project and does not represent an exact count.

It must be noted that those who are employed are often severely under-employed. More than 4,600 working Queenslanders with impaired decision-making capacity work between one and 15 hours per week. Employment at this level does not provide an adequate level of income and suggests a significant risk of poverty. Under the Commonwealth Supported Wage System, Queenslanders with impaired decision-making capacity may be paid a fraction of the minimum wage (\$15.51 per hour<sup>53</sup>) based on a productivity assessment. For some people, as reported recently in the media, this can mean an income of less than \$3 per hour.

Figure 25 illustrates that the majority of Queenslanders with impaired decision-making capacity do not have access to employment. Across Queensland, securing or seeking employment is achieved by two in five people with impaired decision-making capacity.

There needs to be increased government investment targeted at providing employment options. Structural disincentives also need to be addressed, for example, working can lead to a reduced Disability Support Pension.

A number of employment policies are currently in place aimed at increasing workforce participation for people with a disability. To date, these policies, such as the Employment Assistance Fund, the Supported Wage System and the Disability Support Pension Employment Incentive Pilot, focus on increasing incentives for employers seeking to engage people with a disability. These policies will be only partly successful until adequate supports are in place to overcome the barriers to workforce participation faced by people with impaired decision-making capacity.

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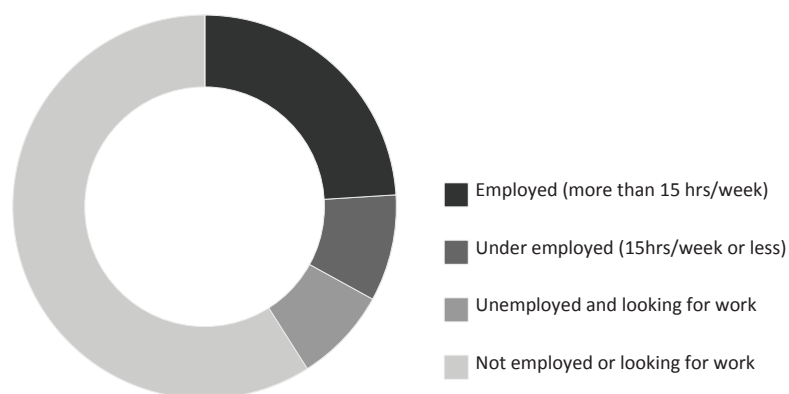
**The disturbing data on education and employment disadvantage highlights two concepts – ‘poverty of opportunity’ and ‘poverty of expectation’.<sup>54</sup> The links between exclusion, disability and poverty are maintained by discrimination, negative attitudes and a lack of understanding of disability, and the barriers created by low expectations about what a person with impaired decision-making capacity can achieve.**

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53 Fair Work Australia 2011, *National Minimum Wage Order 2011*, Fair Work Australia, Canberra.

54 Leonard Cheshire Disability 2008, *Disability Poverty in the UK*, Leonard Cheshire Disability, London.

**Figure 25. Employment opportunity for working age Queenslanders with impaired decision-making capacity**



Source: Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

## Meaningful day activity

In 2011, over 21,700 (43%) working age Queenslanders with impaired decision-making capacity had no meaningful day activity (see Table 6).<sup>55</sup> <sup>56</sup> This means they were not employed, not attending school or post-school education, and not accessing a supervised day activity.

<sup>55</sup> This does not include a further 1,700 working age Queenslanders who were living in cared accommodation (e.g. in a group home, health establishment or institutional setting) for whom no data was available nor does it include the 83,200 Queenslanders with impaired decision-making capacity who are over 65 years.

<sup>56</sup> We operationalise the concept of meaningful day activity as being employed; attending school or post school education; or attending a supervised day activity. We acknowledge that employment or educational activities may not be appropriate for all individual circumstances and life stages, particularly for elders with impaired decision-making capacity.

**Table 6. Meaningful day activity for Queenslanders of working age with impaired decision-making capacity (15-64 years) living in private households (2011)**

**50,600 (Approx.)**

Working age Queenslanders (15-64 years) with impaired decision-making capacity living in private households

**43%**

**21,700** people with impaired decision-making capacity have no meaningful day activity

**34%**

**17,000** are employed

**23%**

**11,800** currently attend school

**10%**

**5,000** are undertaking a post school qualification

**9%**

**4,500** attend a supervised day program

Source: Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

Note: The categories listed above are not mutually exclusive and do not include people with impaired decision-making capacity who live in cared accommodation, for example in a group home, health establishment or institutional setting.

Meaningful day activity was defined as being employed, attending school or post school education, or attending a supervised day activity.

Attendance at a supervised day program was only recorded where the respondent had a profound or severe disability or intellectual disability in addition to having impaired decision-making capacity.

Figure 26 illustrates the unacceptable levels of meaningful day activity available to people with impaired decision-making capacity. Research and related literature suggests that low levels of meaningful participation exacerbate the risks of social exclusion. This may lead to increased risks of poor mental and physical health, boredom and anti-social behaviour (including involvement in often petty criminal activity), family and carer stress, family crisis and family breakdown.

For younger people (15-34 years) with complex needs, access to meaningful day activity, including life skills development, may represent a sustainable, mainstream approach to addressing boredom. More generally, it may promote broader participation opportunities and inclusion and provide opportunity to develop appropriate social behaviours, greater self esteem and independence.

