# Office of the Public Advocate
# Systems Advocacy

# The Adult Guardian Client Profile Project:

An independent analysis of guardianship clients and orders made to the Adult Guardian 2000-2010

**Final Report**

**February 2013**

Queensland Government

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# Foreword and acknowledgments

The Adult Guardian Client Profile Project is a significant achievement for the Office of the Public Advocate. A number of people and agencies contributed to the success of this project and deserve recognition.

This project would not have been possible without the support provided by the Office of the Adult Guardian, including their financial contribution. The collaboration was agreed to by the former Adult Guardian, Ms Dianne Pendergast. This important partnership was continued by the Acting Adult Guardian, Mr Lindsay Irons, and Mr Kevin Martin was appointed as Adult Guardian in August 2012.

The demanding and sensitive nature of the work of the Office of the Adult Guardian is acknowledged and the assistance, time and input afforded by staff is appreciated. The agency is committed to continuous improvement in service delivery and the understanding that robust evidence is needed to support this.

Appreciation is also extended to the Department of Communities, Child Safety and Disability Services (previously the Department of Communities) for sharing an important data resource for the purposes of this project – the Disability Services National Minimum Data Set for Queensland. This additional layer of data enabled greater rigour and richer information to improve our understanding of people with impaired decision-making capacity.

From the Office of the Public Advocate, I thank my predecessors who led and shaped this unique project. The small, dedicated team of staff who contributed to the research, analysis, writing, design and production of this report also deserve commendation.

The findings and issues highlighted in this report open the door for substantive debate amongst stakeholders and the community in the interests of developing better solutions, more effective policies and enhanced service delivery responses. A strong evidence base is a prerequisite for informing sound business planning, strategic directions and risk management decisions. Having such a comprehensive analysis as the starting point to changing and shaping practice supports the delivery of better outcomes to improve and advance the lives of people with impaired decision-making capacity; this being the ultimate purpose and objective.

I trust that this project and report represents the first of many innovative and collaborative projects to be undertaken in the interests of progressively developing a robust and solid evidence base. Doing so will create a strong platform to inform planning, management approaches and the development of strategies to improve the lives of people with impaired decision-making capacity.

**Jodie Cook**

**Public Advocate – Queensland**

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# Introduction

## The notion of guardianship

The involvement and responsibility of the 'State' or government in protecting vulnerable members in the community is a long-standing doctrine of the legal system. That is, it falls to the State to take care of those who cannot take care of themselves - the 'parent of the nation' principle. This concept evolved into the *parens patriae* jurisdiction under common law, where the courts have jurisdiction to make decisions concerning people who are unable to protect themselves.

In the case of the 'guardianship' system, the vulnerable cohort being protected are those who do not have, or who lose, the capacity to understand, make or communicate decisions about their lives – those with 'impaired decision-making capacity'.

The ability to make decisions is not a guarantee. Decision-making ability in adulthood may be affected (temporarily or permanently) through a number of circumstances including, but not limited to:

- being born with an intellectual disability
- acquiring a brain injury through an accident
- episodes of mental illness
- occurring as a result of a coma
- developing age-related dementia.

These are situations that may affect anyone at any time. The guardianship system therefore has widespread importance and broad relevance across the community.

### Substitute decision-making

The significant power represented by the act of 'decision-making' for adults is illustrated by the statement below:

> 'Being recognised as someone who can make decisions is instrumental in taking control over one's life and engaging in society with others…Without it we are non-persons in the eyes of the law and our decisions have no legal force.[1]

A substitute decision-maker is a person who is afforded the role (either informally or formally) of making and communicating decisions on behalf of an adult with impaired decision-making capacity. Decisions may need to be made about a range of matters including both financial and personal matters. In most jurisdictions, decisions made for a person's financial affairs (referred to as 'administration') are treated separately from their personal affairs (referred to as 'guardianship').

A person may prepare legal documentation prior to losing capacity, directing who should make decisions on their behalf should they lose capacity (generally known as an enduring power of attorney).[2] Sometimes decisions can be made for the person on an informal basis by the person's family or existing support network.

It is also possible, when a person loses their capacity to make decisions, for a family member, friend or relative to be formally appointed by a court or tribunal as their guardian (known as a private guardian) to assist the person with certain personal and/or health care decisions. Personal matters may include decisions about medical treatment, where a person resides, and who is responsible for their daily wellbeing. The role of a guardian is to ensure the interests of the adult with impaired decision-making capacity are protected and their needs are met.[3]

A court or tribunal may alternatively appoint the State instead of a private guardian (or private administrator). Circumstances in which this may occur include, for example, where there is evidence that a person with impaired decision-making capacity is unable to care for him/herself and has no family or friends to act as their guardian (or administrator); or when there is serious conflict with a family or support network about the decision/s to be made. The State may also be appointed in situations involving the abuse, neglect or exploitation of the person.[4]

The research underpinning this report predominantly concerns *guardianship* by the State and not financial administration.

[1] Commissioner for Human Rights 2012, *Who gets to decide? Right to legal capacity for persons with intellectual and psychosocial disabilities,* Council of Europe, Strasbourg, p. 6.

[2] An enduring power of attorney is an important legal document prepared to authorise another person to make personal and/or financial decisions on your behalf. The *Powers of Attorney Act 1998* (Qld) regulates the making of an enduring power of attorney.

[3] Queensland Civil and Administration Tribunal 2011, Guardianship for Adults Matters, Department of Justice and Attorney-General, viewed 3 November 2011, <http://www.qcat.qld.gov.au/guardianship-for-adults-matters.htm>.

[4] Office of the Adult Guardian 2010, Role of the Adult Guardian, Department of Justice and Attorney-General, Viewed 3 November 2011, <http://www.justice.qld.gov.au/justice-services/guardianship/adult-guardian/role-of-the-adult-guardian>.

# Guardianship in Australia

In the Australian system of government, the responsibility for guardianship laws rests with each state and territory. Consequently, developments and progress across jurisdictions have varied, although there are a range of common elements.

Victoria was the first state in Australia to review and reform its approach to guardianship, with the enactment of the *Guardianship and Administration Act 1986* (Vic).[5] Over the next 10 years, the other states and territories followed a similar course and introduced separate guardianship legislation. Although Queensland was the last jurisdiction in Australia to introduce guardianship legislation and system reforms (introduced in 1998), doing so enabled Queensland to consider and take into account the experiences and learnings from the other states and territories.

The appointment of the 'State' as guardian for an adult is only intended as a 'last resort' where no other informal or formal option is available. The public official who holds this responsibility is generally an independent person appointed by government within a statutory framework. The role is referred to by a variety of terms across jurisdictions (see Table 1).[6]

***Table 1*** **State appointed guardians for adults with impaired decision-making capacity across Australian jurisdictions**

| Title | Jurisdiction | Legislation |
|---|---|---|
| Adult Guardian | Queensland | *Guardianship and Administration Act 2000* (Qld) |
| Public Guardian | Northern Territory | *Adult Guardianship Act 1988* (NT) |
| | NSW | *Guardianship Act 1987* (NSW) |
| | Tasmania | *Guardianship and Administration Act 1995* (Tas) |
| Public Advocate* | ACT | *Public Advocate Act 2005* (ACT) |
| | South Australia | *Guardianship and Administration Act 1993* (SA) |
| | Victoria | *Guardianship and Administration Act 1986* (Vic) |
| | Western Australia | *Guardianship and Administration Act 1990* (WA) |

*Note: The position of 'Public Advocate' in Queensland has a different context to the other Australian jurisdictions. The Public Advocate in Queensland does not relate to the State acting as an individual's guardian. Rather, it refers to an independent statutory role that undertakes systems advocacy functions on behalf of all adults with impaired decision-making capacity in Queensland (*Guardianship and Administration Act 2000* (Qld), Chapter 9).

The type and model of state intervention in guardianship has shifted over time in both international and local jurisdictions. The spectrum has ranged from a paternalistic approach where it was considered that vulnerable people in society must be shielded from harm, toward the current contemporary and liberal approach that espouses deinstitutionalisation, the protection of human rights, and promotion of social inclusion.

# Guardianship in Queensland

The guardianship regime in Queensland has been in operation for about 15 years. The *Powers of Attorney Act 1998* (Qld) and the *Guardianship and Administration Act 2000* (Qld) are the two primary pieces of governing legislation. The legislation defines the parameters within which the system operates and puts into place safeguards for people who may be vulnerable due to their impaired decision-making capacity. Underpinning the legislation are 11 General Principles and one Health Care Principle to guide the role of substitute decision-making.

## Historical overview

### First guardianship review (1990-1996)

The first substantial review of the Queensland guardianship system and related laws commenced in late 1990. The laws at this time comprised the:

- *Mental Health Act 1974* (Qld)
- *Public Trustee Act 1978* (Qld); and
- *Intellectually Disabled Citizens Act 1985* (Qld)

In addition to the statutory framework, the Supreme Court had, and continues to have, jurisdiction under the *parens patriae* power to appoint substitute decision-makers. This power has not been the subject of review and sits firmly within the common law framework.

[5] The review was undertaken by the Victorian Cocks Committee which produced the *Report of the Minister's Committee on Rights and Protective Legislation for Intellectually Handicapped Persons* in 1982.
[6] Note: These public officials are appointed to make personal decisions not financial administration decisions. The State public official who is appointed to make financial or administrative decisions (often as a last resort) is commonly referred to as the Public Trustee.

In September 1990, the then Attorney-General, the Honourable Dean Wells requested a review of the laws relating to people with disabilities by the Queensland Law Reform Commission (QLRC). The QLRC focused on the laws relating to decision-making by and for persons with impaired capacity; and its findings were delivered in 1996.

At that time, the QLRC found the law in Queensland to be:

> *'outdated, inflexible, and inadequate to meet the needs of people with a decision-making disability, their families and their carers. Its effect is often intrusive, resulting in the appointment of the Public Trustee and the Legal Friend as decision-makers in situations where it is unnecessary.'*[7]

The QLRC found in its background research that the relevant legislation at that time was mainly built on a 'protective approach', although it recognised that the more recent *Intellectually Disabled Citizens Act 1985* had incorporated rights-based elements in line with international movements. At the international level, human rights were being increasingly acknowledged, influenced by the United Nations' *Declaration on the Rights of Mentally Retarded Persons* (1971) and the *Declaration on the Rights of Disabled Persons* (1975).[8]

The 1996 QLRC review noted there was 'unnecessary intrusion into individual and family affairs' and acknowledged the important role of family members and close friends who were often 'in the best position to understand and interpret the wishes' of the person with impaired decision-making capacity.[9]

Central to the QLRC's recommendations was the premise 'that outside intervention should be used only when it is necessary to promote and protect the rights and welfare of a person who lacks the capacity to make his or her own decisions'.[10] The Commission also emphasised the important role of families and carers and considered that greater recognition would mean fewer applications for appointment and reduce the demand on government decision-making services.

While emphasis was placed on close support networks, it was recognised that such networks may not always exist or that family and friends may not always be appropriate and eligible to act as guardians. For these circumstances, the QLRC recommended there be a 'statutory decision-maker of last resort in relation to decisions concerning lifestyle matters and personal welfare' - that is, the establishment of the role of the Adult Guardian.[11]

AT this time, the QLRC also outlined and recommended the application of 11 General Principles and one Health Care Principle to guide all decision-makers.[12] The principles intended to:

> *'strike a balance between, on the one hand, the right of people with a decision-making disability to adequate and appropriate support in their decision-making and to protection from neglect, abuse and exploitation when their disability prevents them from looking after their own interests, and, on the other, their right to the greatest possible degree of autonomy'.*[13]

The 11 General Principles for guardianship are:

1. Presumption of capacity
2. Same human rights
3. Individual value
4. Valued role as member of society
5. Participation in community life
6. Encouragement of self-reliance
7. Maximum participation, minimal limitations and substituted judgement
8. Maintenance of existing supportive relationships
9. Maintenance of environment and values
10. Appropriate to circumstances
11. Confidentiality

The Health Care Principle must be applied to decisions about health or special health matters. This Principle requires that the least restrictive way be undertaken and this power only be exercised if it is necessary and appropriate to maintain or promote the adult's health or wellbeing or where it is in the adult's best interests.

The provisions of the General Principles and Health Care Principle are documented in Appendix 1.

[7] Queensland Law Reform Commission (QLRC) 1996, *Assisted and Substituted Decisions,* Decision-making by and for people with a decision-making disability, Report No. 49, QLRC, Brisbane, Preface.
[8] Queensland Law Reform Commission (QLRC) 1992, *Assisted and Substituted Decisions,* Working Paper 38, QLRC, Brisbane, p.1.
[9] Queensland Law Reform Commission (QLRC) 1996, *Assisted and Substituted Decisions,* Decision-making by and for people with a decision-making disability, Report No. 49, QLRC, Brisbane, p. 182.
[10] Queensland Law Reform Commission (QLRC) 1996, *Assisted and Substituted Decisions,* Decision-making by and for people with a decision-making disability, Report No. 49, QLRC, Brisbane, Preface.
[11] Queensland Law Reform Commission (QLRC) 1996, *Assisted and Substituted Decisions,* Decision-making by and for people with a decision-making disability, Report No. 49, QLRC, Brisbane, p. 183.
[12] The General Principles are replicated in the *Powers of Attorney Act 1998* (Qld) (Schedule 1) and the *Guardianship and Administration Act 2000* (Qld) (Schedule 1).
[13] Queensland Law Reform Commission (QLRC) 1992, *Assisted and Substituted Decisions,* Working Paper 38, QLRC, Brisbane, p.27.

Overall, the 1996 QLRC recommendations were significant, proposing:

- two new independent statutory officers be established – one to act as a systemic advocate on behalf of people with a decision-making capacity (the *Public Advocate*) and one to be the decision-maker of last resort for personal and health care matters (the *Adult Guardian*).
- the existing role of the Public Trustee as decision-maker of last resort for financial matters be affirmed.
- the establishment of an accessible tribunal for guardianship matters.

## Implementation of first wave of guardianship reforms (1998-2000)

The implementation of the 1996 QLRC recommendations report occurred in two phases of legislative reform:

(1) *Powers of Attorney Act 1998* (Qld)

The *Powers of Attorney Act 1998* defined a number of key components of the QLRC recommendations and created a comprehensive scheme around powers of attorney (which until that time had been primarily vested in the *Property Law Act 1974*). These components:

(i) dealt with the appointment of attorneys for financial, personal and health care decisions;

(ii) created advance health care directives;

(iii) created statutory health attorneys;

(iv) established an Adult Guardian to protect the rights of people with impaired decision-making capacity and to act as a health care decision-maker of last resort; and

(v) introduced the 11 General Principles and the Health Care Principle.

(2) *Guardianship and Administration Act 2000* (Qld)

The *Guardianship and Administration Act 2000* (Qld) (The Act) sought to address the remainder of the QLRC recommendations. The Act combined and streamlined all of the complex pieces of legislation applying to people with impaired decision-making capacity - *Mental Health Act 1974, Public Trustee Act 1978* and *Intellectually Disabled Citizens Act 1985*. It also initiated the development of a comprehensive guardianship regime administered by a single government agency by:

(i) Establishing an independent and specialised tribunal - The Guardianship and Administration Tribunal (GAAT) was established to make guardianship appointments under the Act.[14]

(ii) Maintaining the role of the Adult Guardian - The Adult Guardian provisions from the *Powers of Attorney Act 1998* were transferred to the *Guardianship and Administration Act 2000*. The Office of the Adult Guardian was established under Chapter 8 to protect the rights and interests of adults with impaired decision-making capacity. The Adult Guardian is a statutory position appointed by Governor in Council and, in performing the functions of the role, is not under the control or the direction of the Minister.

(iii) Establishing a new independent Public Advocate role as a systems advocate for adults with impaired decision-making capacity. The Office of the Public Advocate was established under Chapter 9 to protect the rights and interests of adults with impaired decision-making capacity through systems advocacy. The Public Advocate is a statutory position appointed by Governor in Council and, in performing the functions of the role, is not under the control or the direction of the Minister.

(iv) Incorporating the General Principles and Health Care Principle in the Act - The General Principles and Health Care Principle apply to all decision makers when exercising their powers and functions under the Act. The Act also goes further and extends its application to the community, which is 'encouraged to apply and promote' the General Principles (s. 11(3)).

(v) Establishing the Community Visitor Program[15] - Community visitors interact with residents at visitable sites such as hostels, supported accommodation and mental health units and are able to accept resident complaints and make enquiries on their behalf. The role provides an additional measure for safeguarding the interests of vulnerable people with impaired decision-making capacity.

[14] In late 2009 the work of this Tribunal was transferred to the amalgamated Queensland Civil and Administrative Tribunal (QCAT). QCAT's guardianship jurisdiction is still derived under the *Guardianship and Administration Act 2000* (Qld).
[15] The Community Visitor Program (CVP) is administered by the Adult Guardian on behalf of the Department of Justice and Attorney-General. The CVP is not directly relevant to the Adult Guardian Client Profile Project.

The Honourable Mr Foley (then Attorney-General and Minister for the Arts) stated during the second reading of the *Guardianship and Administration Bill 1999*:

> *'I cannot think of a more important piece of law reform which this Parliament will undertake during the course of this term. This is a law reform which makes a difference. This is a law reform which represents a sea change in the way the substantive law and the procedural law deal with the rights and dignity of persons in our community who find themselves with an impaired decision-making capacity.'*[16]

The Queensland guardianship model benefited from the learnings of its interstate counterparts. It is also unique in establishing a separate systems advocacy function undertaken by the Public Advocate to promote the rights and interests of all adults with impaired decision-making capacity. In most other jurisdictions the role of independent advocate and systems advocate are combined. This leads to the risk of systems advocacy work being overtaken by competing guardianship priorities.

In recent years, the role of systems advocacy has come under debate in Queensland. The former Queensland Government decided in late 2009 (following the Weller Review) to amalgamate the Public Advocate and Adult Guardian roles.[17] The QLRC was tasked with putting this into effect as part of its second review into the guardianship laws.

However, in April 2012, the newly elected Queensland Government announced there was a need to maintain the Public Advocate as an independent statutory authority and increase the power and independence of the role.[18]

## Second guardianship review (2005-2010)

In October 2005, following five years of operation, the Queensland Government referred a new review of the guardianship legislation to the QLRC. This review was dealt with in two phases.

Phase 1 reported on aspects relating to the confidentiality provisions and was completed in June 2007.[19] This review culminated in May 2008 with legislative amendments introduced to enhance the openness and transparency of the guardianship system.