**We think that further research is required to explore the relationship between low levels of meaningful day activity and contact with the police, criminal justice system, and specialist forensic systems for young people with impaired decision-making capacity.**

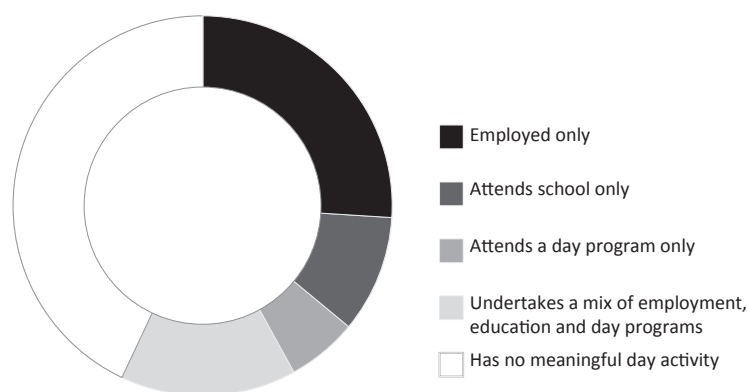
Young people with life-long impaired decision-making capacity will reasonably expect to make natural life transitions from education to employment or meaningful day activity, and from the family home to independent living. Access to meaningful day activity is an integral part of a comprehensive policy response to ensure young people reach the greatest practicable degree of autonomy and independence. The evidence demonstrates that too few have this opportunity.

**Access to meaningful day activity for young people with impaired decision-making capacity must be a human rights priority for the social justice agenda in Queensland.**

Many older people of working age (35-64 years) have acquired impaired decision-making capacity in adult life. Efforts must promote maintaining personal independence and social connections to prevent poor health and mental health outcomes, isolation and the increased risks of elder abuse, neglect and exploitation. Key strategies include: simplifying the service system; ensuring access to meaningful day activity in the community; improving health outcomes through better access to mainstream health services; and respecting rights and civil liberties by applying the least restrictive alternative as appropriate to the circumstances.

**Simplifying the complex service system and maintaining social and community connections will reduce the risks of abuse, neglect and exploitation for older Queenslanders with impaired decision-making capacity.**

**Figure 26. Day activity undertaken by working age Queenslanders with impaired decision-making capacity living in private households**



Source: Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

## Housing and accommodation

Most people with impaired decision-making capacity (75%) live in private households (see Table 7).

Our research has shown that almost 32,800 Queenslanders with impaired decision-making capacity and two in three Queenslanders subject to a guardianship order made to the Adult Guardian live in cared accommodation, for example, in a group home, health establishment or institutional setting.

**Table 7. Housing and accommodation for adult Queenslanders with impaired decision-making capacity living in private households (2011)**

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**129,800 (Approx.)**

Queenslanders have impaired decision-making capacity<sup>1</sup>

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**75%**

**97,000** Queenslanders with impaired decision-making capacity live in private households<sup>1</sup>

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**25%**

**32,800** Queenslanders with impaired decision-making capacity live in cared accommodation<sup>1</sup>

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**68%**

**1,170** Queenslanders who are subject to guardianship orders made to the Adult Guardian live in cared accommodation<sup>2</sup>

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Sources: 1) Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.o.30.002, Australian Bureau of Statistics, Canberra; 2) Adult Guardian Client Profile Project 2011, Matched Clients, n=1,019.

Note: More than one denominator was used in the calculation of the above percentages. Cared accommodation includes group homes, health establishments and institutional settings.



We know that people with impaired decision-making capacity are about three times more likely to live in precarious housing situations (that is, unstable or inappropriate housing) than people with other disabilities.<sup>57</sup> We also know that a gap in one system compromises progress in another, for example, suitable housing is made available to the person but appropriate support services are not, or vice versa. It is a relatively common occurrence and a key reason for the failure of housing arrangements.<sup>58 59</sup> This leads to a high risk of homelessness which is also a trigger for entry into the guardianship system.

Appropriate housing solutions are urgently required for people with impaired decision-making capacity. Precarious housing becomes a more common outcome when a vulnerable person's circumstances are complex.<sup>60</sup> Arguably, it is inappropriate and unsustainable to use guardianship as a method to address precarious housing issues (refer to Key Result Area 1).

Figure 27 illustrates the types of cared accommodation (excluding private households) used by people with impaired decision-making capacity. The most common type of cared accommodation was aged homes, followed by hospitals. In part, this is a reflection of the general poor health of people with impaired decision-making capacity and also the high proportion of people over 65 years.

Living in cared accommodation (e.g. a group home, health establishment or institutional setting) is the reality for:

- 1 in 68 people with a disability
- 1 in 4 people with impaired decision-making capacity
- 2 in 3 people subject to a guardianship order made to the Adult Guardian.

Research and measurement on the dynamics of disability suggest that the impact of different forms of disability can result in different levels of social exclusion. For example, people with complex needs or demanding behaviours face seemingly intractable barriers to access and retain appropriate housing.

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**We are cautious about placing too much emphasis on the individual characteristics of a person's disability. We think that doing this can sometimes mask the underlying relationships, causes and impacts of exclusion and distract debate from structural issues that create and exacerbate discrimination and disadvantage in accessing appropriate and sustainable housing.**

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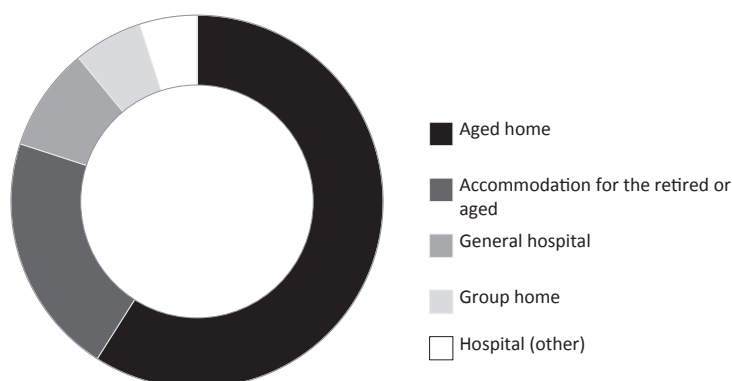
<sup>57</sup> Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

<sup>58</sup> Bleasdale, M. 2006, *Supporting the Housing Needs of People with Complex Needs*, Positioning Paper No. 89, Australian Housing and Urban Research Institute, Melbourne.

<sup>59</sup> Bleasdale, M. 2007, *Supporting the Housing of People with Complex Needs Research and Policy*, Research and Policy Bulletin Issue. 90, Australian Housing and Urban Research Institute, Melbourne.

<sup>60</sup> Mallet, S., Bentley, R., Baker, E., Mason, K., Keys, D., Kolar, V. and Krnjacki, L. 2011, *Precarious Housing and Health Inequalities: What are the Links?*, Hanover Welfare Services, University of Melbourne, University of Adelaide, Melbourne Citymission, Australia.

**Figure 27. Type of cared accommodation used by Queenslanders with impaired decision-making capacity**



Source: Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

## Health

Exclusion and disadvantage are high risk factors for poor outcomes in health and wellbeing. Research shows that people with disability and their families: live with preventable disease; benefit less from preventative health measures and existing health promotion initiatives; and generally have poorer access to all levels of health care than the general population.<sup>61</sup>

Our research shows that almost 27,000 people with impaired decision-making capacity live with multiple health conditions impacting on their daily lives (see Table 8). The Australian Institute of Health and Welfare has also confirmed that having multiple disabilities and health conditions is strongly associated with reduced levels of social participation (social activities) and increased risks for social exclusion (social isolation).<sup>62</sup> These circumstances increase the risks of abuse, neglect and exploitation.

<sup>61</sup> Australian Institute of Health and Welfare 2006, *Life Expectancy and Disability in Australia 1988 – 2003*, Cat No. DIS 47, Australian Institute of Health and Welfare, Canberra.

<sup>62</sup> Australian Institute of Health and Welfare 2009, *Disability in Australia: Multiple Disabilities and Need for Assistance*, Cat No. DIS 55, Australian Institute of Health and Welfare, Canberra.

**Table 8. Health of adult Queenslanders with impaired decision-making capacity living in private households (2011)**

**44,900 (Approx.)**

Queenslanders with impaired decision-making capacity experience fair or poor health

**92%**

**41,300** experience limits to their social activities due to poor health

**86%**

**38,500** cannot complete daily activities as much as they would like to because of their poor health

**60%**

**27,000** have more than three health conditions

Source: Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

Note: The three categories listed above (number of health conditions, limitations to social activities and the inability to complete daily activities) are not mutually exclusive. The figures also do not include people with impaired decision-making capacity who live in cared accommodation, for example in a group home, health establishment or institutional setting.

The category 'experience of limits to social activities' was based on the SDAC variable "How often physical health or emotional problems interfered with social activities during last 4 weeks?"

Figure 28 illustrates how the complex health conditions experienced by people with impaired decision-making capacity limits the ability of individuals to participate in social activities and poor health will also prevent them from undertaking daily activities.

The consequences for people with impaired decision-making capacity and complex health situations are evident when:

- 3 out of 5 live with more than three different health conditions
- 6 out of 7 cannot complete daily activities as much as they would like because of their poor health
- 9 out of 10 are limited socially by poor health.

**People with impaired decision-making capacity live with preventable health conditions but do not have appropriate access to primary health care and health promotion programs.**

We know that for people with impaired decision-making capacity, poor health can limit the maintenance of existing social networks and significantly reduce levels of social activity. Strong social networks help protect health.<sup>63 64 65</sup> Social networks promote self-esteem, coping effectiveness and sense of wellbeing by providing emotional support, companionship and opportunities for meaningful social participation.

Poor health also affects the carers of Queenslanders with impaired decision-making capacity. Almost twice as many carers are in poor physical health compared to the general population.<sup>66 67 68</sup> Research shows that primary carers aged 18-50 years may have poor mental health outcomes with much higher rates of clinical depression, anxiety and family breakdown than non-carers.<sup>69</sup>

The poor health and ageing of carers destabilises informal support networks. Queenslanders with impaired decision-making capacity are highly vulnerable to entering the guardianship system when they do not have an informal support network (refer to Key Result Area 1 for further information).

63 Berry, H. and Butterworth, P. 2003, *Overcoming Mental Health Barriers to Social and Economic Participation*, Family and Community Health Research Unit, The Australian National University, Canberra.