Phase 2 dealt with the remaining matters including the General Principles, and the scope, functions, powers and protections afforded by the legislation. This component was completed in September 2010 and a comprehensive 317 recommendations were made in the final report.[20] In particular, the review recommended:

- strengthening the human rights focus
- maximising individual choice and participation
- improving safeguards for adults with impaired decision-making capacity; and
- providing a simple and accessible guardianship system.

## Implementation of second wave of guardianship reforms – current status

In October 2011, the Bligh Government provided an initial response to the QLRC review, indicating levels of support for each recommendation.[21] A number of matters were then referred to the Health and Disabilities Parliamentary Committee in November 2011 for further consideration and public consultation.[22]

On 19 February 2012, the Queensland Parliament was dissolved due to the State election being called. The Health and Disabilities Parliamentary Committee ceased to exist and the review into the QLRC guardianship recommendations lapsed.

The Newman Government was subsequently elected in late March 2012. In May 2012, the Queensland Legislative Assembly established the Health and Community Services Committee, which retains the responsibilities held by the previous Health and Disabilities Parliamentary Committee.

[16] Queensland Parliament 2000, *Guardianship and Administration Bill 1999,* Second Reading, Hansard, 12 April 2000, p. 787.
[17] See Webbe, S. & Weller, P. 2008, A Public Interest Map: An Independent Review of Queensland Government Boards, Committees and Statutory Authorities, Part A Report, Brisbane; Webbe, S. & 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.
[18] Media Statement 23 April 2012, 'Public Advocate to have greater power and independence', Attorney-General and Minister for Justice, The Honourable Jarrod Bleijie.

[19] Queensland Law Reform Commission (QLRC) 2007, Public Justice, Private Lives: A New Approach to Confidentiality in the Guardianship System, Report No. 62, QLRC, Brisbane.
[20] Queensland Law Reform Commission (QLRC) 2010, A Review of Queensland's Guardianship Laws, Report No. 67, QLRC, Brisbane.
[21] Queensland Government 2011, Queensland Government initial response to Queensland Law Reform Commission's Report: A Review of Queensland's Guardianship Laws, Department of Justice and Attorney-General, Brisbane (see online at http://www.parliament.qld.gov.au/documents/tableOffice/TabledPapers/2011/5311T5556.pdf
[22] Further information is available online, including the terms of reference and process for the initial Parliamentary Committee inquiry, at http://www.parliament.qld.gov.au/work-of-committees/former-committees/HDC/inquiries/past-inquiries/QLRC-RoGL

At the time of finalising this research report, the current Queensland Government has not made any announcements in relation to the recommendations made by the 2010 QLRC guardianship review. QLRC recommendations that may be relevant to specific areas of this research are noted throughout the report.

# Human rights and social inclusion

Community attitudes toward people with disability have been influenced by the human rights movement and social justice platforms. The right to individual autonomy is an accepted fundamental right in a democratic society, although its application proves more difficult. Any legislation passed by Parliament, or programs or services administered by the Queensland Government, should adhere to the human rights instruments that have been ratified by Australia and to the human rights principles contained within those instruments.

There have been some positive advances for people with impaired decision-making capacity with the reforms to the guardianship legislation and social policy developments. The platform of human rights and the importance of the family or support network are integral elements to the *Guardianship and Administration Act 2000* (Qld):

> *'The Bill recognises the right of an adult with impaired capacity to be involved in decisions that affect the adult's life. It also enables members of an adult's support network to be involved in decision-making by and for the adult'.*[23]

Individual autonomy is expressed as a human right under Article 3 of the United Nations' *Universal Declaration of Human Rights* (1948)[24], and a civil right under Article 1 of the *International Covenant on Civil and Political Rights* (1966).[25] Other more recent and significant developments include the United Nations' *Principles for the Protection and Care of People with Mental Illness and for the Improvement of Mental Care* (1991) and the *Convention on the Rights of Persons with Disabilities* (2007).

## Principles for the Protection and Care of People with Mental Illness

The United Nations' *Principles for the Protection and Care of People with Mental Illness and for the Improvement of Mental Care* was adopted by the United Nations General Assembly in 1991.[26] The principles were endorsed by the Australian Government in 1992, including support for their adoption within Australian mental health legislation. The principles also contain relevant provisions relating to persons who lack legal capacity, and their entitlements to various protections. Of note is Principle 1 on fundamental freedoms and basic rights:

**Principle 1: Fundamental freedoms and basic rights**

- This principle provides for a fair hearing by an independent and impartial tribunal where it is proposed to appoint someone to make decisions on behalf of a person with mental illness who is believed to lack capacity. It also makes the point that the person should be entitled to representation by independent counsel, that decisions should be reviewed regularly, and that the person (or other interested persons) have the right to appeal any such decision.

**Convention on the Rights of Persons with Disabilities**

On 30 March 2007, the Australian Government signed the United Nations' *Convention on the Rights of Persons with Disabilities* (the Convention) and Australia ratified the Convention on 17 July 2008, with a reservation.[27]

The purpose of the *Convention on the Rights of Persons with Disabilities* 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'.

Subject to the reservation, both Australia and the State of Queensland have a duty to ensure that domestic laws conform to the obligations contained within the Convention. Of particular relevance to guardianship are:

- Article 3: General principles
- Article 12: Equal recognition before the law
- Article 16: Freedom from exploitation, violence and abuse
- Article 17: Protecting the integrity of the person
- Article 22: Respect for privacy

[23] *Guardianship and Administration Bill 1999*, Explanatory notes p. 2.
[24] Article 3: Everyone has the right to life, liberty and security of person.
[25] Article 1:
(1) All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development. […]
(3) The States Parties to the present Covenant[….]shall promote the realization of the right of self-determination, and shall respect that right, in conformity with the provisions of the Charter of the United Nations.

[26] Adopted by General Assembly Resolution 46/119 of 17 December 1991.
[27] Australia does not support being bound to stop the practice of forcibly medicating mentally ill persons.

Article 12 of the Convention, which concerns equal recognition before the law states, among other things:

- States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
- States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
- States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

On 21 August 2009, Australia ratified the Optional Protocol to the Convention without reservation. The Optional Protocol is a supporting agreement to the Convention, which allows its parties to recognise the competence of the Committee on the Rights of Persons with Disabilities to consider complaints from individuals.

The application of the Convention is continuing to unfold within the practice of guardianship in Queensland. For example, the recent 2010 QLRC guardianship review made recommendations concerning the refinement of the General Principles to better reflect the Convention.[28] Similarly, the Australian Guardianship and Administration Council (AGAC), the national forum for all guardianship bodies in Australia, reviewed its National Standards of Public Guardianship in late 2009 (see Appendix 2) to ensure consistency with the Convention (particularly Article 12).[29]

## Social policy developments

At the national and state level, there has been a concerted approach by governments to recognise the rights of people with disability in community life. The Australian Government has articulated a social inclusion agenda that encompasses the National Disability Strategy 2010-2020.[30] In Queensland, this strategy has been operationalised and adopted, with the launch of the 10-year plan for people with disability, *Absolutely everybody: enabling Queenslanders with a disability*, in October 2011.[31]

Both of these long-term plans are firmly aimed at entrenching the human rights principles outlined in the United Nations' *Convention on the Rights of Persons with Disabilities* and aim to improve the opportunities and participation of people with disability.

[28] The 2010 QLRC guardianship review made a number of recommendations relating to the General Principles. A key recommendation is that the General Principles reflect more closely the relevant articles of the United Nations' *Convention on the Rights of Persons with Disabilities* (Recs 4-1; 4-3; 4-5; and 4-6). There is also a recommendation that the General Principles apply to informal support networks (Rec 4-2).

[29] For more details about AGAC, see the website at www.agac.org.au

[30] Commonwealth of Australia 2011, *National Disability Strategy 2010-2020*, An initiative of the Council of Australian Governments, Commonwealth of Australia, Canberra.

[31] Queensland Government 2011, *Absolutely everybody: enabling Queenslanders with a disability*, Department of Communities (Disability and Community Care Services), Brisbane.

# Profiling the guardianship client population – the Adult Guardian Client Profile Project

The Office of the Public Advocate (OPA) embarked on this significant research exercise, in partnership with the Office of the Adult Guardian (OAG), to build an evidence base to better inform both the service delivery functions and statutory systems advocacy around guardianship in Queensland.

The Public Advocate was established under the *Guardianship and Administration Act 2000* (Qld) (the Act) to promote and protect the rights and interests of people with impaired decision-making capacity through systems advocacy. The functions of the Public Advocate are outlined in section 209 of the Act.

The Adult Guardian is also given authority by the *Guardianship and Administration Act 2000* (Qld) and has a wide range of functions including individual advocacy, appointment as state guardian of last resort, investigation, protection, promotion and education. The functions of this role are outlined in section 174 of the Act and can be summarised as follows:

- protecting adults with impaired decision-making capacity from abuse, neglect and exploitation
- investigating allegations of abuse, neglect and exploitation
- investigating complaints about the actions of attorneys, guardians and administrators
- acting as guardian, personal attorney or statutory health attorney of last resort where no family or friends are available or appropriate
- making representation to agencies to seek assistance
- informally mediating between attorneys, guardians and others
- providing education and advice regarding the *Guardianship and Administration Act 2000* and *Powers of Attorney Act 1998.*

As a last resort, the Adult Guardian can act as the guardian for adults with impaired decision-making capacity. The people represented by the Adult Guardian Client Profile Project are those who have the Adult Guardian appointed because the Queensland Civil and Administrative Tribunal has considered that there is no other appropriate person available for appointment.

This research exercise – the Adult Guardian Client Profile Project – has enabled the first comprehensive and independent analysis of guardianship clients and orders made to the Adult Guardian, since the inception of the role under the Act in 2000. The research is specifically about the significant State guardianship role held by the Adult Guardian under the *Guardianship and Administration Act 2000* (Qld). The project does not analyse the other functions or services provided by the office.[32]

For the OPA, this research and report contributed to the key result area 'Knowledge and Evidence' of the Office's *Systems Advocacy Framework 2010-2012*. This framework is the blueprint for the work of the OPA and recognises the importance of an evidence-based approach in fulfilling the role and functions of systems advocacy. It reflects the importance of ensuring that management approaches correlate with 'systemic assessment based on objective data', which was a key point raised during the course of the 2009 Weller Review into Queensland government boards, committees and statutory authorities.[33]

The report describes the approach taken for the Adult Guardian Client Profile Project (including its conceptual framework and the methodology) and provides an analysis of Adult Guardian clients and the nature of their guardianship.

The information is reported as follows:

| | |
|---|---|
| Part 1: | An overview of the conceptual framework for the project |
| Part 2: | An outline of the project objectives, scope, and methodology |
| Part 3: | Project analysis and findings in relation to guardianship demand; clients; and guardianship orders |
| Part 4: | Linkages and next steps |

[32] The *Powers of Attorney Act 1998* (Qld) and *Public Trustee Act 1978* (Qld), whilst also applicable legislation within the arena of guardianship, are not relevant to the purpose and analysis undertaken for the Adult Guardian Client Profile Project. The statutory health attorney and enduring power of attorney roles of the Adult Guardian are not relevant to the scope of this project.

[33] See Webbe, S. & Weller, P. 2008, A Public Interest Map: An Independent Review of Queensland Government Boards, Committees and Statutory Authorities, Part A Report, Brisbane; Webbe, S. & 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.

# Part 1: Conceptual framework

## Legislative provisions

The *Guardianship and Administration Act 2000* (Qld) (the Act) is a comprehensive piece of legislation relating to the appointment of guardians to manage the personal and financial affairs of persons with impaired decision-making capacity. The following areas of the Act are relevant to the Adult Guardian Client Profile Project:

- the key premises of the guardianship legislation
- definition of impaired decision-making capacity
- an independent and specialised tribunal to make decisions about capacity and need for a guardian
- appointment of a guardian
- appointment of the Adult Guardian
- personal matter decisions
- interim orders
- review of orders
- restrictive practice matters.

Sections from the *Guardianship and Administration Act 2000* (Qld) that are relevant to this project are outlined or referenced throughout the report however the official Act should be consulted for a full interpretation and understanding of the legislative requirements.[34]

## Key parameters of the guardianship legislation

The Act is based on a range of human rights principles articulated within sections 5 to 7 and the General Principles (Schedule 1) and sets out a number of key premises, including:

- the 'presumption of capacity' – a legal principle that presumes people can make their own decisions.
- recognising the rights of adults with impaired decision-making capacity to be involved in decisions that affect their lives and the importance of maintaining the involvement of family and support networks in decisions.
- balancing 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 notion that intervention should be the last resort and, where it is required, the least intrusive by ensuring that least restrictive alternatives are pursued.

Further, the Act acknowledges that:

- An adult's right to make decisions is fundamental to the adult's inherent dignity.
- The right to make decisions includes the right to make decisions that others may not agree with.
- The capacity of an adult with impaired capacity to make decisions may differ according to the nature and extent of the impairment, the type of decision to be made, and the support available from members of the adult's existing support network.
- The right of an adult with impaired capacity to make decisions should be restricted, and interfered with, to the least possible extent.

## Impaired decision-making capacity

Impaired decision-making capacity is the inability to follow through the process of reaching a decision and putting the decision into effect. There are three elements to making a decision including:

- understanding the nature and effect of the decision
- freely and voluntarily making a decision, and
- communicating the decision in some way.

If an adult is unable to carry out any part of this process for decision making, the adult is said to have impaired decision-making capacity.[35]

Impaired decision-making capacity may be related to, but not limited to, dementia, intellectual disability, acquired brain injury, or a mental illness. A person's inability to make decisions may be temporary, permanent, or could fluctuate over time.

[34] An electronic copy of the latest reprint of the legislation may be accessed from the Office of the Queensland Parliamentary Counsel website at http://www.legislation.qld.gov.au/Acts_SLs/Acts_SL.htm

[35] Queensland Civil and Administration Tribunal 2011, Guardianship for Adults Fact Sheet, Department of Justice and Attorney-General, viewed 3 November 2011, http://www.qcat.qld.gov.au/Publications/Guard_for_adults.pdf>.

An independent tribunal determines whether a person has impaired decision-making capacity relating to specific decisions. An adult may have impaired decision-making capacity for some types of decisions (e.g. financial decisions), but retain capacity to make other decisions (e.g. personal or health care decisions).[36]

# Independent and specialised tribunal

Since the implementation of significant reforms to the Queensland guardianship system in 2000, an independent and specialised tribunal, which is also accessible and informal, has been in place to make appointments, directions and reviews. If the tribunal is satisfied that an adult does not have capacity to make some types of decisions (based on medical and other evidence), it may appoint a specific guardian/s to make decisions on behalf of the adult.

Until late 2009, the Guardianship and Administration Tribunal (GAAT) was the responsible tribunal under the Act. In late 2009, the Queensland Civil and Administrative Tribunal (QCAT) was established under the *Queensland Civil and Administrative Tribunal Act 2009* as a central tribunal for a wide range of civil and administrative matters. This legislation amalgamated 18 tribunals and 23 jurisdictions into one tribunal.[37] This included the responsibility for dealing with guardianship matters, which is overseen by the QCAT Human Rights Division. QCAT's guardianship jurisdiction is still derived from the *Guardianship and Administration Act 2000* (Qld).

# Appointment of a guardian - substitute decision-makers

Section 9 of the Act recognises several types of 'substitute decision-makers' for adults with impaired decision-making capacity. These include:

- informal arrangements that do not require legal intervention in order to give them decision-making authority (i.e. a person's established support network of family or friends);
- existing relationships given automatic recognition by the law that permit a person to make health care decisions only (i.e. a statutory health attorney); and
- formal arrangements that are either based on formal legal appointments made by the adult before they were deemed to demonstrate incapacity (e.g. enduring power of attorney or advance health directive), or by appointment of the court or tribunal after a person has been deemed to demonstrate incapacity (formal guardian or administrator).

The tribunal may appoint a guardian for a personal matter for an adult if the tribunal is satisfied:

- the adult has impaired capacity for the matter, and
- there is a need for a decision in relation to the matter or the adult is likely to do something in relation to the matter that involves, or is likely to involve, unreasonable risk to the adult's health, welfare or property, and
- without an appointment the adult's needs will not be adequately met, or the adult's interests will not be adequately protected.

An appointed guardian must be at least 18 years of age and cannot be a health provider or paid carer. There are a range of eligibility provisions provided under section 15 of the Act to ensure an appropriate and competent guardian is appointed.

One of the options to fulfil the role of a legal guardian for a person who has been found by the Tribunal to have impaired decision-making capacity is to appoint the 'Adult Guardian' (s. 174(2)(e)). The Act explicitly states that, the tribunal may appoint the Adult Guardian as guardian for a matter only if there is no other appropriate person available for appointment for the matter (s. 14(2)).

# Personal matters

A guardian may make decisions for personal matters only. A personal matter is defined in Part 2 (Schedule 2) of the Act. It includes, for example, decisions about: accommodation or place of residence, support services, certain restrictive practice matters, general health care matters, or other day-to-day issues.[38]

A guardian is not permitted to make decisions about financial or property matters (see Administration order), special health care (e.g. sterilisation or tissue donation) or special personal matters (e.g. making or revoking a will, consenting to marriage or relinquishing a child).

If an adult is able to communicate their views, a guardian should consider them when making a decision.[39]

[36] Queensland Law Reform Commission (QLRC) 2010, *A Review of Queensland's Guardianship Laws, Report Volume 1*, QLRC, Brisbane.
[37] Queensland Civil and Administration Tribunal 2011, Department of Justice and Attorney-General, viewed 30 June 2011, <http://www.qcat.qld.gov.au/about-qcat.htm>.
[38] The 2010 QLRC guardianship review included a recommendation to expand the meaning of 'personal matter' to encompass contact/access visits and advocacy relating to the adult's care and welfare (Recommendation 6-2).
[39] Queensland Civil and Administration Tribunal 2011, Guardianship for Adults Matters, Department of Justice and Attorney-General, viewed 3 November 2011, <http://www.qcat.qld.gov.au/guardianship-for-adults-matters.htm>.

# Administration order

An administration order is put in place to assist and protect adults with impaired decision-making capacity in making certain financial and legal decisions. An administrator appointed by the tribunal may be a private administrator or the Public Trustee. The Adult Guardian is not authorised to act as an administrator.