64 Hayes, A., Gray, M. and Edwards, B. 2008, *Social Inclusion: Origins, Concepts and Key Themes*, prepared for the Social Inclusion Unit, the Department of the Prime Minister and the Cabinet, Commonwealth of Australia, Canberra.

65 VicHealth 2005, *Social Inclusion as a Determinant of Mental Health and Wellbeing*, Research Summary 2, Vic Health, Melbourne.

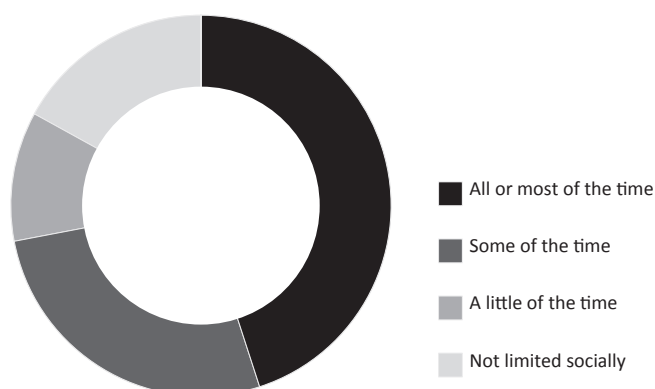
66 Australian Bureau of Statistics 2003, *National Health Survey: Mental Health*, Cat No. 4811.0, Australian Bureau of Statistics, Canberra.

67 Australian Bureau of Statistics 2003, *Survey of Disability Ageing and Carers*, Cat No. 4430.0, Australian Bureau of Statistics, Canberra.

68 Australian Bureau of Statistics 2004, *Disability Ageing and Carers Australia: Summary of Findings 2003*, Cat No. 4430.0, Australian Bureau of Statistics, Canberra.

69 Australian Institute of Health and Welfare 2008, *Disability in Australia: Trends in Prevalence, Education, Employment and Community Living*, Bulletin No.61, Cat No. AUS 103, Australian Institute of Health and Welfare, Canberra.

**Figure 28. Queenslanders with impaired decision-making capacity who are limited socially by poor health**



Source: Australian Bureau of Statistics 2005, *Survey of Disability, Ageing and Carers, Basic CURF 2003 (Reissue)*, Cat No. 4430.0.30.002, Australian Bureau of Statistics, Canberra.

## Issues

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**Our ‘advocacy and inclusion’ findings tells us that unequal and limited access to basic social and economic resources places people with impaired decision-making capacity at very high risk of exclusion and alarming risks of abuse, neglect and exploitation.**

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Complex and fragmented service systems and a lack of accessible information to help navigate government, non-government and private sector providers compound the stress and frustration experienced by people with impaired decision-making, their families and support networks as they attempt to identify and secure services. (These circumstances were common to the types of enquiries received by our Office – refer to section ‘Enquiries – information and referral’.)

In the snapshot of the Adult Guardian Client Profile Project (see Key Result Area 1), we also highlighted that the appointment of a guardian – a legal intervention of last resort – may be in large part, the result of social safety nets being compromised and overwhelmed by multiple layers of persistent exclusion and disadvantage. This can lead to individual and family crisis.

Whilst guardianship is a necessary part of a comprehensive system of social care and support, it is neither sustainable nor appropriate for the broader population of people with impaired decision-making capacity. It is by its nature a reactive and crisis driven response after bad things have happened.

**The evidence we have presented suggests the critical and immediate need for all levels of government, across all sectors, to invest in a sustainable social system that embeds fair access to social, economic and civic resources for people with impaired decision-making capacity, their families and support networks. We think this is the primary way to promote and protect rights and interests and reduce risks of abuse, exploitation and neglect.**

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We acknowledge that there are choices to be made about where to put effort and emphasis to address disadvantage and exclusion, given competing priorities and scarce resources. We also recognise that social and economic disadvantage is by its nature multi-dimensional and its extent, nature, causes and consequences cannot be understood by looking at single measures. For these reasons, there must be continued investment in the development of measures that capture levels of participation and the desire to participate by people with impaired decision-making capacity, their families and support networks.

Accordingly, our Office advocates for urgent investigation into finding ways to:

- reduce disadvantage
- increase social, civil and economic participation
- give a high priority to early responses and prevention to reduce risk
- build inclusive service models and whole-of-government(s) responsibility
- use evidence and integrated data to inform policy and service planning
- plan for sustainability and promote innovation.

## Advancing systems advocacy through enquiries, engagement and partnerships

We acknowledge the importance of a collaborative approach to advancing our systems advocacy work. Our Office welcomes information and feedback on systems issues from the public. As a small team, it is also vital that we participate in engagement opportunities and seek to leverage partnerships with a range of stakeholders. These activities all contribute to the promotion and protection of the rights and interests of people with impaired decision-making capacity.

## Enquiries – information and referral

Enquiries made to our Office play an important role in identifying systems barriers. Our information and referral activity provides us with contemporaneous information from the public and the health and human services sectors on a diverse range of issues that impact on the rights and interests of people with impaired decision-making capacity,

As a public agency, any member of the community or a representative of an organisation may seek assistance from the Office of the Public Advocate. Over the past year, we have received a range of enquiries including concerns about systems issues, advice and information requests. We record enquiries to provide a further information source for identification of systems issues.

Overall, across all types of enquiries, we provided general information relating to health and community care services to about 24% of enquirers and suggested an alternative and appropriate referral point to approximately 23% of enquirers.

The most common type of enquiry we received was a request for assistance. Approximately 35% of enquirers sought help relating to complex individual matters.

The volume of enquiries from members of the public seeking assistance with complex individual matters highlights a gap in the availability of accessible information. It also suggests the need for improved communication by government departments and other agencies. People often seek information on complex matters and circumstances during times of significant stress and crisis.

Of note is that Article 21 of the United Nations Convention on the Rights of Persons with Disabilities compels governments at all levels to take action to ensure that people with disability are able to find, receive and impart information on an equal basis with others.<sup>70</sup> The article also includes the protection and promotion of freedom of opinion and expression.

Enquirers also experience difficulties navigating the guardianship and administration system. This can be at an individual level, for example by families and carers, as well as at an organisational level, for example by practitioners and service providers. In large part, this may be due to confusion (and fear) about the roles and functions of different agencies (including the Queensland Civil and Administrative Tribunal, the Public Trustee, the Office of the Adult Guardian, and the Office of the Public Advocate) and how the guardianship system operates.

Governments at all levels have acknowledged that limited access to information is a barrier to accessing the social resources necessary for social and civic participation.<sup>71</sup>

Thirty-nine percent of enquirers raised a systems issue or service delivery concern. The majority (66%) of these were representatives of government and non-government bodies and private organisations. The remainder were individuals, usually family members, raising systems issues or related service delivery complaints.

About half of the enquiries received (51%) were via telephone, with a further 38% received via email and 10% through a letter or fax.

The complex service system places additional demands on individuals and their families requiring them to have a breadth of knowledge and diversity of skills to access appropriate mainstream and specialist services. A key issue consistently raised is access to timely information. This assists people to identify services and to make informed decisions about which services are best for them. However, this is not the reality for many individuals and families who report that the onus is on them to ask the right questions, to the right agency, to elicit relevant information to inform their decisions.<sup>72</sup>

## Engagement activities

Our Office has been involved in a range of engagement activities over the past year in relation to strategic planning, policy development and law reform matters which impact on Queenslanders with impaired decision-making capacity.

We have sought to ensure that the rights and interests of all people with impaired decision-making are actively promoted and taken into account during the developmental and implementation stages of reforms. A positive development has been an increasing awareness and take-up amongst government stakeholders of our evidence-based approach and a better understanding that the role for statutory systems advocacy is not limited to specialist health, disability or guardianship matters. In this respect, the Office has been approached on a broad range of matters, including mainstream policy and service issues which impact on people with impaired decision-making capacity as citizens.

Over the year, the Office has been involved in many engagement activities to promote the rights and interests of people with impaired decision-making capacity. These ranged from issues with specialist or disability focus, to matters which affect the community more broadly.

<sup>70</sup> French, P. 2008, *Human Rights Indicators for People with Disability*, Disability Studies and Research Institute, Queensland Advocacy Organisation Incorporated, Brisbane.

<sup>71</sup> Australian Social Inclusion Board 2010, *Social Inclusion in Australia: How Australia is Faring*, Australian Social Inclusion Board, Canberra.

<sup>72</sup> The Parliament of the Commonwealth 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, April 2009, The Commonwealth of Australia, Canberra.

Some examples of our engagement activity include:

#### Law reform

- Queensland Law Reform Commission's guardianship review
- Review of the *Disability Services Act 2006* (Qld), including restrictive practices
- Forensic disability legislation
- Review of the *Domestic and Family Violence Protection Act 1989*.

#### Strategic policy

- 10-year plan for supporting Queenslanders with a disability (Department of Communities)
- State and federal health reforms, including the electronic health record initiative, health consumers framework and a strategy for palliative care; practice and professional standards for health and allied health practitioners; and the mental health community services plan
- National Disability Insurance Scheme
- Carer Action Plan (Department of Communities)
- Criminal justice system issues such as the State Penalties Enforcement Register; offenders with impaired decision-making capacity; and parents with intellectual disability and child protection implications
- Disability Service Plan (Department of Justice and Attorney-General).

#### Advisory groups / workshops

- Workshop for Specialist Response Service clinicians to identify opportunities for greater and more meaningful inclusion and participation for adults with a disability who are subject to restrictive practices
- International Symposium on Abuse and Neglect of People with Intellectual Disability
- Expert Advisory Group for the new QHealth Disability Service Plan 2011-2013
- Positively Ageless, Interdepartmental Strategy Group (Department of Communities).

All of these are issues impacting on people with impaired decision-making capacity and further detail on some of the engagement activities is provided below to help illustrate the breadth of this work. Many of our engagement activities remain ongoing.

We have been consulted regularly on the Government's response to the Queensland Law Review Commission's guardianship review. This consultation has continued beyond the reporting period for this report.

We have contributed to discussions on a range of Queensland Health reforms including, the Queensland Health Palliative Care Strategy which will guide the future provision of palliative

care services in Queensland. The Office has strongly supported the need to genuinely seek the participation of 'consumers' – individuals, families and carers – in health care decisions and program and services development.

The views of the Office have been sought in relation to the rights and interests of people with impaired decision-making capacity as a consumer of mainstream health services, including the proposed electronic health record initiative and the development of the health consumers' framework.