Generally, the types of decisions that administrators have authority to make on behalf of the adult include:

- buying or selling property
- maintaining property
- paying bills
- making business decisions
- managing investments

# Adult Guardian appointments

People who have the Adult Guardian appointed as their guardian are generally among the most vulnerable adults with impaired decision-making capacity. The appointment of a guardian is made because the person has impaired decision-making capacity and, without an appointment, the person's needs will not be adequately met or their interests will not be adequately protected (s. 12).

An important caveat to appointing the Adult Guardian is that it is 'the last resort' option. The tribunal must first consider all other options, and only if there is no 'other appropriate person' from the person's family and support network available or eligible to be guardian, may the Adult Guardian be appointed.

When making decisions on behalf of an adult with impaired decision-making capacity, the primary concern of the Adult Guardian is the adult's care and protection. In some cases, this means the decision of the Adult Guardian may override the adult's wishes. Before making a decision, the Adult Guardian will consider the adult's views and wishes, the opinions of family members, friends or other people who support the adult and the General Principles, Health Care Principle and other principles outlined in the Act.[40]

The Adult Guardian is not permitted to make decisions about financial, property or special health care matters (e.g. sterilisation or pregnancy termination). The Adult Guardian is not permitted to act as an adult's personal carer, case manager or coordinator and is not able to make referrals to services or provide legal advice. If the adult already has a guardian or attorney acting on their behalf, the Adult Guardian is not authorised to intervene, unless there is evidence of inappropriate behaviour.[41]

# Review of appointment orders

In line with human rights principles and the requirements for natural justice, a review mechanism for guardianship appointments is an essential component of the legislation. The right to review by an independent and impartial body is emphasised under the *Principles for the Protection and Care of People with Mental Illness* and the *Convention on the Rights of Persons with Disabilities.*

The Act provides for periodic review of appointment orders at least every five years or in accordance with the order (s. 28).[42] Alternatively, under section 29, a review can be sought at any time upon the initiation of the following parties:

- the tribunal
- the adult
- an interested person.

Following a review of an appointment order, the tribunal may:

- revoke the order
- continue the order, or
- change the order (includes changing the terms[43] of the appointment; or removing an appointee; or making a new appointment (ss. 31-31).

Of note, the tribunal must revoke the guardianship order unless it is satisfied that it would make an appointment if a new application for an appointment was made (s. 31(2)).

[40] Office of the Adult Guardian 2010, *Making Decisions About an Adult's Care*, Department of Justice and Attorney-General, Viewed 3 November 2011, <http://www.justice.qld.gov.au/justice-services/guardianship/adult-guardian/role-of-the-adult-guardian>.

[41] Office of the Adult Guardian 2010, *Making Decisions about an Adult's Care*, Department of Justice and Attorney-General, Viewed 3 November 2011, <http://www.justice.qld.gov.au/justice-services/guardianship/adult-guardian/role-of-the-adult-guardian>.

[42] Note: separate review provisions apply in the case of restrictive practices.

[43] Under the Act, the definition of 'term' includes 'condition, limitation and instruction' (Schedule 4).

## Interim orders

The tribunal has authority under the legislation to make interim orders where urgent action is warranted for a person with impaired decision-making capacity (s. 129). An interim order can be made without a hearing or complying with procedural requirements (such as advising parties under section s. 118).

Interim orders are made where the tribunal is satisfied on reasonable grounds there is an immediate risk of harm to health, welfare or property of the adult concerned (including because of the risk of abuse, exploitation, neglect of, or self neglect by the adult). 'These orders are only issued in accordance with stringent guidelines and a strict set of criteria. The risk needs to be immediate and the Tribunal must be satisfied on the balance of probabilities that harm would result'.[44]

Interim orders can not be made to consent to matters categorised as 'special health care matters' under Schedule 2 (including for example, sterilisation or electroconvulsive therapy).

Interim orders can only be made by the President, Deputy President, a legal member or the Registrar of the tribunal. Originally, under the Act, interim orders were allowed for a maximum period of 28 days. This was later amended in 2003 to a maximum of six months (including renewals).[45] In 2007, the maximum period for interim orders was reduced again to the current three month period. The amendment also introduced the power for the tribunal to renew the interim order in exceptional circumstances. The related explanatory notes state that 'a reduction in the period of time for an interim order is consistent with the least restrictive principle of the Act'.[46]

A renewal of an interim order is permitted under the Act, however, only where the Tribunal is satisfied there are 'exceptional circumstances' justifying the renewal (s. 129(6)).

## Restrictive practices

Restrictive practices refer to the use of 'restraints' in circumstances where a person exhibits 'challenging behaviour' that causes or has the potential to cause serious harm to themselves or others. A restrictive practice generally involves an infringement on human rights and therefore must be subject to strict provisions. Significant reforms in this area occurred in Queensland in 2008 following an in-depth review into the issues by the Honourable Justice Bill Carter QC (commonly known as the Carter Report).[47]

In 2008, the *Disability Services Act 2006* (Qld) and the *Guardianship and Administration Act 2000* (Qld) were amended to improve the regulation and management of restrictive practices.[48] The overall aim of these reforms was 'to drive service improvements to reduce or eliminate the use of restrictive practices; promote positive behavioural support; reduce the incidence of 'challenging behaviour'; and improve the quality of life for adults with an intellectual or cognitive disability'.[49] The amendments were phased in and full implementation occurred in April 2011.

The restrictive practices legislation applies only to adults with an intellectual or cognitive disability who access disability services from a 'funded service provider' as defined by the *Disability Services Act 2006* (Qld). The types of restrictive practices covered by the legislation are:

- containment
- seclusion
- chemical restraint
- mechanical restraint
- physical restraint
- restricting access.

Under the Act, the Adult Guardian may be appointed as a guardian for a restrictive practice matter (as may others). The Adult Guardian may also be required to approve short term use for restrictive practices that involve containment or seclusion; as well as chemical, mechanical or physical restraints or restricting access, where they are used in conjunction with containment and/or seclusion.

*The Disability Services Act 2006* (Qld) is currently under review by the Department of Communities, Child Safety and Disability Services (formerly Department of Communities). The responsible Minister is required under section 233 of the *Disability Services Act 2006* (Qld) to undertake a review after the end of five years of its commencement (i.e. after 1 July 2011).

In October 2010, the Department decided to review the legislation in two stages, with first priority given to the provisions that cover the use of restrictive practices in the *Disability Services Act 2006* (Qld) and the *Guardianship and Administration Act 2000* (Qld).

[44] See Queensland Guardianship and Administration Tribunal Presidential Direction No 3 of 2007, Interim orders.
[45] *Guardianship and Administration Act and Other Amendments Act 2003*.
[46] *Justice and Other Legislation Amendment Bill 2007*, Explanatory Notes, p. 19.
[47] The Hon WJ Carter QC 2006, *Challenging Behaviour and Disability: A Targeted Response — Report to Honourable Warren Pitt MP Minister for Communities Disability Services and Seniors*, Brisbane (see paper tabled in Parliament at http://www.parliament.qld.gov.au/documents/tableoffice/tabledpapers/2007/tp1428-2007.pdf )
[48] The amendments inserted Part 10A of the *Disability Services Act 2006* and Chapter 5B of the *Guardianship and Administration Act 2000*, which commenced 1 July 2008.
[49] *Disability Services and Other Legislation Amendment Bill 2008*, Explanatory Notes, p. 1.

# Key conceptual themes

The combination of social and legal policy reforms, legislative developments and human rights principles, has influenced the intention, purpose, framework and desired outcomes of the guardianship system in Queensland.

The key themes arising from these developments have shaped the context or lens against which the research findings have been considered, including:

- a presumption of capacity for the adult
- the intention of guardianship being of last resort
- the protection of rights, civil liberties and autonomy
- guardianship should apply the least restrictive and least intrusive alternative in all circumstances
- guardianship should maintain existing family relationships and support networks
- guardianship should maximise social participation and social inclusion
- decisions made under guardianship should do no harm or cause further exclusion or disadvantage
- the application of the General Principles and Health Care Principle by decision-makers and the community
- the guardianship regime is firmly based on human rights principles and conventions.

# Part 2: Overview of objectives and methodology

Prior to undertaking this project, there were large knowledge gaps in relation to Queenslanders who are subject to a guardianship order made to the Adult Guardian. Little was known about the characteristics and circumstances of this group of people. Previous reporting was constrained by a reliance on anecdotal information and relatively unsophisticated statistical data.

The Adult Guardian Client Profile Project was a joint initiative, sponsored by the Office of the Adult Guardian (OAG) and independently managed and conducted by the Office of the Public Advocate (OPA). This is the first systematic analysis of Adult Guardian clients (i.e. those persons under State guardianship) and is based on records available over the 10-year period 2000 to 2010. The methodological approach, which is summarised below, is the first of its kind in Australia.

The research aims to provide a better understanding of the composition of the Adult Guardian client population (a profile) and the needs and disadvantages faced by persons with impaired decision-making capacity.

This significant research also demonstrates the benefits and possibilities of information-sharing between agencies with shared clients and is of interest to guardianship jurisdictions in other states and territories.

## Objectives

The primary objective of this research was to develop an evidence base to support the work of the Adult Guardian and identify issues of importance for systems advocacy in relation to people with impaired decision-making capacity. More specifically, the research sought to:

- establish a demographic profile of people subject to a guardianship order made to the Adult Guardian over the period 2000-2010;
- describe the composition and circumstances of the Adult Guardian client population;
- outline trends in guardianship in Queensland, including projected growth and the administrative aspects of guardianship orders; and
- illuminate hidden or emerging issues in the Adult Guardian client base, family environments and service systems.

## Scope

The Adult Guardian Client Profile Project is based on Queenslanders with impaired decision-making capacity who have been subject to a guardianship order made to the Adult Guardian. The time span for the project is the 10-year period from 2000 (when the *Guardianship and Administration Act 2000* (Qld) (the Act) commenced) to 2010.

Other types of guardianship, for example, the appointment of a family member as a private guardian, are outside the scope of the research. Functions or services performed by the Adult Guardian that do not relate to the role of appointed state guardian are also out of scope. The project is not a review or evaluation of the OAG or the Queensland guardianship system.

## Project outcomes

The findings presented in this report provide an evidence base for decision-making and a platform to improve and maximise client outcomes. This will assist the Adult Guardian to better identify and meet client needs, undertake business planning, allocate resources, implement risk mitigation and determine priorities.

The Office of the Public Advocate will use the findings to support an evidence-based approach to systems issues relating to the legal intervention of guardianship. The Office hopes the evidence compiled for this research will generate debate about how best to promote inclusive and sustainable policies, programs and practices that improve life-outcomes for people subject to a guardianship order made to the Adult Guardian.

The Adult Guardian Client Profile Project may also assist the Queensland Government and, more specifically, the Department of Justice and Attorney-General with strategic planning, resource allocation, service delivery planning and reducing crisis interventions. The findings support risk mitigation activities by illuminating the current environment as an early alert in identifying emerging and critical issues to the Department and Government.

# Methodology

The research objectives and parameters were both quantitative and qualitative in nature. The primary research for the Adult Guardian Client Profile Project involved the collation and detailed examination of key data sources:

1. The Adult Guardian client database is derived from the Adult Guardian System. The client information system records broad information on Adult Guardian clients. Approximately 21,300 client records were extracted from the OAG initial client information system for the project period 2000-10. Data cleaning and the elimination of duplicates reduced this figure to 6,684 individual client records. After excluding records for services other than guardianship, a database was created of unique clients who had been subject to a guardianship order made to the Adult Guardian as at 31 October 2010. The Adult Guardian client database used for this project represents 45% of the total clients of the OAG.[50] (n=2,978)

2. A shared client database that matched client records from the Adult Guardian client database with the 2008-09 Disability Services National Minimum Data Set data (DS NMDS) managed by the then Department of Communities.[51] Matching these two data sets expanded this analysis to include DS NMDS variables. While not all Adult Guardian clients were recipients of specialist disability services, the sample of shared clients was, nonetheless, determined to be representative of the broader Adult Guardian client base for age profile (when limited to clients under 65 years of age), gender, case active status and time of entry into the guardianship system. The shared client database was not representative of the overall population of guardianship clients because matched clients were by definition limited to those who were prioritised for services by the then Department of Communities. This meant that matched clients had a higher degree of disability and hence a greater need for assistance. (n=978)

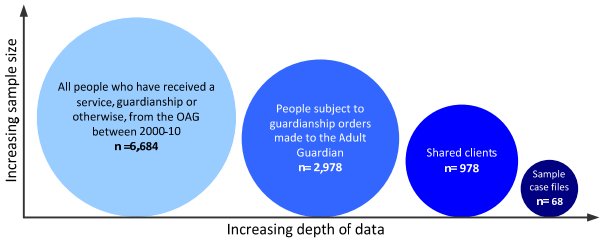
3. The Adult Guardian client sample case files provided additional rich information from client case files held by the OAG. This data set was representative of the guardianship client population for age profile, gender, case active status and time of entry into the guardianship system. (n=68)

Together, these data sources contributed to building a reliable evidence base to develop an understanding of the characteristics and needs of Adult Guardian clients and the administrative aspects relating to guardianship orders made to the Adult Guardian.

There were some constraints in the ability to analyse certain issues due to the nature of the data sources. For example, the profile of Aboriginal and Torres Strait Islander Queenslanders subject to a guardianship order made to the Adult Guardian was largely based on the shared client database, as there was no Indigenous identifier in the Adult Guardian database, and because of the small number (n=4) of Aboriginal and Torres Strait Islander clients in the sample case files. This meant that some information about guardianship orders was unable to be reported on, such as duration of order and the number of multiple orders for Aboriginal and Torres Strait Islanders. The figure derived from the shared client data should also be used with caution given that it is not representative of the broader client population.

Figure 1 presents a diagrammatic representation of the relationship between the sample size of each data source and the depth of data provided.

***Figure 1*** **The relationship between size of sample and depth of data (not to scale)**




The research findings were also subjected to a final validation process involving an OAG workshop in April 2012. The OAG workshop was attended by the Acting Adult Guardian, five key senior OAG officers from Brisbane and by OPA staff.

The views of officers who are immersed in the operational aspects of guardianship are extremely important. Overall, the officers' experiences supported the findings from the research. Where relevant, supplementary feedback raised through this process is described in the report.

This report presents evidence from a range of data sources. To allow comparison between these sources, national or otherwise established standards of measurement have been used wherever possible. This report identifies whenever there was not an established framework, or where none were considered suitable. In these instances, the rationale that was used to categorise variables is described.

Explanatory footnotes are provided to clarify assumptions and limitations of the data throughout the report. Operational definitions were adopted from related data sources or research where possible. Where no definitions existed, or where existing definitions were not appropriate, new ones were developed. These are identified and explained throughout the report where applicable.

[50] The remaining 55% represented individuals who had never been subject to a guardianship order but who had received another type of service provided by the OAG.
[51] As of April 2012, the Department of Communities has been renamed Department of Communities, Child Safety and Disability Services. For ease of reference, the former title is maintained in the report.

Important note: A list of definitions and terms used for this research project is provided in Appendix 3. A detailed description of the methodological approach; the strengths and limitations of each database; and how each database was created and used for analysis is provided in Appendix 4.

It is important that the analysis and findings reported for the project are interpreted and understood within the definitions provided and the methodological framework.

# Technical overview

The unit record files for the Adult Guardian client database, shared client database and sample case files were imported into SPSS (Statistical Package for Social Sciences), a computer application that enables the preparation, statistical analysis and modelling of data. Progressive data modelling and analysis activities, however, were undertaken using Microsoft Access and Excel.

The quantitative data from all sources was cleaned and prepared for analysis. A series of frequencies and cross-tabulations were undertaken to understand the data and investigate the relationship between variables.

# Privacy and confidentiality

Maintaining privacy and confidentiality throughout the research was of primary concern to OPA. A limited number of staff had access to client records and staff involved in the research project signed deeds of confidentiality and privacy. Under section 249 of the Act, staff employed within OPA are able to access confidential information when undertaking and performing statutory functions.[52]

Data linkage and data transmission between the OAG, OPA and the then Department of Communities was undertaken by written agreement and within the privacy, confidentiality and code of conduct arrangements applying to public service officers.

All client information in the Adult Guardian client database and the DS NMDS was de-identified using a Statistical Linkage Key (SLK). This constructed code provided a unique identifier for each client record while ensuring the privacy of client information was protected.

All databases are stored electronically on a secure network hosted by the Department of Justice and Attorney-General. This network complies with Queensland Government security and information technology standards.

The research findings in this report present summary findings only. Individual clients cannot be identified in any of the figures or tables presented in this report. On this basis, ethical clearance by a duly constituted ethics committee was not necessary. However, staff involved in the project considered the broader application of the *National Statement on Ethical Conduct in Research* and adhered to its values and ideals in undertaking this research.

# Partnership and innovation

This project represents the first systematic analysis of Adult Guardian clients since the inception of the Office. The project was made possible through a collaborative approach between OPA and OAG. In 2009, the Weller Review recognised the benefits that could be derived from such a shared knowledge base.[53]

The data linking process undertaken for this research also demonstrates the benefits and possibilities of information sharing between agencies with shared clients. The collaborative work with the then Department of Communities enabled the creation of unique evidence and delivery of new insights into the shared client base across the two human services agencies.

This research is of interest to guardianship jurisdictions, locally in other states and territories, and may also be of interest internationally. It is the first time research of this kind has been undertaken in Queensland, or nationally, as far as OPA can establish.

[52] See Part 4 of the *Guardianship and Administration Act 2000* (Qld).

[53] See Webbe, S. & Weller, P. 2008, A Public Interest Map: An Independent Review of Queensland Government Boards, Committees and Statutory Authorities, Part A Report, Brisbane; Webbe, S. & 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.

# Part 3: Adult Guardian Client Profile Project – analysis and findings

## Trends in guardianship

This research examined the growth in the number of adults subject to guardianship orders to provide insight in the trends in guardianship and sustainability of the system. In particular the following issues were analysed:

- Growth in new clients 2000-10
- Projected growth 2010-20

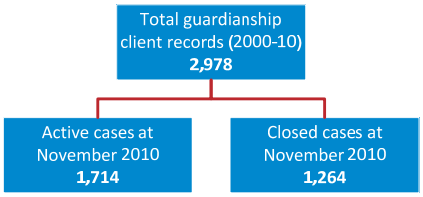
Since the implementation of the *Guardianship and Administration Act 2000* (Qld) in 2000 and up to 2010, the tribunal appointed the Adult Guardian for a total of 2,978 individual adults.