#### Engagement – guardianship jurisdictions

Engagement with other guardianship jurisdictions is also important in advancing our systems advocacy framework which is unique in Australia. The Public Advocate or delegate attends bi-annual meetings of the Australian Guardianship and Administration Council which is the key national information-sharing forum.

This year, our Office funded the South Australian Public Advocate to deliver a workshop to staff and also staff of the Office of the Adult Guardian on a South Australian Supported Decision-Making pilot. The pilot trials a new decision-making model which establishes supported decision-making agreements for people with impaired decision-making capacity, instead of the legal intervention of guardianship. In this model, decisions are effectively being made by the person but with support as identified and agreed by the secondary parties involved. Assistance is provided to support all people participating in the agreements and their support team.

The South Australian trial will cover decision-making in the areas of accommodation, lifestyle, and health. The model is less restrictive of the rights and interests of people with impaired decision-making capacity and positions formal guardianship as a model of 'last resort'.

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**Other suggested improvements to the guardianship system include statutory individual advocacy as a less intrusive approach; and alternative dispute resolution like mediation where there is less impact on a person's civil liberties and human rights.**

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We will continue to monitor the outcomes of the South Australian pilot. If successful, the pilot may provide important lessons on how to better meet the needs of marginalised groups, including Indigenous Queenslanders with impaired decision-making capacity and their families in the guardianship system. As discussed in Key Result Area 1, supported decision-making may be a more culturally appropriate approach than the current guardianship system and lead to better outcomes for Indigenous Queenslanders with impaired decision-making capacity and their communities.



In late 2010, we also hosted a senior staff member from the New South Wales Public Guardian office interested in obtaining information about our statutory systems advocacy and evidence-based approach to systems issues. The New South Wales office is in the process of examining a statutory systems advocacy role and function and was interested in learning from the Queensland experience.

## Partnership activities

The Office undertook a range of initiatives this year which contribute to the promotion and protection of the rights and interests of people with impaired decision-making capacity. One of our important partnerships is with the Office of the Adult Guardian, in relation to the Adult Guardian Client Profile Project. Examples of other partnership outcomes are outlined below.

## Data sharing between agencies – innovation and success

The Adult Guardian Client Profile Project initiated by our Office is a recent practical example of cross-agency data sharing and collaborative research activities. To fill a significant evidence gap in the Adult Guardian client profile, de-identified client data of the Adult Guardian was integrated with specialist disability data from the Department of Communities (Disability and Community Care Services).

This was the first time that the two Queensland government agencies with mutual clients shared administrative data for research purposes. The integration of the two datasets was highly successful and has provided new evidence and insights into the Adult Guardian client profile.

There has been keen interest from various government departments in the data integration methodology used by our Office. We presented the data integration methodology and outcomes to a Statistical Liaison network, which includes representatives from the Department of the Premier and Cabinet, Department of Justice and Attorney-General, Department of Communities, Department of Transport and Main Roads, Queensland Health, Queensland Treasury (the Office of Economic and Statistical Research), the Parliamentary Library, Health Quality and Complaints Commission and the Australian Bureau of Statistics.

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**Data sharing to develop a robust evidence base to better understand the needs and interests of shared clients is critical to improving the responsiveness and sustainability of the guardianship system.**

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## Elder abuse – helping to raise awareness

Elder abuse continued to be a priority systems area during the year. Elder abuse is a significant and often hidden issue in our communities. The Office has been involved in a number of related projects, seeking to make a contribution to identify policy and service gaps. Like other agencies, we appreciate that a reduction in the level of social isolation and a promotion of inclusive policy and programs for elders is a key factor in minimising the risk of elder abuse.

We contributed to the Queensland Government *Positively Ageless Queensland Seniors Strategy 2010-20* as a participant of the reference group and leading actions under the priority area of ‘valuing and empowering seniors’.

The Office delivered a joint discussion paper with the Queensland Law Society to promote dialogue about improving legislative responses to elder abuse in Queensland.<sup>73</sup> The Office has collated the information received through the submissions process and has briefed the Department of Justice and Attorney-General for its consideration of potential future action in this important area of law reform.

We also developed an *Elder abuse resource directory* to provide a guide to services, assistance and information available in Queensland. The guide was released on World Elder Abuse Awareness Day (15 June) at a celebratory event hosted by the Office for Seniors within the Department of Communities. Key stakeholders at the event expressed support for the directory and identified it filled an information gap for people, their carers, and other support networks faced with the issue of elder abuse. The Queensland Police Service has found the resource directory to be a useful product for distribution at relevant community engagement activities.

We have fostered strong partnerships in this area and look forward to continuing these into the future. Identifying innovative responses to promoting and protecting the rights, interests and wellbeing of seniors in our communities will continue to be a priority of our systems advocacy work.

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<sup>73</sup> Office of the Public Advocate and Queensland Law Society 2010, *Elder Abuse. How Well Does the Law in Queensland Cope?*, Office of the Public Advocate (Qld) and Queensland Law Society, Brisbane.

## **Our ongoing commitment**

The evidence is hard to ignore. The pressures on health and social care service systems are well known. The exponential growth in people with impaired decision-making capacity means that guardianship and specialist service systems in current forms are unsustainable, and we do not have a clear indication of the individual outcomes delivered.

Systems advocacy plays an important role in influencing the development of policies, programs and services that respect rights, promote inclusion and deliver improved opportunities for participation in social, economic and civic life for all Queenslanders with impaired decision-making capacity. Without fair access to social, economic and legal resources, the opportunity to participate is denied.

Our Office will continue with its evidence-based approach to advance inclusion. We think promoting mutual responsibilities and interests, collaboration and fostering partnerships with our stakeholders is essential to protecting the rights and interests of Queenslanders with impaired decision-making capacity.



## Key Result Area 4

### Business Processes

The Public Advocate is an independent statutory appointment.

The Office of the Public Advocate operates within the broader strategic and business planning processes undertaken by the Department of Justice and Attorney-General.

Our key objectives are to operate transparently and with accountability; and to ensure effective business and risk processes are in place for our work.

## Approach to business

The statutory systems advocacy roles and responsibilities undertaken by the Office are outlined at section 209 of the *Guardianship and Administration Act 2000*. The key functions relate to promoting, encouraging, monitoring and reviewing at a systems level on behalf of the broad population of adults with impaired decision-making capacity.

The Office operates in the context of broader strategic and business planning processes undertaken by the Department of Justice and Attorney-General. We also aim to strategically align with Queensland Government objectives, as acknowledged in our Systems Advocacy Framework.

As part of our commitment to accountability and good governance we use the following organisational management tools:

- An annual report to report on our operations over each financial year, in accordance with our legislative requirement under the *Guardianship and Administration Act 2000*.
- A strategic framework for systems advocacy underpins our work.
- An annual business plan to support our Systems Advocacy Framework.
- A policy suite to guide our workplace in the delivery of systems advocacy (further information on this is provided below).

During the year we have built upon the relationship between our systems advocacy approach and our commitment to transparency and accountability in supporting business processes.

Our business practices are guided by the following aims:

- We recognise the importance of delivering continuous improvement in governance, legislative compliance, planning, and risk and performance management.
- We use our knowledge, experiences and outcomes to improve the delivery and impact of our systems advocacy.
- We are collegiate in all our business activity and consult with business stakeholders.
- We leverage strategic partnerships at national, state and local government levels as appropriate.
- We deliver improved business products that are relevant and accessible to our stakeholders and audiences.

Our business approach is guided by the following principles:

- promote transparency and accountability
- be flexible and adaptable to change
- maximise quality, efficiency and effectiveness
- promote innovative and collaborative teamwork

- encourage staff endeavour and provide opportunities for career development
- create a culture of learning and excellence
- strengthen management and leadership capability.

## Policy suite

The Office implements a range of policies and practices to promote best practice and accountability within our workplace. Where appropriate, the Office has adopted departmental administrative policy and practices. As a result, our policy and practices in relation to business planning, risk management, complaints, public interest disclosures, privacy, record-keeping, and employee performance is guided by the Department of Justice and Attorney-General policy and practices. The Office also contributes to whole-of-government reporting in relation to key corporate policy areas, pursuant to Queensland Government requirements.

We participate in the Corporate Services quarterly forums to ensure the Office remains abreast of key information, developments and issues. This was particularly relevant this year which saw unprecedented developments arising from the January 2011 floods experienced in Queensland.

Due to the specialised nature of our systems advocacy work, two policy areas were considered for development this year:

- management of enquiries received by the Office
- management of research and grants arrangements.

It is important for transparency, accountability and probity to document our approach to these areas in policy documents.

### Enquiries management policy

As a public agency, any member of the community or a representative from an organisation may seek assistance from the Office of the Public Advocate. The nature of enquiries may range from seeking general information or advice, requesting specialised input to an official consultation exercise, to seeking assistance with a complaint. The collective analysis of the information received by our Office is important for the identification of potential systems issues and also contributes to our function to monitor services and facilities. It is therefore essential, as part of our evidence-building, to record this information systematically.

During the year we developed an enquiries management policy and supporting procedures that provide us with a framework to better capture and understand the issues raised; make a decision about what to do in the particular situation; provide advice and information and to make an appropriate referral. The enquiries management policy helps in determining the most appropriate response and course of action for each enquiry we receive, within the context of our roles, responsibilities and legislative framework.

The enquiries management policy is accompanied by internal procedures to guide staff in how to deal with the collection and management of information through a structured and consistent approach. The Office will continue to refine the data collection tools in the next year to determine the most suitable and efficient way to systematically collect information resulting from our enquiries management process.

### **Protocols and principles for dealing with enquiries**

This year we have implemented protocols and principles for dealing with enquiries. Seeking guidance from legislation and policy is very important however it must be recognised that not every particular situation or issue can be captured.

We deal with diverse and often complex inquiries from individuals and from large and small agencies. There is always a need for professional judgement balanced by pragmatism and sensitivity given the difficult life circumstances and crisis often faced by people with impaired decision-making capacity, their families and carers. The Office is mindful of ensuring that each person is treated respectfully and courteously in all communications and interactions. Similarly, an appropriate standard of behaviour is expected from persons making enquiries to the Office.

Every effort is made to assist persons if the person has difficulty in communicating. The Office is also able to utilise interpreter services if required.

The legislative mandate of our Office and our systems advocacy role is to be made clear in communications and interactions. Whilst the resolution of individual cases is not within our legislative responsibilities, we endeavour to provide enquirers with appropriate points of referral where possible. Privacy and confidentiality are also paramount considerations.