As Figure 2 shows, in late 2010, there were 1,714 active cases. Active cases were those Adult Guardian clients with guardianship orders in force at the time of data extraction (ie as at 30 December 2010). Active cases accounted for 58% of the total number of clients between 2000 and 2010.

Conversely, over this period, there were 1,264 (42%) closed cases. For the purpose of this research, a case was treated as closed where an Adult Guardian client had no guardianship orders in force at the time of the data extraction (i.e. as at 30 December 2010). Further analysis revealed that 70% (883 clients) were closed following a review of an order. In the remaining 30% (381 clients), the closed case was due to the death of the client.

Under the *Guardianship and Administration Act 2000* (Qld) (ss. 28-29), an appointment order can be revoked, either automatically, following a periodic review by the tribunal, or following a review initiated by the tribunal or other specified relevant person (e.g. the adult or an interested person for the adult). Under s. 26 (f), the appointment of the Adult Guardian ends automatically if the client dies.

***Figure 2*** **Adult Guardian clients cases 2000–10**




Source: Adult Guardian client database, n=2,978.

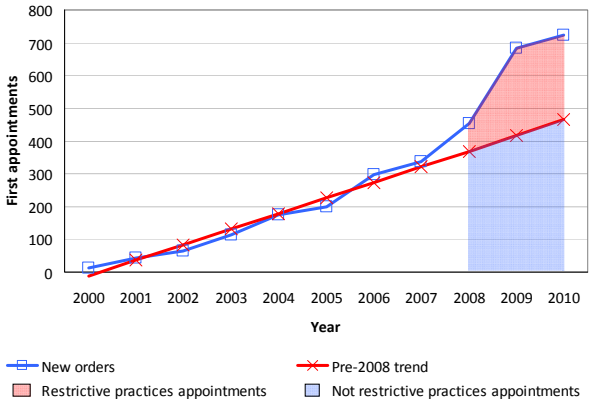
## Growth in new clients 2000–10

Over the 10-year period examined, the number of new clients entering guardianship for the first time per year increased from 13 people during 2000 to an estimated 722 during 2010 (see Figure 3).

The number of new guardianship clients increased at a constant rate between 2000 and 2007 (Figure 3). In 2008, there was a marked increase in people entering the guardianship system. This corresponds to the influx of people subject to restrictive practices as a result of the introduction of amendments to the *Disability Services Act 2006* (Qld) and *Guardianship and Administration Act 2000* (Qld) in relation to the use of restrictive practices, which came into effect in 2008.[54] The rate of new guardianship clients entering the system is expected to return to the pre-2008 rate now that the existing restrictive practices clients have entered the system.

Amendments to the *Guardianship and Administration Act 2000* introduced in 2008 require the Adult Guardian to consent to the positive behaviour support plans for individuals for whom it acts as guardian for a restrictive practice matter, for physical, mechanical or chemical restraint. This includes the initial positive behaviour support plan and revised plans resulting from annual reviews of the use of restrictive practices.

***Figure 3*** **Growth in new Adult Guardian clients 2000-10**



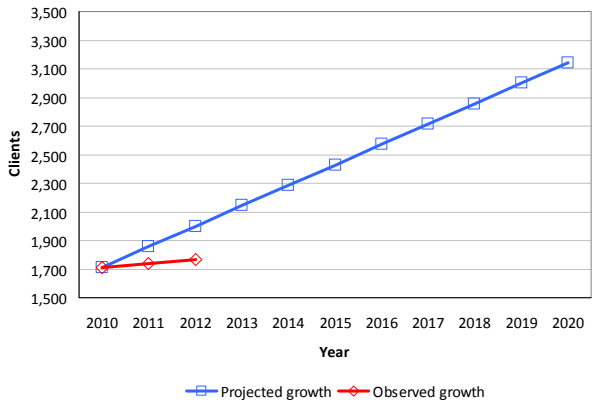

Source: Adult Guardian client database, n=2,978.
Notes: The number of new guardianship clients in 2010 was extrapolated using the ten months of first-time appointment data available for 2010. The number of new clients is calculated based on the date of first appointment.

[54] *Disability Services Act 2006* (Qld), Use of Restrictive Practices (Part 10A) and *Guardianship and Administration Act 2000* (Qld), Restrictive Practices (Chapter 5B).

# Projected growth of the guardianship client population

Based on the trend observed from 2000 to 2010, the size of the guardianship client population was projected to grow to almost 3,200 by 2020 (Figure 4). Supplementary data provided by the OAG in mid 2012 showed this projection to be inaccurate. The model shown in Figure 4 predicts that the Adult Guardian client population would have grown to approximately 2,100 by May 2012. Instead, a figure provide by the OAG indicated that the number of active clients at this time was closer to 1,770.

***Figure 4*** **Projected growth in the adult guardianship population**




Source: Adult Guardian Client Database, n=2,978.
Note: The projected number of new clients was calculated from a linear regression using first-time appointment data from the Adult Guardian client database for 2000-2010. It assumes that there will be an annual rate of growth of new clients consistent with the pre-2008 trend and that guardianship appointments in relation to restrictive practice matters will not make a significant contribution beyond 2008-2009.

During the workshop with the Adult Guardian, it was identified that the OAG was taking some steps toward instigating more active review processes to identify cases where revocation of guardianship orders might be appropriate. The results of this more active review process may account for some of the observed differences between the actual number of Adult Guardian clients in 2012, compared to the previous projections, as depicted in Figure 4.

While the initial projected growth rate in guardianship clients raised urgent questions about the sustainability of the guardianship system over the longer term, the more recent observations indicate that stress on the system due to increased demand maybe less than previously anticipated.

While the initial projected growth rate raised questions about the sustainability of the guardianship system over the longer term, the more recent observations suggest growth may be slower than anticipated. The Office of the Public Advocate will continue to monitor trends in the overall level of guardianship.

# Who are the guardianship clients?

Analysis of the demographic attributes of Adult Guardian clients is important to inform an understanding of this vulnerable group of people and to develop appropriate policies and service responses. A profile of adults subject to a guardianship order made to the Adult Guardian was established to better understand their characteristics, circumstances and needs.

Methodological note:
This section discusses the age profile of OAG clients based on their age at entry. For guardianship clients, there is little variation between the age profile presented in this way and one based on the clients' age as the time of data extraction. Using age at entry negates the influence of a number of factors such as the duration of a client's guardianship, whether clients are now deceased and whether the client's guardianship status is currently active or closed.

## Age

Figure 5 show the age profile of Adult Guardian clients at the time of entry into guardianship. This profile displays three broad peaks corresponding to entry into guardianship in:

1. Early adulthood
2. Mid-life
3. Older age.

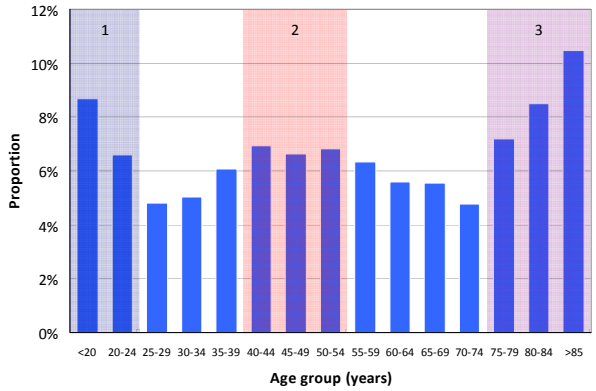
While this pattern holds true for clients entering guardianship, the age profile of the population at a given point in time will be influenced by guardianship trends over time. For example, the number of clients who remain subject to long term guardianship will cause this pattern to shift as they age.

The age profile of guardianship clients has not changed substantially over the 10 year period of this profile. Even the introduction of amendments to the *Disability Services Act 2006* (Qld) and the *Guardianship and Administration Act 2000* in relation to the use of restrictive practices has not impacted the age profile (data not shown).

This suggests that the profile of people who become subject to guardianship is remaining stable, despite the impact of changing legislation. This, coupled with the growth in guardianship numbers, suggests that over the past 10 years, QCAT have increased their throughput without any bias towards a particular age bracket.

The peak in the older age groups is primarily attributable to the increased prevalence of age-related conditions that 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 who may have previously provided care and support.

***Figure 5*** **Age profile of Adult Guardian clients**




Source: Adult Guardian client database, n=2,866 (112 missing values).
Note: Includes people subject to appointment orders and interim orders (i.e. both types of guardianship orders). Age is age at time of entry to guardianship.

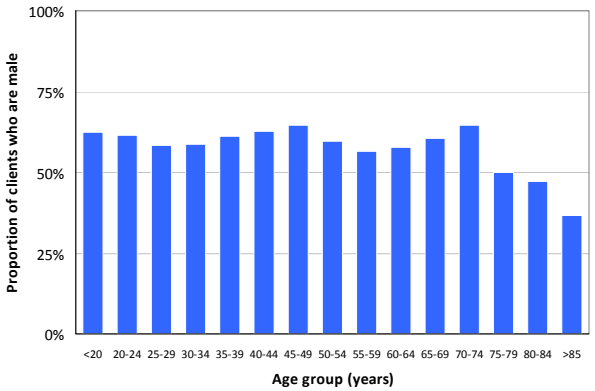
The three peaks identified in Figure 5 can be explained by three generalised set of circumstances:

- Young adults with life-long impaired decision-making capacity who become subject to guardianship for accommodation or service provision matters, who exhibit challenging behaviours or whose families are no longer able to provide support for decision-making.
- Middle aged people who may have acquired a disability later in life. Alternatively, this group may have had life-long disability and parent carers who are now unable to provide the same level of care due to their own old age.
- Older people with age related disability. These people may have no family to make decisions on their behalf.

# Gender

Overall, 55% of Adult Guardian clients were male. In the general population of adult Queenslanders, males represent almost exactly 50%. A more telling comparison can be made with the potential population in which males represent only 44%. This finding indicates that being male with impaired decision-making capacity significantly increases the likelihood of becoming subject to guardianship.

***Figure 6*** **Gender balance of guardianship clients**




Source: Adult Guardian client database, n=2,866 (Males, 1584, Females, 1282) (112 missing values).
Note: Age is age at time of entry to guardianship.

There are a number of factors that can contribute to the over-representation of males in the guardianship client population:

- Some conditions that can impair a person's decision-making capacity are more common in men than women. For example, both intellectual disability and schizophrenia are more common in men.
- Amongst shared clients, males are 2.5 times more likely to be subject to restrictive practices. As consent for many restrictive practice matters resulted in the appointment of the Adult Guardian, this may contribute to the gender balance.

The gender balance shifts dramatically for clients over the age of 74 years. Below this threshold, 61% of clients are male while above it, males represent only 42%.

The frequency of women in the older age groups is likely due to their greater life expectancy compared to men, and the associated prevalence of age related conditions resulting in impaired decision-making, such as dementia. Other factors such as women's greater tendency to be living with family may delay entry into guardianship.

## Country of birth

The analysis revealed a diverse geography in relation to the country of birth of shared clients however the overwhelming majority (94%) were born in Australia (Table 2).

***Table 2*** **Shared clients by geographic region of birth**

| Geographic region | Shared clients |
|---|---|
| Americas | 2 |
| Australia | 917 |
| North Africa and the Middle East | 4 |
| North East Asia | 1 |
| North West Europe | 15 |
| Oceania | 17 |
| South East Asia | 4 |
| South Eastern Europe | 2 |
| Southern and Central Asia | 2 |
| Sub-Saharan Africa | 1 |
| Unknown | 13 |
| Total | 978 |

Source: Shared client database (18-64 years) n = 978.
Note: There were 24 shared clients aged 18 to 64 years born in overseas countries where English is the main spoken language (Canada, 1, England 8, New Zealand 13, Scotland 1, South Africa 1).

Approximately 3% of shared clients (24 individuals) were born overseas in countries where English was not the main spoken language. In this report, people who were born in countries where a language other than English was the main spoken language are referred to as people from culturally and linguistically diverse (CALD) backgrounds.

While the percentage of shared clients from CALD backgrounds is about the same as the percentage of people from CALD backgrounds who accessed specialist disability services in 2008-09 (2.7%), it is about half the percentage of the total Queensland population, aged 18 to 64 years (7%).[55] [56] [57]

## Aboriginal and Torres Strait Islander clients

People from Aboriginal and Torres Strait Island backgrounds accounted for a much larger proportion (13%) of shared clients, than the proportion of Indigenous Queenslanders accessing specialist disability services (6%) or who are resident in Queensland (2.8%).[58] [59]

Furthermore, almost half (45%) of Aboriginal and Torres Strait Islander shared clients were younger than 30 years, compared to approximately 30% of non-Aboriginal and Torres Strait Islander clients.

This research recognises that a person's overall health and wellbeing results from a complex interplay of factors, and that the subject of Indigenous mental health and social and emotional wellbeing is an important and contested area in Australian public health policy.[60] [61] Nevertheless, a number of factors that may be contributing to the high proportions of Indigenous Australians amongst the shared client population, as well as their younger profile are identified below.

- The over-representation of young Indigenous Queenslanders in the child protection system may be a contributing factor to their higher incidence among shared clients as well as their younger age profile.[62] Young Indigenous people with a disability, who have been subject to child guardianship, may move into the adult guardianship system upon turning 18 years of age.
- Overall, there is a higher prevalence of disability and long-term health conditions amongst Indigenous Australians compared to the non-Indigenous population. In 2008, an estimated 8% of Indigenous Australians had a profound or severe core activity limitation, and the level of need for assistance among Indigenous Australians was more than twice as high as that among non-Indigenous Australians.[63] This indicates a greater proportion of the Indigenous population are likely to need or benefit from the provision of specialist disability services.

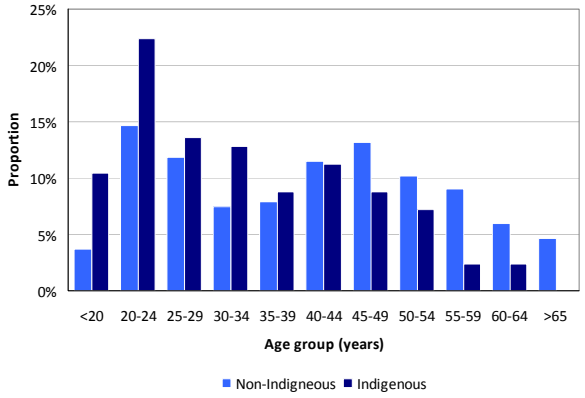
[55] Australian Institute of Health and Welfare (AIHW) 2011, *Disability Support Services 2008-09: Report on services provided under the Commonwealth State/Territory Disability Agreement and the National Disability Agreement*, Cat. No. DIS 58, Table A2.12, AIHW, Canberra.
[56] This figure includes people aged under 18 years.
[57] Australian Bureau of Statistics (ABS) 2006, *Census of Population and Housing*, Cat. No. 2068.0, ABS, Canberra.

[58] Australian Institute of Health and Welfare (AIHW) 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, AIHW, Canberra.
[59] Australian Bureau of Statistics (ABS) 2006, 2006 Census of Population and Housing, ABS, Canberra.
[60] For example, the Australian Institute of Health and Welfare recognises the interplay of socioeconomic characteristics, housing and transport, community capacity, behavioural factors and social and emotional wellbeing. Source: Australian Institute of Health and Welfare (AIHW) 2011, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander People: An Overview 2011,* Cat No. AIHW 42, AIHW, Canberra.
[61] Purdie, Nola, Pat Dudgeon and Roz Walker, 2010, *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice,* Department of Health and Ageing, Canberra.
[62] Australian Institute of Health and Welfare (AIHW) 2011, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander People: An Overview 2011,* Cat No. AIHW 42, AIHW, Canberra.
[63] Australian Institute of Health and Welfare (AIHW) 2011, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander People: An Overview 2011,* Cat No. AIHW 42, AIHW, Canberra.

- The negative impact of the poor physical and mental health of many people in the Aboriginal and Torres Strait Islander population is reflected in their much lower life expectancy compared to the rest of the Australian population. 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.[64]
- The rate of hospitalisation of Aboriginal and Torres Strait Islander people for mental health problems is almost twice as high as that for other Australians.[65] While this suggests there may be a higher rate of impaired decision making capacity amongst the Indigenous population, linked to mental health issues requiring hospitalisation, it also suggests hospitals and health care workers may have a role to play in facilitating access to Adult Guardianship services.

Further discussion of the complex interplay of factors that are likely to be contributing to the observed high proportion of Indigenous people among shared clients, including the identification of further research to help identify ways to redress this is provided in the Linkages and Next Steps section of this report.

***Figure 7*** **Age profile of Indigenous and Non-Indigenous shared clients**




Source: Shared client database n= 1012. (7 missing values)

# Geographic location

Analysis of the geographic distribution of guardianship clients was excluded from the scope of this project due to the available resources. However, some limited inferences can be made from the postcodes included in the shared client data.

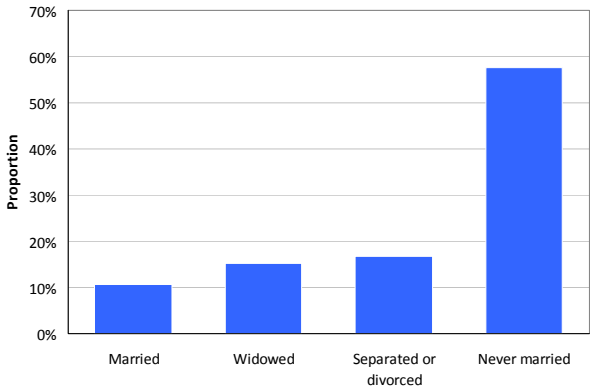
Nearly half of Adult Guardian shared clients (44%) live in or around the state's capital, Brisbane.[66] Beyond this, most clients clustered around coastal metropolitan areas.

The OAG workshop considered that there had been a steady increase in guardianship clients from the far north and northern regions in recent years following the opening of an additional regional office in Townsville in 2008.

# Marital status and children

Over half (58%) of guardianship clients had never been married, 15% were widowed, 17% were separated or divorced from their partner, and 11% were married (including de facto relationships) (Figure 8).