We only collect information to the extent necessary to assess the nature of the enquiry, whether it falls within our responsibilities, and to determine the most appropriate course of action. The information collected is recorded for internal use to enable analysis of potential systems advocacy issues.

### **Research and grants policy**

The Office acknowledges that with a small contingent of staff, research partnerships are vital to maximise our commitment to evidence-based systems advocacy. As is documented throughout this report, the Office actively engages with a broad range of academic partners in working together to foster important research on issues affecting people with impaired decision-making capacity.

We are keen to continue to grow and expand these relationships and to partner with innovative research projects. To encourage this, the Office is working toward developing a fit for purpose research and grants policy. The Office is already engaging with new innovative projects such as the proposal for a Disability Training Partnership between the Department of Justice and Attorney-General and the Endeavour Foundation. The Office is currently in discussions with the Endeavour Foundation about potential research assistance we may provide for this project.

### **Our ongoing commitment**

We will continue to monitor and refine our business processes, policies and procedures to ensure that the Office operates effectively and with accountability and transparency.

# Office of the Public Advocate – Operations

## Organisational structure

The Public Advocate is an independent statutory position appointed by Governor in Council in accordance with the *Guardianship and Administration Act 2000*. The Act permits an acting Public Advocate to be appointed when the office is vacant or the Public Advocate is absent from duty or is unable to perform the duties.

In 2010-11, the Public Advocate position was shared between Mr Lindsay Irons and Dr Susan Brady. Dr Susan Brady was the Acting Public Advocate as at 30 June 2011 and at the time of writing this report.

The *Guardianship and Administration Act 2000* provides that staff may be appointed to assist the Public Advocate to perform the functions under the Act. It is a requirement that staff are appointed under the provisions of the *Public Service Act 2008*.

Over the course of 2010-11, the Public Advocate position was supported by a small contingent of staff. The majority of these are temporary positions and not all positions were filled across the full financial year:

- an Executive Manager (Advocacy, Policy and Evidence)
- a Research Manager (Client Profile)<sup>74</sup>
- a part-time Manager (Strategic Projects)
- two part-time Principal Research Officers
- two Senior Research Officers
- one part-time Administration Officer (supported by one part-time Administration Officer up to 8 hours per month).

## Financial summary

Funding for the office is appropriated from the Queensland Government as part of the appropriation for the Department of Justice and Attorney-General. The Director-General of the Department of Justice and Attorney-General is the Accountable Officer pursuant to the *Financial Administration and Audit Act 1977*.

A summary of the expenditure for the Office of the Public Advocate for the 2010-2011 financial year is provided in Table 9. Comprehensive financial details relating to the operations of the department are reported in the 2010-2011 annual report for the Department of Justice and Attorney-General.

**Table 9. Office of the Public Advocate Financial summary 2010-11**

Expenditure items	
Employee related expenses	\$632,000
Supplies and services	\$154,000
Grants	\$10,000
Depreciation*	\$23,000
<b>Total</b>	<b>\$819,000</b>

\* The Office of the Public Advocate does not incur any amortisation and deferred maintenance expenditure.

## Travel expenditure

There was no overseas travel undertaken by the Public Advocate or staff during the year.

Interstate travel was undertaken to attend the bi-annual Australian Guardianship and Administration Council meetings. This is the key national forum for state and territory agencies to promote the interests of people with impaired decision-making capacity. All key leaders in the guardianship jurisdictions across Australia, including Public Trustees and heads of tribunals, are members of this forum.

In June 2011, the Office funded travel to Queensland by the Public Advocate for South Australia and a research officer. The South Australian office is leading the way among public guardians across Australia in piloting a small supported decision-making project for people with impaired decision-making capacity. The two invitees led a workshop about a supported decision-making project and presented to officers from both the Office of the Adult Guardian and the Office of the Public Advocate.

## Grants expenditure

In 2010-11, grants were made in relation to the ongoing research project – ‘Withholding and withdrawing life sustaining treatment from adults lacking capacity’. This is a three year project which is led by the Law Faculty of the Queensland University of Technology. The Office of the Public Advocate is one of a number of research partners and the project is also partially funded by an Australian Research Council Grant. The final research report is expected in late 2012.

Further details about this project and our other research partnerships are reported in the Key Result Area 1.

<sup>74</sup> The Research Manager (Client Profile) position was a temporary 12-month position established for the Client Profile project. The position was funded by the Office of the Adult Guardian as part of the joint agreement for the project.



## Staff development

The staff of the Office of the Public Advocate are highly valued and as members of a small team, it is acknowledged that each officer contributes to the delivery of our business outcomes.

In 2010-11, a substantial investment was made toward staff training and professional development. This included the purchase of specialised training courses and computer software to support staff in meeting our commitments to an evidence-based systems advocacy approach. It is important that staff continue to expand their expertise and skills in the latest research and data analysis techniques.

Staff professional development was also enhanced through attendance at significant conferences held by external organisations across the sector. Staff also participated in a range of in-house training or information sessions provided by the Department of Justice and Attorney-General.

## Work-life balance

The Office is supportive of staff work-life balance. Some members of the team are engaged under flexible working arrangements. This assists staff in maintaining an optimum balance in relation to other aspects of their lives such as family caring responsibilities and higher education pursuits.

Notes:

## Office of the Public Advocate

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