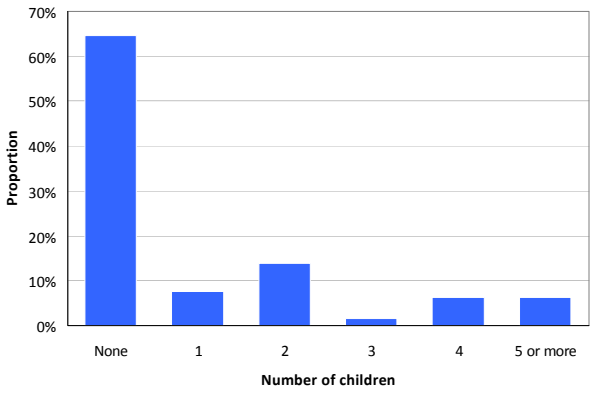
***Figure 8*** **Marital status of guardianship clients**




Source: Sample case files, n=66 (2 missing values).

Around two-thirds (65%) of clients did not have children, 8% had one child, 14% had two children, and 18% had more than two children.

***Figure 9*** **Number of children of guardianship clients**




Source: Sample case files, n=65 (3 missing values).

[64] Australian Bureau of Statistics (ABS) 2010, *Deaths, Australia,* Cat No. 3302.0, ABS, Canberra.
[65] Australian Institute of Health and Welfare (AIHW) 2011, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander People: An Overview 2011,* Cat No. AIHW 42, AIHW, Canberra.

[66] All regional geographic analysis conducted in this report was based on postcodes. Postcodes do not align precisely with Statistical Local Areas. Results reported are therefore approximations and don't represent exact counts.

## Living arrangements

Table 3 shows the living arrangements for guardianship clients compared to the estimated living arrangements of the general Queensland population.

***Table 3*** **Living arrangements**

| | Queensland population | Guardianship clients | Specialist disability clients |
|---|---|---|---|
| Lives alone | 9% | 22% | **13%** |
| Lives with family | 87% | 11% | **63%** |
| Lives with others | 4% | 68% | **24%** |

Source: Sample case files, n = 68 and ABS 2006 Census of Population and Housing.
Note: Queensland figures include data for all ages while Adult Guardian clients were limited to people aged 18 years and over.

In the general Queensland population, the vast majority of people live with family members (parents, children or their spouse or partner). While the same is often true for people accessing specialist disability services, there is a significant proportion (24%) living with others in either institutional settings or shared community accommodation.

The majority of guardianship clients do not live with their family. This is not unexpected given that the Adult Guardian is most often appointed for a person when there are no family or friends who are willing or able to serve as a substituted decision maker.

The high proportion of guardianship clients living with others is likely to result from the age distribution of guardianship clients. As guardianship clients tend to be older than either the general or specialist disability services client populations, they are more likely to require the support provided by facilities such as nursing homes.

The condition that has resulted in a person's impaired decision-making capacity may also influence the person's living arrangements in younger age groups. People with complex or terminal health conditions may require a level of support that cannot be provided in a family home. This can be seen in the significant proportion of the guardianship client population who reside in residential aged care or hospitals (see 'Accommodation type' for more detail).

The sample of case files examined client's living arrangements prior to and after the appointment of the Adult Guardian:

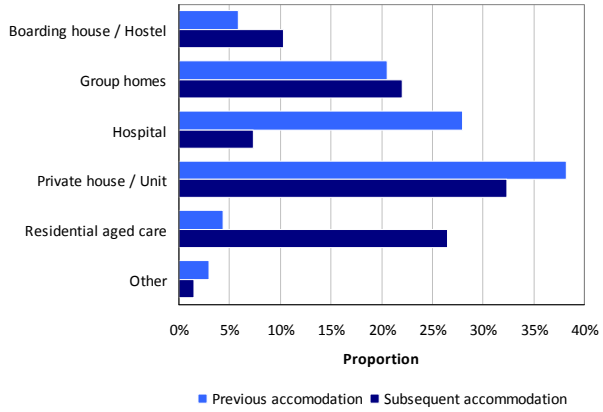
- Of those clients who were living alone, almost half of them transitioned to living with others after entering guardianship.
- Of those clients who were living with family, 63% transitioned to living with others.
- Of those clients who were living with others, the majority (76%) continued living with others.

These findings are consistent with one of the major conclusions of this research; that guardianship often functions as a facilitating agent for accommodation transitions for people with impaired decision-making capacity.

## Accommodation type

As with living arrangements, the sample of case files examined the type of accommodation used by clients prior to, and after, they became subject to guardianship orders. These results can be seen in Figure 10.

***Figure 10*** **Type of accommodation prior to, and after, becoming subject to a guardianship order**




Source: Sample of case files n = 68

Only 32% of guardianship clients live in private homes after entering guardianship. Most of the remainder of the population live in residential aged care (26%), group homes (22%) or boarding houses or hostels (10%). This result is not unexpected given that these types of accommodation provide support as part of the accommodation service and guardianship clients tend to have high levels of need for support.

Generally speaking, younger clients tend to live in private homes or group homes while older clients tend to live in residential aged care or hospitals.

There are some notable differences when comparing the profile of accommodation types used by clients prior to and after entering guardianship. Most notably, the proportions of clients living in hospitals and private homes decrease and the proportions living in residential aged care and boarding houses or hostels increase. These figures however, disguise substantial reciprocal movement between categories. There were an almost equal number of clients who moved from private homes to hospitals as vice versa. The same is true of group homes and private homes

As indicated below, many of these clients are also likely to have high and complex needs, perhaps beyond the capacity of families to provide.

# Disability types

Below is an examination of the Adult Guardian client data base, and the shared client data base to help understand the nature and prevalence of disability in the Adult Guardian population.

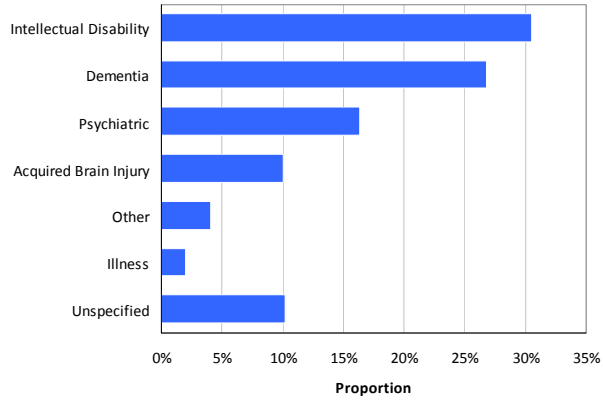
Understanding the prevalence and types of disability that guardianship clients have is important to more fully understand their situation, their need for support services, and their overall level of vulnerability and ability.

Quantifying and describing the nature of an individual disability is a complex undertaking. Within Australia there are a range of administrative, clinical and legal definitions of disability in use.

While the Office of the Adult Guardian routinely collects information on the impairments of its clients, it has not historically had a robust set of definitions to use in its collection. The profile of primary impairments in the Adult Guardian Client Database is shown below in Figure 11.

While the profile shown in Figure 11 represents the entire population of Adult Guardian clients, the impairment categories do not necessarily represent official diagnoses. In addition to the lack of robust definitions that would help ensure the categories are applied consistently, there are potential overlaps between categories. (e.g, the primary impairment category "illness" and other categories such as "dementia" and "acquired brain injury").

***Figure 11*** **Primary impairment of guardianship clients**



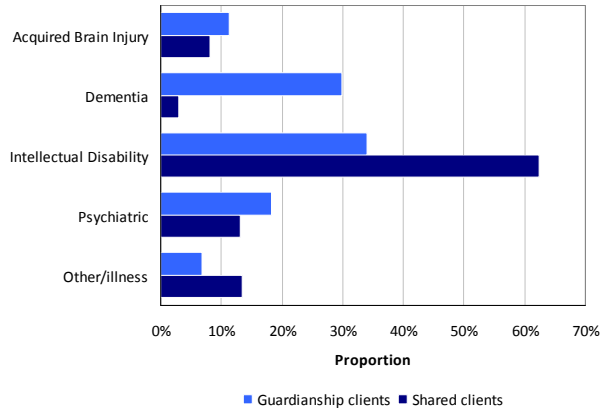

Source: Adult Guardian client database, n = 2,978.(There were 303 missing values where primary impairment was not specified).

Figure 11 shows that 31% of Adult Guardian clients have an intellectual disability, 27% have dementia, 16% have a primary impairment associated with a psychiatric condition and 10% have an acquired brain injury.

The prevalence and profile of disability types amongst shared clients was also examined and compared to the profile for the entire Adult Guardian population. The type and prevalence of disability amongst shared clients is biased and cannot be taken as indicative of the overall population of people subject to guardianship.[67]

The DS NMDS uses a system of twelve disability types. Under the DS NMDS a person's primary disability is the disability type that most clearly expresses the experience of disability by an individual. It is also the type of disability that causes the greatest challenge to the individual, i.e. the greatest overall difficulty in daily life. While there are some overlaps between the categories used in the DS NMDS, they are applied consistently using a robust set of definitions.

***Figure 12*** **Comparison of disability profiles in the shared client and guardianship populations.**[68]




Source: Adult Guardian client database n = 1718 and shared client database n = 978

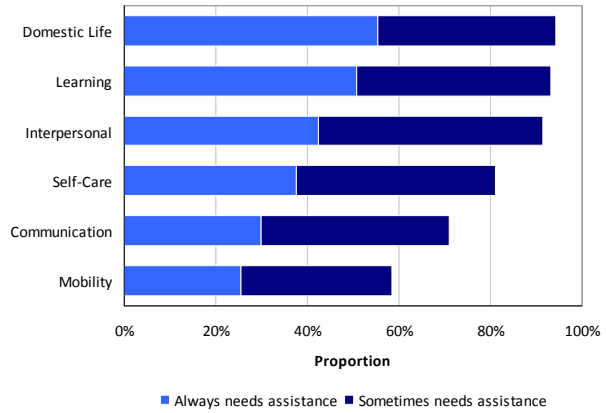
A notable difference in the comparison of the two data sets in Figure 12 is in the prevalence of intellectual disability and dementia. The differences in prevalence of intellectual disability and dementia/neurological disorders between the two datasets is most likely related to the younger age profile of the shared client data base (dementia is associated with older age cohorts) as well as its bias towards high needs clients in the shared client data (i.e. those who access specialist disability services).

[67] Due to the differences in classification systems, age profiles and level of need, the shared client data and adult guardian client database findings are not directly comparable.
[68] The guardianship population in this figure has been limited to those clients under the age of 65 years to improve comparability between the data sets.

## Support needs

Figure 13 presents the support needs of shared clients by broad activity. The term 'support need' reflects an individual's need for assistance or supervision with one of nine broad activities that are aligned with the broad activities used in the World Health Organisation's International Classification of Disability and Functioning.[69]

***Figure 13*** **Support needs of shared clients**




Source: Shared client database n = 1003 missing = 16

Almost all shared clients required some assistance with activities relating to the following areas: domestic life and tasks (94%), learning and applying knowledge, including making decisions (94%), and interpersonal interactions and relationships (92%).

Many clients also required assistance with other tasks such as self-care (82%) and communication (71%).

The large proportion of clients who 'sometimes' or 'always' require assistance with general interpersonal interactions (92%), which include the ability to make and keep friends, behave within accepted limits and deal with emotions, and communication (71%), suggests complex needs and vulnerability.

While comparative data is not provided, when compared to the overall DS NMDS client population, the shared client population has a higher prevalence of need for support in all categories except for mobility. This indicates that even within the high needs group of DS NMDS clients, the shared clients have a high need for support.

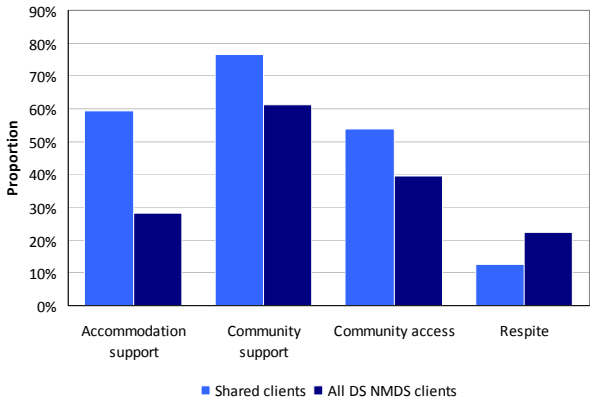
[69] See Appendix 5 for definition of level and categories of support needs

## Access to specialist disability services

The type and number of specialist disability services accessed by shared clients was also examined.[70]

Figure 14 shows the profile of access to specialist disability services under the DS NMDS. Shared clients most commonly access community support (78%), accommodation support (60%) and community access support (53%).

***Figure 14*** **Specialist disability services accessed by shared clients and the all DS NMDS clients.**




Source: Shared client database n = 1,019 and Australian Institute of Health and Welfare (AIHW) 2011, Disability Support Services 2008-09: Report on services provided under the Commonwealth State/Territory Disability Agreement and the National Disability Agreement, Cat. No. DIS 58, Table A2.12, AIHW, Canberra.

When comparing the shared client population to the overall DS NMDS client population, it can be seen that shared clients have a higher rate of access to all service types except respite. This can be best illustrated by examining the rate of multiple service access (MSA).

MSA is the average number of service types that were accessed by a group of clients. A higher MSA indicates that clients accessed a greater array of services and suggests that they also accessed a greater volume of service.[71] Given that services are delivered on a needs basis, it is also reasonable to assume that a higher rate or FMSA is generally commensurate with higher levels of need.

On average, shared clients accessed 2.0 service types each while the overall DS NMDS population accessed 1.5. This indicates a higher level of need for assistance in the shared client population than the general DS NMDS client population. Alternatively, this finding may indicate that being subject to guardianship increases access to specialist services.

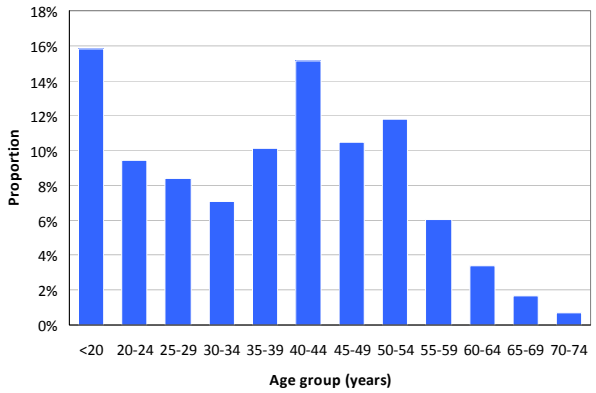
[70] See Appendix 5 for a description and list of all the elements of each service type

[71] It is impossible to determine the actual number of service events that a DS NMDS client accessed because this level of detail is not captured in the data set. Access to a service in this context indicates that a client accessed at least one instance of the service during the collection period.

# Application of restrictive practices

There were 297 (29%) shared clients who were subject to restrictive practices in 2008-09. The age profile of guardianship clients who were subjected to restrictive practices displayed two peaks. The first was in the under 20 year age group and the second in the 40-44 year age group.

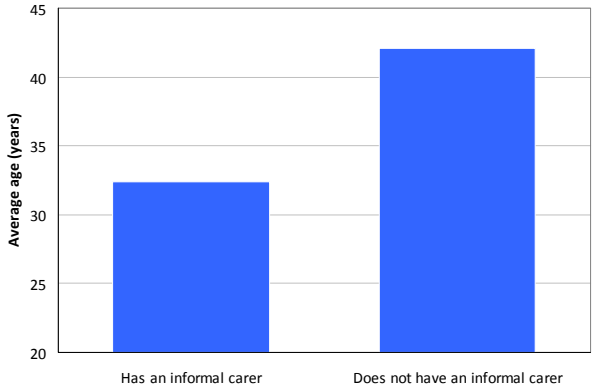
***Figure 15*** **Age profile of guardianship clients subject to restrictive practices.**




Source: shared client database n = 297
Note: Age is calculated based on age at entry into guardianship

The average age of shared clients subject to restrictive practices who had an informal carer was lower (average age of 30.6 years) than those who did not have an informal carer (average age 40 years) (Figure 16).

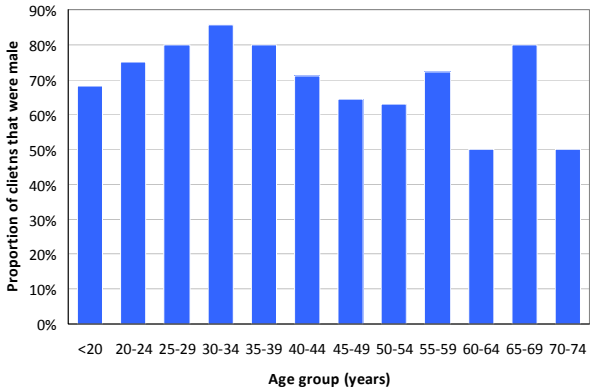
***Figure 16*** **Average age of shared clients subject to restrictive practices by presence of an informal carer**




Source: shared client database n = 295 (2 missing)

Shared clients subject to restrictive practices were more likely to be male across all age groups (Figure 17).

***Figure 17*** **Age profile of shared clients subject to restrictive practices who were male.**




Source: shared client database n = 297
Note: Age is calculated based on age at entry into guardianship

## Presence of an informal carer

An informal carer is someone who provides a significant amount of care and/or assistance to the person on a regular and sustained basis. Informal carers include people who receive no monetary assistance as well as those people who receive a pension or benefit in their caring role but does not include paid or volunteer carers.

There is growing recognition of the critical role that informal support networks including the work of informal carers, play in caring for people with disabilities, including through helping people to remain within the community.[72]

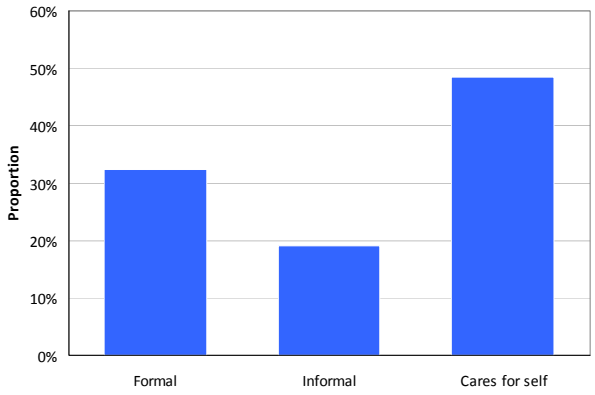
The absence of informal carers amongst a significant majority of Queensland adults with impaired decision making capacity who are subject to guardianship by the Adult Guardian, as outlined below, is therefore of interest. The lack of an informal carer may be a factor for adults with impaired decision making capacity entering into or remaining in formal state guardianship.

[72] Department of Families, Housing, Communities Services and Indigenous Australians (FaHCSIA), 2011, *National Carer Strategy*, 2011, Cat. No.11489.1106. FaHCSIA, Canberra.

## With informal carer

Only about one-third (32%) of shared clients had an informal carer. The sample case files indicate that in the overall guardianship client population, this figure is much lower (19%).

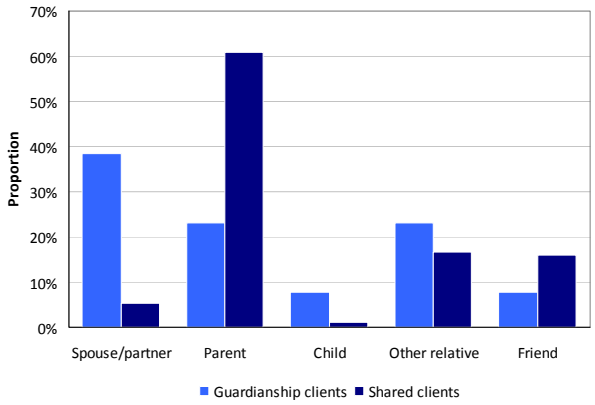
***Figure 18*** **Presence of carers in the guardianship client population**




Source: Sample of case files n = 68

It is difficult to make estimates of carer relationship or carer age from the sample case files given the small number of cases in which the client had an informal carer. For this reason, these results should be read with caution as they may be subject to significant statistical error.

***Figure 19*** **Relationship of informal carer to client**




Source: Sample of case files n = 13 and Shared client database n = 282

Almost one in five (38%) guardianship clients with an informal carer is cared for by their spouse or partner. This is markedly different than the profile seen amongst shared clients where the bulk of carers are parents. This is likely to be a result of the difference in age and disability type profile in the shared client population.

The figures for guardianship clients shown in Figure 20 can be explained by two factors:

- Many guardianship clients are too old to have parents who are able to provide care for them.
- Older guardianship clients may have acquired impaired decision-making capacity in later life. Because of their age, there is an increased likelihood of them having a spouse/partner or having children.

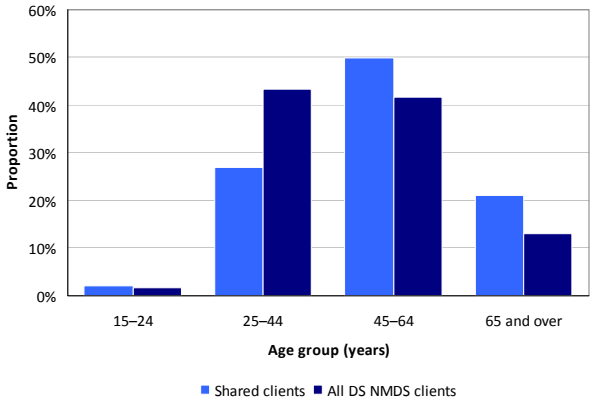
Around 79% of carers of shared clients were related to the client, with 62% of clients being cared for by parents. This contrasts with the sample of case files, which indicate that over 92% of informal carers were related to the client and only 23% of carers were parents.

It is worth noting that in both the shared client population and the guardianship client population more broadly, women account for almost 75% of all informal carers. This supports other sources of evidence that also suggest that there is a wide gender disparity amongst informal carers.[73]

Almost two in five (38%) informal carers of guardianship clients are aged 65 years and over and only 8% were aged under 35 years.

The age profile of carers for shared clients is notably higher that that of the overall DS NMDS client population. This is not surprising given that the age profile of the shared clients themselves is higher than that of the overall DS NMDS client population.

***Figure 20*** **Age of informal carer of shared clients**




Source: Shared client database n = 277. (28 missing) and Australian Institute of Health and Welfare (AIHW) 2011, Disability Support Services 2008-09: Report on services provided under the Commonwealth State/Territory Disability Agreement and the National Disability Agreement, Cat. No. DIS 58, Table A2.29, AIHW, Canberra.

[73] Australian Bureau of Statistics (ABS) 2011, *Caring in the Community, Australia, 2009,* Cat no 4436.0, ABS Canberra.

The analysis for this report revealed that 30% of the total number of shared clients who had an informal carer (90 clients) were aged less than 25 years. In 68% of these cases the carer was a parent.[74] This was not the case in the sample of case files where the average age of clients with informal carers was 65.8 years. Only three of the clients in the sample case files were aged less than 45 years with the youngest being 29 years of age.

The available information does not provide a complete insight into why these young shared clients are subject to guardianship when their parents provide informal care, however:

- Twenty four of these people were subject to restrictive practices and were required by the *Disability Services Act 2006* to be subject to guardianship orders.
- Additionally, almost 20% of informal carers of young shared clients who were not subject to restrictive practices did not provide assistance with core activities. This suggests that these carers may not be willing or able to provide the level of care needed by the recipient or that they require additional assistance. In this situation, a guardian may be necessary to make decisions about accessing the services necessary to meet the shared client's need for assistance.

This area may benefit from further investigation.

### Without informal carer

The majority (81%) of guardianship clients and the majority (70%) of shared clients had no informal carer. While the shared clients without an informal carer tended to be older than those who had an informal carer, the opposite was true in the sample of case files (Table 4).

***Table 4*** **Median age of shared clients and those clients in the sample of case files by presence of an informal carer**

| Data source | Has an informal carer | Does not have an informal carer |
|---|---|---|
| Shared clients | 31 years | 43 years |
| Sample case files | 68 years | 60 years |

While the age bias in the shared client data has been established, the age disparity in the presence of an informal carer cannot be explain with the available data. This may warrant further investigation.

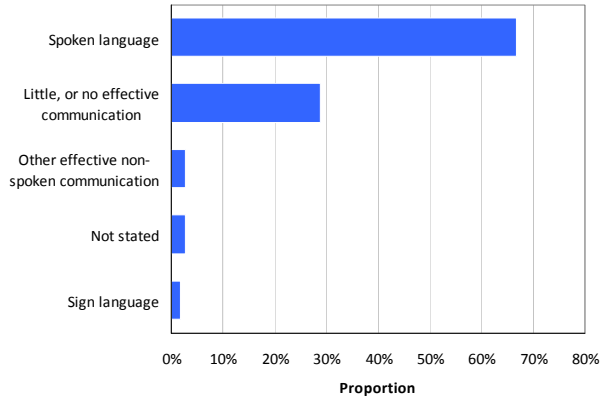
[74] The percentages quoted here differs slightly from the figures published in the *Office of the Public Advocate Annual Report 2010-2011* as the findings published there were preliminary.

## Communication

For the purposes of this report, the term communication is used to describe the method of communication most effectively used by an individual. Figure 21 shows that the majority (67%) of shared clients used spoken language as their most effective means of communication.

Nearly one-third (29%) have little or no effective communication while another 3% communicate through means other than the spoken word, such as gestures.

***Figure 21*** **Most effective communication method of shared clients**




Source: Shared client database n = 992 (27 missing)

In Queensland, the ability to communicate a decision is necessary to demonstrate decision-making capacity. It is therefore not unexpected that a sizeable proportion of guardianship clients would have little or no communication ability.

## Employment and income

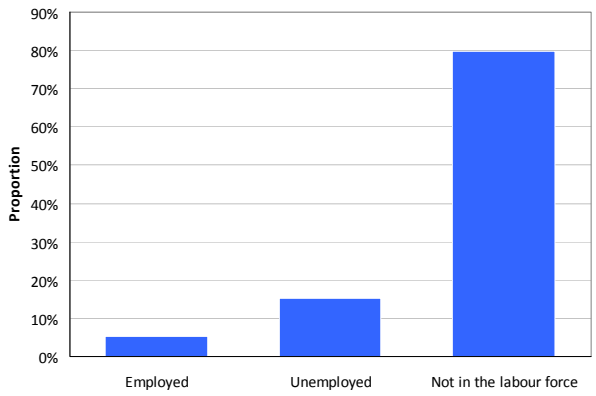
Employment is a meaningful day activity and plays an important role in economic security, social inclusion and health and wellbeing. Through the National Disability Strategy, for example, Australian national, state and local governments have recognised the positive contribution that suitable paid employment can make to the wellbeing of people with a disability through improved physical and mental health, a stronger sense of identity, increased social participation and contribution to the community.[75]

People with a disability can face a greater cost of living than other people because of additional expenses with transport, personal and health care, diet, communication requirements, social participation. Income from employment is therefore also important for financial independence and raises living standards.[76]

[75] Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) 2010, *National Disability Strategy 2010-2020,* Cat. No. 10754.1103. FaHCSIA, Canberra.
[76] Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) 2010, *National Disability Strategy 2010-2020,* Cat. No. 10754.1103. FaHCSIA, Canberra.

Overall, this research indicated a lower labour force participation rate for shared clients. Furthermore, the majority of the shared clients who were able to participate in the labour force were unemployed. Only 20% of shared clients of working age were in the labour force. Of these, three-quarters were unemployed (Figure 22).

***Figure 22*** **Proportions of the shared client population who are employed, unemployed and not in the labour force.**

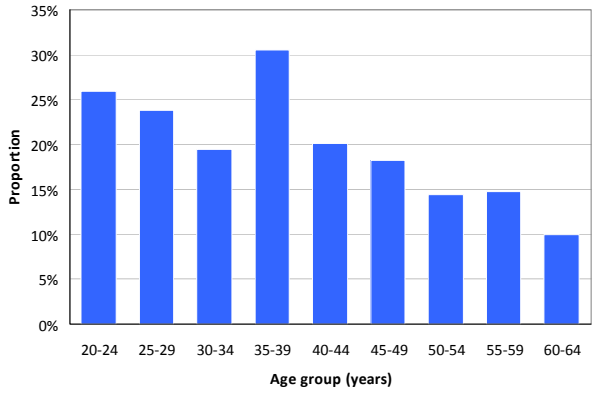



Source: Shared client data base n = 955. (23 missing)

Labour force participation decreased consistently with the age of shared clients (Figure 23). Across all of these age groups there was an almost constant number of shared clients in employment.

While this does not represent longitudinal data, it is reasonable to conclude that a very small number of shared clients obtain employment at an early age and remain employed as they age. The remaining shared clients do not find employment and, over time, stop seeking employment and leave the labour pool. This contrasts sharply with labour force participation rates in the general population where participation remains at or around 81% for these age groups.

***Figure 23*** **Labour force participation by age of shared clients**



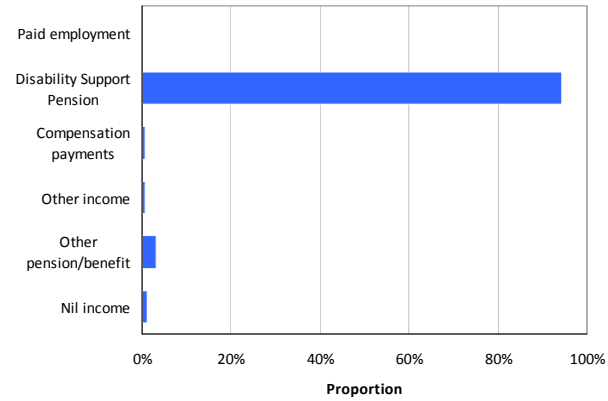

Source: Shared client data base, (18 to 64 years), n = 955. (23 missing values).

This is a concerning observation as it suggests that a failure to obtain support in finding employment during young adulthood may lead to long term unemployment. This reflects an example of the costs that can arise when early intervention services are unavailable or ineffective.

Nationally there are programmes in place that target these issues but their efficacy has not been established for people with impaired decision-making capacity.

The low rate of employment and labour force participation align with the profile of main income sources for shared clients (Figure 24). Only one shared client identified their main source of income as paid employment while 94% stated that their main source of income was the disability support pension (DSP).

***Figure 24*** **Main source of income for shared clients**




Source: Shared client database n = 936 (24 missing)

Interestingly, a shared client's employment status had no impact on what their main source of income was. Regardless of whether a shared client was employed, unemployed or not participating in the labour fore, 94-98% of shared clients listed the DSP as their main income source. This suggests that even when employed, shared clients derived very little income from their endeavours.

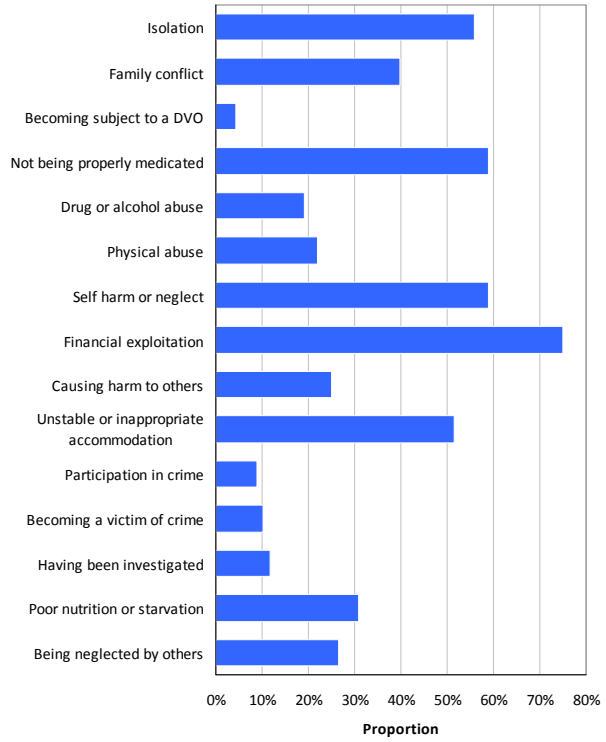
It was not possible to collate information about the value of assets owned by guardianship clients or their incomes from any of the databases developed as part of this project. It would be useful to undertake further research into this area to enable a better understanding of the financial situation of guardianship clients.

## Vulnerabilities

The sample of case files recorded whether a client was subject to risk across a range of issues including health, finance, relationships and accommodation.

Figure 25 shows that the most common risks faced by guardianship clients were financial exploitation, self harm or neglect, inappropriate medication, isolation, and unstable or inappropriate accommodation.

***Figure 25*** **Situations at which guardianship clients may be at risk**




Source: Sample of case files n = 68
Note: These categories are not mutually exclusive and percentages do not add up to 100 as guardianship clients may experience more than one risk.

These findings indicate the serious nature and complexity of issues affecting guardianship clients. While each of these issues individually may be harmful, many clients experienced multiple issues. This suggests that many clients may be in danger of serious abuse and/or neglect.

# Summary of guardianship client analysis

### Growth in the guardianship client population

The growth in the guardianship client population has slowed to less that the trend observed prior to the introduction of amendments to the *Disability Services Act 2006* and the *Guardianship and Administration Act 2000* in relation to the use of restrictive practice.

### Age

Overall there were 122.7 male clients per 100 female clients. The gender balance ranged from 211 males per 100 females in clients aged 35-39 years to 74 males per 100 females in clients aged over 84 years.

The average age of guardianship clients was 56 years, the median age was 57 years and the standard deviation of the age was 22.8 years.

The age profile of Adult Guardian clients (at time of entry into guardianship) is broadly characterised by three noticeable peaks: young adults, the middle aged and the elderly. These peaks suggest a strong relationship between life transitions and entry into the guardianship system.

### Gender

Overall, 55% of Adult Guardian clients were male.

Almost 58% of clients aged 75 years and over were female.

### Country of birth

The majority (94%) of shared clients were born in Australia.

A small proportion (3%) of shared clients were from culturally and linguistically diverse backgrounds.

### Indigenous clients

Approximately 13% of shared clients were from Aboriginal and Torres Strait Islander backgrounds. This is unlikely to be representative of the guardianship client population.

Almost half (46%) of Aboriginal and Torres Strait Islander shared clients were younger than 30 years.

### Living arrangements

Around 11% of guardianship clients lived with family, and 22% live alone.

Once a client becomes subject to guardianship, the most likely change to living arrangements is a change to living with others.

## Accommodation type

Only 32% of Adult Guardian clients lived in a private house or unit.

Around 55% of Adult Guardian clients lived in supported accommodation, while 11% live in non-private accommodation where support is not provided as part of the service (e.g. boarding houses, hostels, shelters etc).

When a person becomes subject to guardianship, the most common change in accommodation type was from private homes and hospitals to residential aged care.

## Disability

The majority of shared clients experienced multiple disabilities. Intellectual disability was the most prevalent primary impairment (31%), followed by dementia (27%).

## Support needs

Over 90% of shared clients required support with activities relating to domestic life, learning or interpersonal interactions and relationships.

Over 70% of shared clients required assistance with the core activities of self-care and communication.

The shared client population has a higher prevalence of need for support with all broad activities (except for mobility) than the overall DS NMDS client population.

## Specialist disability services

Shared clients have a higher rate of access to all broad service types (accommodation support, community support and community access) except respite, than the general DS NMDS client population.

Shared clients have a higher rate of multiple service access than the general DS NMDS client population.

## Carers and carer support

Only 19% of guardianship clients had an informal carer.

While the shared clients without an informal carer tended to be older than those who had an informal carer, the opposite was true for the overall guardianship client population.

It is worth noting that in both the shared client population, and the guardianship client population more broadly, women account for almost 75% of all informal carers.

## Communication

Nearly one-third of shared clients had little or no effective communication while another 3% communicate through means other than the spoken word, such as gestures.

## Employment and income

The majority of shared clients (80%) of working age were not actively looking for work.

Of the 20% of shared clients who were in the workforce, 75% were unemployed.

Labour force participation decreases with age amongst the shared clients.

Even when employed, the main source of income for shared clients was the disability support pension.

## Vulnerabilities

The most common risks faced by guardianship clients were financial exploitation, self harm or neglect, inappropriate medication, isolation, and unstable or inappropriate accommodation.

# Part 4: What are the characteristics of guardianship orders?

The administrative aspects of guardianship orders were examined to provide an understanding of guardianship undertaken by the Adult Guardian. In particular the following issues were analysed:

- Numbers of orders per client
- Date of appointment
- Combination of interim orders and guardianship appointments
- Term of orders
- Triggers and applicants for orders
- Matters of appointment, and
- Reasons for termination of appointments

## Terms used in this section

This section uses a number of terms to describe research findings on guardianship orders. These terms are fully defined in Appendix 3 but for ease of reference, a summary of relevant terms is provided below:

| Term | Meaning |
|---|---|
| Interim order | A guardianship order made by QCAT without a hearing in accordance with section 129 of the *Guardianship and Administration Act 2000* |
| Appointment order | A guardianship order made by QCAT with a hearing in accordance with the *Guardianship and Administration Act 2000* |
| Term (of an order) | The length of time for which the tribunal has stated that an order will remain current. An order must be reviewed at the end of its term. |
| First order | The chronologically first guardianship order to which a person has been subject. |
| Subsequent order | Any guardianship order, other than the first guardianship order, to which a person has been subject. |
| Duration of guardianship | The length of time to which a client has been subject to guardianship. |

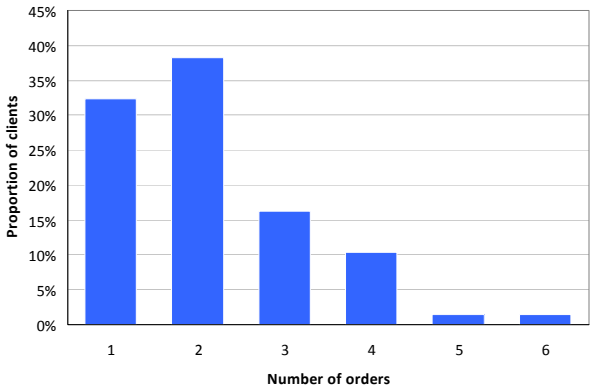
## Numbers of guardianship orders

Figure 26 shows that for the sample of 68 case files a total of 146 guardianship orders were made to the Adult Guardian. Of the 146 orders, 126 (86%) were appointment orders while 20 (14%) were interim orders.

While 32% of Adult Guardian clients were subject to a single order, most commonly, clients were subject to multiple orders (68%).

On average, adults were subject to 2.15 guardianship orders by the Adult Guardian.

***Figure 26*** **Guardianship clients by the number of guardianship orders to which they were subject**




**Source:** Sample case files, n=68.
Notes: Total orders equals 146. Table includes all guardianship orders (126 appointment orders; 20 interim orders).

As the sample of case files included both active and closed cases, these figures are representative of the population of guardianship clients at a given time but do not provide an accurate guide to the number of orders an individual is likely to experience throughout their life.

For example, the average number of orders per closed case is higher (2.32) than the overall average (2.15) and the average for active cases (2.05).

These figures are themselves limited by the fact that there are a number of clients in the sample with active cases who have been subject to more than four orders each. This suggests that if a longer period of guardianship were examined, the average number of orders per client would be higher than 2.32.

# Interim orders

Of the 68 cases in the sample, 28% had been subject to an interim guardianship order. While only one sample case file recorded a second interim order, interim orders were not always the first order to which a client had been subject.

One in four clients had been subject to an interim order that was not their first order. While the sample did not specifically capture the reasons why these interim orders were made, the data that was collected suggests that these situations arose principally when the matters of appointment had to be amended.

Only one client was subject to a single interim order only. Consideration of the need for a subsequent appointment order for this individual was unnecessary due to the client having passed away.

Only one client in the sample was subject to more than one interim order. This situation arose because the Adult Guardian sought to amend the initial interim order to include the matter of contact. The first interim order lasted only one month before being replaced by the second order.

The interim orders recorded in the sample of case files had either three or six month terms with roughly equal numbers of each.

# Administration orders

The *Guardianship and Administration Act 2000* authorises QCAT to simultaneously consider an application for the appointment of an administrator for financial matters and the Adult Guardian for personal matters.[77]

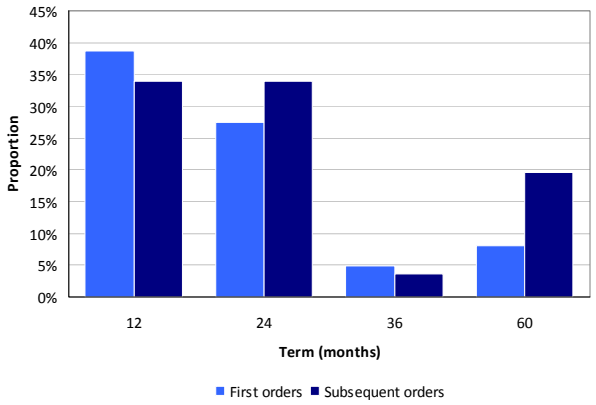
The research found it was common for guardianship clients to also have the Public Trustee appointed to make decisions for financial matters. Overall, approximately 78% of the sample case files included the appointment of the Public Trustee at least once while subject to guardianship. The sample did not specifically record the chronology of administration orders so no comment can be made on the sequence of administration orders relative to guardianship or the duration of the administration appointment.

# Term of appointment orders

This research has identified that a client's first order was typically shorter than subsequent orders (Figure 27), possibly indicating a "trial" before the longer term guardianship is established. While this finding is influenced by the 20 interim orders that were included in this calculation, interim orders tend to be both shorter in duration and tend not to be preceded by any other type of order. This almost guarantees that interim orders are "first orders" and the shorter duration reinforces the above pattern.

However, first orders are still generally shorter than subsequent orders even when interim orders are excluded from the analysis. This reinforces the notion of the "trial" order regardless of whether the client enters the system via an interim order or not.

***Figure 27*** **Term of first and subsequent orders (excluding interim orders)**




**Source:** Sample of case files n =118 orders, 8 missing

QCAT most often made appointment orders with terms of 12 or 24 months. Around one quarter (24%) of appointment orders were for terms of greater than two years, with 20% of terms being for 60 months and 4% being for 36 months.

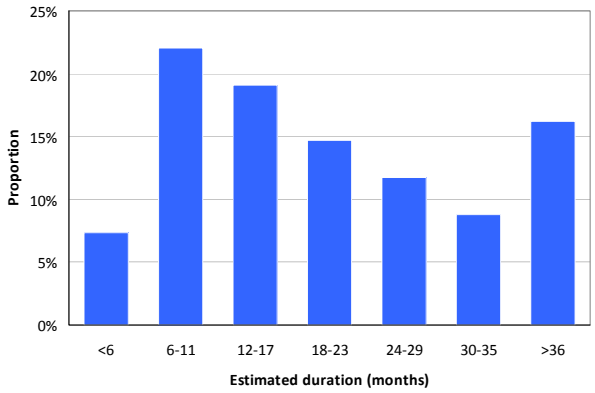
# Duration

It is important to note in this section that more than half of all the clients in this analysis had active cases at the time of collection. This means that any analysis of the duration of guardianship will return shorter values because active orders have not yet reached closure. It follows then that the following charts can provide some insight into how long clients have been subject to guardianship but limited insight into how long they will remain subject to guardianship.

While the above analysis describes the terms of individual guardianship orders, Figure 28 shows the estimated duration that guardianship clients were actually subject to guardianship.

[77] *Guardianship and Administration Act 2000* (Qld), Part 1, S(12).

***Figure 28*** **Profile of total estimated duration of guardianship**




Methodological note:
The duration to which a client was subject to guardianship was estimated by using the sum of the terms of all of a client's orders and then adjusting for the client's date of death, date at which cases were closed and date of most recent case activity. The duration of an individual's guardianship is an estimate that relies on the assumption that a client was in continuous guardianship, rather than exiting and re-entering at a later time.

Figure 28 indicates that there were three distinct groups of guardianship clients based on estimated duration of their guardianship.

The first group experienced a very short period of guardianship (less than six months). These cases were all closed and were primarily males aged over 60. Half of these cases included short durations because the client passed away while subject to guardianship.

The second group is the largest and includes clients with durations of six to 35 months. This group exhibits an inverse relationship between the duration of guardianship and the proportion of clients: the longer the client remains subject to guardianship, the more likely they are to leave the system. This is exactly the pattern that would be expected with a service that is intended to be of last resort and limited duration.

The third group comprises the same individuals as mentioned earlier in this section. These are the long term guardianship clients, all of whom have been subject to guardianship for more than three years. These eleven cases were predominately female but otherwise dissimilar. The ages of these clients ranged between 24 and 81 years and included both open and closed cases.

The Adult Guardian client database indicates that long term guardianship is not uncommon. There are more than 165 active clients who entered the guardianship system at least 5 years ago and 16 who entered the system more than a decade ago.

***Table 5*** **Active case by year of entry to the guardianship system**

| Year of entry | Clients |
|---|---|
| 2000 | 5 |
| 2001 | 11 |
| 2002 | 20 |
| 2003 | 41 |
| 2004 | 46 |
| 2005 | 41 |
| 2006 | 89 |
| 2007 | 126 |
| 2008 | 261 |
| 2009 | 528 |
| 2010 | 545 |
| **Total**[78] | **1713** |

These findings suggest that long term guardianship is a systemic issue that may require further research.

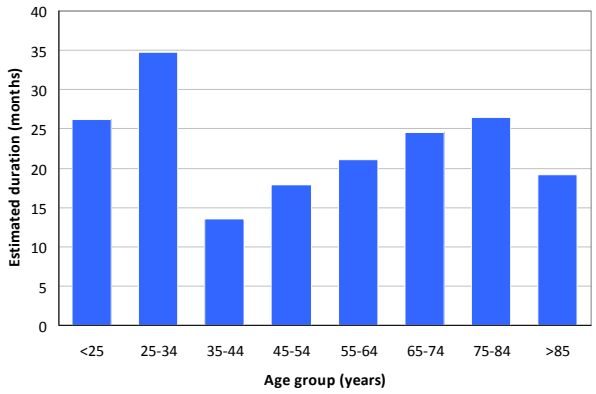
## Duration in guardianship by current age

The analysis of duration of guardianship by client age (Figure 29) suggests that there are three factors influencing duration:

- Young clients have the longest durations. This suggests that it is this group that form the bulk of the long-term guardianship population. Many of these clients have been subject to guardianship for most, if not all, of their adult lives. Restrictive practices only partly explain this as the majority of clients subject to restrictive practices are middle aged.
- Excluding young clients (aged less than 35 years), the older the client, the longer the duration of their guardianship.
- Advanced older age limits the duration of guardianship. This can be explained by the high rate of mortality on clients older than 84 years.

[78] The data exported from the Adult Guardian System indicated that one active client had a date of first appointment in 1998. This record was removed from this total as the date preceded the *Guardianship and Administration Act (2000)*.

***Figure 29*** **Average estimated duration of guardianship by current age.**




**Source:** Sample case files n=68
**Notes:** Current age is age as at 30 November 2011.

The fact that younger clients are subject to the longest durations of guardianship is of concern and may benefit from further research. As stated earlier, this can only be partly attributed to restrictive practices and may be influenced by the life transitions associated with early adulthood (such as changes in accommodation and access to adult specific services such as employment and day programmes). Some of these clients may be transitioning directly from the child guardianship system.

# Triggers for guardianship

The triggers for guardianship described below, are based on reviewing the life circumstances of the client at the time that QCAT made the appointment order.

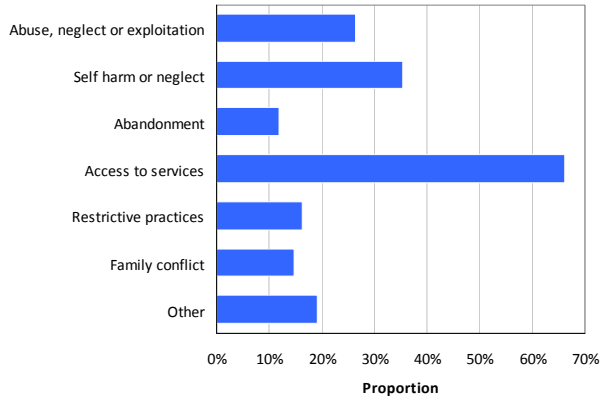
Methodological note:
It is important to note that the concept of triggers, as it is defined here, does not constitute a legal rationale for the appointment of the Adult Guardian. The data collection tool for the sample of case files sought to identify whether any of nine specific circumstances acted to trigger the client's application for guardianship. These nine categories represented areas of interest that were identified during project scoping and were not intended to represent an exhaustive list of all possible triggers.

Information regarding the triggers for guardianship orders was extracted from the sample case files based on information contained in a diverse range of documentation. In many instances, these documents were not intended to record triggers and the information in them has been standardised to inform this research.

While a guardianship order may have been prompted by several triggers, no more than two triggers were identified for each order.

Figure 30 shows the triggers for first guardianship orders in the sample of case files. The need for access to services was by far the most common trigger (66% of cases) followed by the risks of self harm or self neglect (35%), or of abuse, neglect or exploitation (26%).

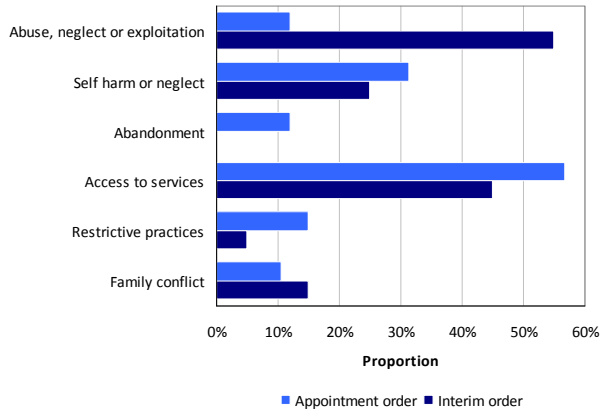
***Figure 30*** **Triggers for first orders**




**Source:** Sample of case files n = 68
**Note:** Percentages will not sum to 100 as each case may have had more than one trigger.

This analysis becomes more informative when the triggers for first orders are examined separately for interim and appointment orders (Figure 31). While access to services remains a significant trigger for both interim and appointment orders, the risk of abuse, neglect or exploitation is far more common where the first order was an interim order. This aligns well with the legislative requirement for interim orders (s129 of the *Guardianship and Administration Act 2000*).

***Figure 31*** **Triggers for first orders by interim and appointment orders**




Source: Sample of case files n = 68

Note: Percentages will not sum to 100 as each case may have had more than one trigger.

There were two interim orders in the sample of case files for which the risk of abuse, neglect or exploitation, or the risks of self harm or neglect, were not triggers. In both these cases, the client's situation was complex and the trigger was access to services. Both clients passed away shortly after the interim orders were made. This suggests that while the trigger that was recorded was not specifically related to the risk of imminent harm (as required by the legislation), the interim order was justified in terms of an immediate risk to the health of the individual.

When subsequent orders were examined, it was found that access to services was still the most common trigger (21% of clients) although much less than for first orders.

# Restrictive practices

The analysis of the sample case files found that the use of restrictive practices was the trigger for a minority of guardianship orders (16%), although the use of restrictive practices was a trigger for approximately 11% of subsequent orders.

It is important to note that consent for the use of restrictive practices by a guardian for a restrictive practice matter has been a mandatory legislative requirement since 2008. As a guardian for a restrictive practice matter, legislation requires the Adult Guardian to consent to the positive behaviour support plans for individuals subject to an order for whom it acts. This includes the initial positive behaviour support plan and revised plans resulting from annual reviews of the use of restrictive practices.

# Guardianship applicants

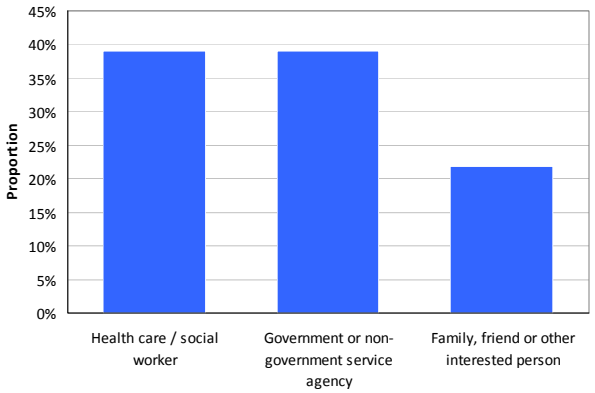
Under the Act (s.12), there are a number of avenues by which an application for a guardianship order may be made.[79] Any person who has a sufficient and continuing interest in the welfare of a person with impaired decision-making capacity can apply for a guardian to be appointed. Applications may also be made by the Adult Guardian or by the person with impaired decision-making capacity on their own behalf. The Tribunal may also make an order on its own initiative.

This research indicated that the vast majority of applications for first orders were made by health care or social workers (39%) or government or non-government service providers[80] (39%) (Figure 32).

This is consistent with the data regarding application triggers, which showed that applications were regularly heard by the Tribunal because of issues such as the need to access services (refer to previous Figure 31).

[79] These provisions do not apply to appointment of a guardian for a restrictive practice matter (s. 12(4)).
[80] The category "government service provider" included the Adult Guardian and Public Trustee however neither of these organisations were recorded as the applicant in a first order.

***Figure 32*** **Applicants for first orders**

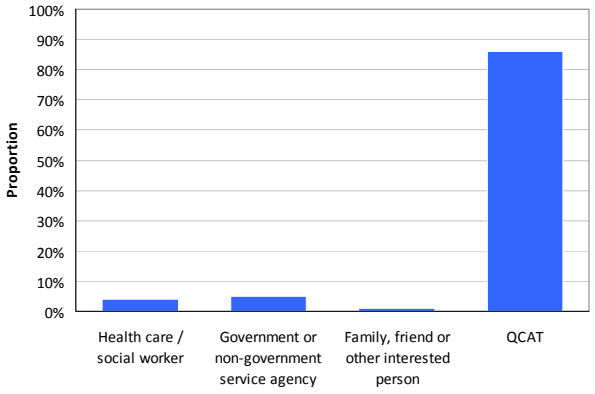



**Source:** Sample case files n = 63 (5 missing)

Families, friends and others, were less likely (22%) than health care or social workers to apply for guardianship orders. This is not unexpected given that family members or close friends often act as informal decision-makers for people with impaired decision-making capacity and thus negate the need for Adult Guardian appointment. Alternatively, families and friends may have limited awareness of the Adult Guardian and its role with respect to substitute decision making.

Subsequent orders were almost entirely the result of scheduled or tribunal initiated reviews. In these situations, QCAT does not file an application for guardianship form so applicants were not recorded in these cases. These missing data have been recoded as "QCAT" in Figure 33.

***Figure 33*** **Applicants for subsequent orders**




**Source:** Sample case files n= 74 (4 missing)
**Note:** The category "QCAT" was not specifically recorded during the sample of case files. This data has been inferred on the basis of advice from QCAT on how reviews and subsequent orders are recorded in the case files.

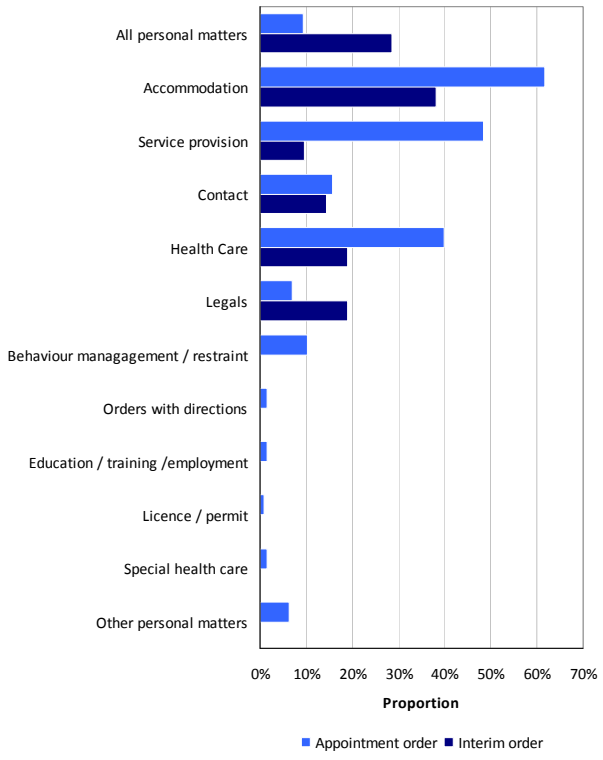
As Figure 33 shows, the vast majority of subsequent orders arose through either a scheduled review or tribunal initiated review. Subsequent orders where there were applicants were most often instigated when the OAG sought an amendment to the matters of the original order or sought an extension of guardianship. There were rare occasions where a social worker or family member successfully made an application for the amendment or extension of guardianship.

# Matters for appointment

Under the *Guardianship and Administration Act 2000*, the Adult Guardian is appointed as guardian for personal matters. These matters range from frequently arising issues (e.g. deciding where the adult lives, with whom the adult has contact, and general health care) to the less common (e.g. approval of restrictive practices and personal legal matters).[81]

The most common matters for appointment of an interim order were personal matters (29%) and accommodation (38%) (Figure 34). This is not unexpected given the serious and urgent circumstances that are required to justify an interim order.

***Figure 34*** **Matters of appointment for interim and appointment orders.**




Orders for all personal matters were less common in appointment orders than interim orders. This may indicate that the Tribunal is only appointing the Adult Guardian for those matters for which decisions are required. This approach is consistent with the principle of minimal limitation and substituted judgement.[82]

The most common matters of appointment for appointment orders were accommodation (62%), service provision (48%) and health care (40%).

These finding on matters of appointment reaffirm the significance of accommodation as a matter in the guardianship system.

It is interesting to note that on average (and excluding those orders made for all personal matters), interim orders were made for fewer matters than appointment orders (Table 6).

***Table 6*** **Average number of matters of appointment by interim and appointment order**

| Type of order | Average number of matters of appointment |
|---|---|
| Appointment order | 2.2 |
| Interim order | 1.5 |
| **Overall** | **2.1** |

**Source:** Sample of case files n = 128 orders

The average interim order was made for 1.5 matters whereas the average appointment order was made for 2.2 matters. This suggests that when it makes interim orders, QCAT tends to be more prescriptive regarding matters for which it appoints the Adult Guardian.

# Review of appointment orders

Under section 31 of the *Guardianship and Administration Act 2000*, QCAT is required to review orders prior to the end of their term. The tribunal must revoke the order unless it is satisfied that there are appropriate grounds for the appointment to continue. Interested parties may convey their views or provide information to the Tribunal on new or changed circumstances.

There are three different avenues for review under the Act:

- periodic review based on the order or at least every five years;
- a request by an interested person[83]
- or the tribunal may initiate a review on its own accord (ss. 28-29).[84]

Under the Act (ss. 31-31), following a review, the tribunal may:

- revoke the order[85]
- continue the order, or
- change the order.[86]

[81] The personal matters for which the Adult Guardian is appointed are recorded in the guardianship orders, and correspond to categories specified in Schedule 2 of the *Guardianship and Administration Act 2000* (Qld).
[82] *Guardianship and Administration Act 2000*, schedule, part 1, page 202.
[83] Under the Act, the definition of 'interested person' means 'a person who has sufficient and continuing interest in the other person' (Schedule 4).
[84] These provisions do not apply to guardians for a restrictive practice matter.
[85] The Tribunal must revoke the guardianship order unless it is satisfied that it would make an appointment if a new application for an appointment was made (s. 31(2)).

## Outcomes of reviews

The outcome of the review of orders is shown in Table 7. Only closed cases are included in this analysis.

The review of an order most commonly resulted in a new appointment order for the same matters, which extended the guardianship. Overall 71 guardianship orders (76% of all orders) made to the Adult Guardian were reviewed and renewed for a total of 41 individual clients.

Seventeen orders (18%) of the 93 orders were revoked by the Tribunal. Six guardianship orders made to the Adult Guardian were reviewed without further re-appointment. In five of the sample case files, an order was revoked due to the death of the client.

***Table 7*** **Outcomes of reviews of closed guardianship orders**[87]

| Circumstances of termination | Count | Percent |
|---|---|---|
| Order reviewed and reaffirmed[88] | 71 | 76% |
| Order revoked by Tribunal upon review | 17 | 18% |
| Order revoked due to death | 5 | 5% |
| **Total** | **93** | **100%** |

**Source:** Sample case files n=93
**Notes:** The 93 orders excludes 43 orders that were active at the time of the review and four orders where the circumstances surrounding the end of the order were not stated.

About half of the 17 orders revoked by the Tribunal occurred following a periodic review. In five cases, the Adult Guardian requested a review from the Tribunal prior to the mandatory review period.

[86] Under the Act changing the order includes changing the terms of the appointment; or removing an appointee; or making a new appointment (Part 3, Division 2). The definition of 'term' includes 'condition, limitation and instruction' (Schedule 4).
[87] The data presented in this table was obtained through a process which included tracking cases back to original data collection notes, reviewing that information and sorting according to the 'termination' categories.
[88] An individual may have consecutive appointments to the Adult Guardian. 71 orders were replaced by a new appointment for 41 individual clients.

# Summary of guardianship orders analysis

### Numbers of orders

On average, clients were subject to 2.15 guardianship orders each, however this figure is likely to be higher if active, long-term guardianship cases are factored in.

Approximately 12% of clients were subject to four or more orders.

### Interim orders

Almost 28% of guardianship clients have been subject to an interim order.

Interim orders are occasionally used to adjust or amend existing guardianship orders.

### Administration orders

More than three in four guardianship clients have been subject to an administration order in addition to a guardianship order.

### Term of orders

First orders generally have shorter terms than any subsequent orders.

Most terms of appointment orders ranged from 12 months to sixty months, with 68% of all terms being either for 12 months or 24 months.

Twenty percent (20%) of appointments were for 60 month terms.

### Duration of Guardianship

For the majority of clients (63%), the total period of time they were subject to guardianship order made to the Adult Guardian was no more than two years.[89]

Based on the sample case files, 16% of clients subject to guardianship by the Adult Guardian were subject to guardianship for three or more years, with the longest period for an individual client in the sample case files being 7 years and 9 months.

The Adult Guardian client database shows there were around 165 active clients who had entered the guardianship system at least five years ago and six who entered the system more than a decade ago.

Young clients (under 35 years old) are the most likely to be subject to long periods of guardianship.

[89] As previously noted, more than half of all appointment orders clients in the analysis were active at the time of the review of the sample case files.

## Triggers

Access to services was the single most common trigger for a first-time order, although more common for appointment orders than interim orders.

The risk of abuse, neglect or exploitation was the most significant trigger for clients with interim orders.

Restrictive practices were a trigger for entry into guardianship for about 16% of first orders.

## Guardianship applicants

This research indicated that the vast majority of applications for first orders were made by health care or social workers (39%) or government or non-government service providers.

Families, friends and others were less likely to apply for guardianship orders.

Subsequent orders were almost entirely the result of scheduled or tribunal initiated reviews.

## Matters of appointment

Overall, the most frequent matters for appointment of the Adult Guardian were accommodation, service provision and health care.

A large proportion (30%) of interim orders were made for all personal matters compared with only 9% of appointment orders.

On average (and excluding those orders made for all personal matters), interim orders were made for fewer matters than appointment orders.

## Revocation of guardianship orders

Overall, 76% of guardianship orders over the ten year period were reviewed by the Tribunal and replaced by a new appointment. In only 18% of cases was an order revoked by the Tribunal.

# Part 5: Linkages and next steps

The primary aim of the Adult Guardian Client Profile Project was to develop an evidence base that would:

- support the guardianship work of the Office of the Adult Guardian (OAG)
- identify potential systems advocacy issues for the Office of the Public Advocate (OPA) in relation to people with impaired decision-making capacity
- inform future planning and service delivery by the Queensland Government in relation to people with impaired decision-making capacity and adults under guardianship of the state.

The Adult Guardian Client Profile Project sought to meet the following objectives:

- establish a demographic profile of people subject to a guardianship order made to the Adult Guardian over the period 2000-2010;
- describe the composition and circumstances of the Adult Guardian client population;
- outline trends in guardianship in Queensland, including projected growth and the administrative aspects of guardianship orders; and
- illuminate hidden or emerging issues in the Adult Guardian client base, family environments and service systems.

The research findings in this report on state guardianship in Queensland (see Part 3) are based on an independent analysis by OPA. These findings have been themed as follows: and highlight a number of issues for further consideration within each section:

- Client characteristics
- Guardianship - entry and administration
- Sustainability

# Client Characteristics

## Age and gender

The age-gender profile of Adult Guardian clients shows an unbalanced gender ratio with males accounting for 55% of clients. 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.

The age profile of Adult Guardian clients (at the time of a guardian first being appointed) is broadly characterised by three noticeable peaks: young adults, the middle aged and older adults. The data also showed that the peaks for young and middle aged adults are mainly driven by males, while the peak in older adults is driven by females.

## Disability profile

Adult Guardian clients are, by legislative definition, people who have impaired decision-making capacity. This research indicated that intellectual disability was the most prevalent impairment for Adult Guardian clients, followed by psychiatric disability and acquired brain injury.

The OAG concurs through its annual reporting that intellectual disability, in recent years, has consistently been the primary disability type for the largest proportion of its clients. This is followed by psychiatric disability and then dementia.

Interestingly, the prevalence of intellectual disability is not experienced by other Australian guardianship jurisdictions, where dementia tends to be the most common impairment for clients under State guardianship.

Furthermore, according to the AIHW, the prevalence rate of intellectual disability for those under 65 years peaks in the 10 to 14 years age group for males and females, and then peaks again for males in the 25-29 year age group, and 35 to 39 year age group.[90] This may also help to explain why employment outcomes were worse for younger shared clients.

Further research may assist in understanding the different trend in disability type that is evident for Adult Guardian clients in Queensland as opposed to other Australian jurisdictions.

## Support and care arrangements

This research showed that the majority of Adult Guardian clients require support with activities relating to independent and daily living. Furthermore, the majority of Adult Guardian clients did not have an informal carer and lived primarily in cared accommodation (e.g. group homes and hostels) rather than in private households.

For those who do have an informal carer, 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 provide necessary supports. This is particularly relevant given that demand for funded services far exceeds the level of available supports.

[90] Australian Institute of Health and Welfare, (AIHW) 2008, *Disability in Australia: intellectual disability*, Bulletin No. 67. Cat. No. AUS 110. AIHW, Canberra.

The data also revealed a number of young Queenslanders (under 25 years) with impaired decision-making capacity had informal carers. Unsurprisingly, in 53% of these cases the carer was a parent.

> The available data for this research 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. It may be due to family conflict or family breakdown, however this issue and alternative guardianship options require further investigation.

This research indicates that two in five informal carers of guardianship clients were aged 65 years and over. Aged carers are a cause for concern in terms of the ongoing availability of informal supports for adults with impaired capacity, as well as in terms of the health impacts on carers themselves.

Carers of all ages may be at risk of developing a range of adverse health outcomes. In the field of mental health, research has identified primary carers aged 18-50 years tend to have poor mental health outcomes with very high rates of clinical depression, anxiety and family breakdown.[91] 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. It also highlights the importance of supporting carers in their caring role.

A small percentage of informal carers of shared clients were young, with 2% being 24 years or under. While caring can be a positive experience for young people, inadequate support may negatively impact young carers' health and wellbeing during a formative period in their lives.[92]

Living arrangements generally may also have a bearing on guardianship outcomes across gender. For example, this research suggests that not living with family is linked with entry into guardianship, with a correspondingly higher proportion of males than females not living with family.

# Complexity of cases

The vulnerability of Adult Guardian clients is also corroborated by this research.

While it is important to note this evidence is based on the information stored in the sample case files, and not on clinical or formal assessments, the findings show the serious circumstances faced by this client group, particularly when considered in light of their disability profile.

Common circumstances identified include:

- financial exploitation
- physical abuse
- neglect by self or others including failure to properly medicate, poor nutrition and/or starvation
- unstable accommodation (including eviction, end of lease, inappropriate accommodation)
- family conflict
- isolation from friends and family
- causing harm to others or harming self
- drug, alcohol or substance abuse

In addition, just over one third of Adult Guardian clients accessed a specialist disability service in 2008-09 (the shared clients of this report).[93]

The level of case complexity has the potential to impact on the workload and resources of the OAG. In the 2008-09 Annual Report, the Office of the Adult Guardian noted that about one-third of all of its guardianship clients are allocated at highest priority due to the adults being at significant risk of harm from their own or another's actions.[94] Staff participating in the OAG workshop also highlighted the increasing level of complexity experienced in undertaking the guardian role.

Complexity often arises from the client's circumstances and is also complicated by the problems of an overstretched service system and the possible flow-on effect of a high level of unmet support needs.

## Other research findings

Family conflict is an important issue identified by a range of reliable sources. The 2010 QLRC guardianship review noted that there was a perception among some respondents that the appointment of the Adult Guardian or the Public Trustee is sometimes too readily made in situations of family conflict. Accordingly, the QLRC recommended that 'the fact that a person who is a family member of the adult is in conflict with another family member does not, of itself, mean that the person is not appropriate for appointment as a guardian or an administrator for the adult.'[95]

[91] Australian Institute of Health and Welfare (AIHW) 2008(a), *Disability in Australia: Trends in Prevalence, Education, Employment and Community Living,* Bulletin No. 61, Cat No. AUS 103, AIHW, Canberra.
[92] Carers Australia website. http://www.carersaustralia.com.au/about-carers/young-carers2/

[93] Source: Shared clients data base (all shared clients) n = 1,019. This figure includes 41 shared clients aged 65 years and over.
[94] Office of the Adult Guardian 2009, Annual Report 2008-09, Office of the Adult Guardian, Brisbane, p. 14.
[95] Queensland Law Reform Commission (QLRC) 2010, A Review of Queensland's Guardianship Laws, Report No 67. Vol 3, Rec 14-9, p. 81.

The QLRC also recommended that the Tribunal should ensure that family members who are involved in guardianship proceedings are provided with sufficient information about the possible outcomes of proceedings involving family conflict, and the options available for resolving or managing facility conflict before, during and after a guardianship proceeding.[96]

As previously noted, families and broader support networks may face significant strains in undertaking their guardianship roles. The contemporary family dynamic is increasingly diverse and dynamic, and with increased mobility, families may be separated by distance. However, family networks are vital and investment in providing appropriate and sustainable supports to maintain these networks is a critical factor in managing the demand for guardianship services.

It is also worth noting that the information on areas of vulnerability noted in this research is supported by recent national evidence with respect to the experience of people living with disability and their carers, as detailed in the 2009 report *Shut Out: The Experience of People with Disabilities and their Families in Australia (Shut Out).* Shut Out was the National Disability Strategy Consultation Report prepared by the National People with Disabilities Carer Council for the Australian Government.[97]

The National Disability Strategy 2010-2020 is now in place and the Australian Government with the support of State, Territory and Local Governments is seeking to promote social inclusion and equality through enhancements in:

- inclusive and accessible communities
- rights protection
- justice and legislation
- economic security
- personal and community support
- learning and skills
- health and wellbeing.[98]

The *Shut Out* report painted a very bleak picture of the experiences of people living with disability and the situation of their carers in Australia, including specific insights into the experiences of those living with intellectual disability.

Some of the key findings focussed on widespread experiences of social isolation, economic exclusion, discrimination and poverty. People with intellectual disability were identified as being particularly vulnerable in their struggle for, and lack of access to, meaningful engagement with the community, and were also identified as being among the most isolated groups.[99] The report also highlights the gap in policy and programs to secure employment or meaningful day activity for people with disability who are able and willing to participate in the economic and social opportunities available to most Queenslanders.

People with impaired decision-making capacity continue to face discrimination and disadvantage in attempts to secure employment or meaningful day activity. Data from the Survey of Disability, Ageing and Carers 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.

A range of factors are likely to be informing the low employment and labour force participation rates of shared clients. The Australian Institute of Health and Welfare (AIHW) identified the following factors as potentially significant in relation to lower employment rates for adults with intellectual disability: difficulty in obtaining open employment opportunities; lack of training in skills needed to succeed in the work environment; lack of employer awareness of the needs of people with disabilities; or employer unwillingness to accommodate in the workplace.[100]

Many of the issues identified by the AIHW are likely to be relevant to adults with impaired decision-making capacity. The Adult Guardian Client Profile Project found that only one shared client identified their main source of income as paid employment with 94% stating their main source of income was the disability support pension.[101] Shared clients also appear to have much higher levels of unemployment compared to those in the potential population of Queenslanders with impaired decision-making capacity (26%).

This research corroborates international research that shows employment for people with disability is an area where Australia is lagging behind other countries.[102] The findings also raise the question of the extent to which poverty is an independent indicator in the overall rate of guardianship orders. Further investigation into this area is warranted.

[96] QLRC 2010, p. xviii.
[97] Shut Out: The Experience of People with Disabilities and their Families in Australia. National Disability Strategy Consultation Report. 2008, FAHCSIA 10307.0908, Canberra.
[98] Commonwealth of Australia 2011, *National Disability Strategy 2010-2020, An initiative of the Council of Australian Governments*, Commonwealth of Australia, Canberra.
[99] Shut Out: The Experience of People with Disabilities and their Families in Australia. National Disability Strategy Consultation Report. 2008. FAHCSIA 10307.0908, Canberra.
[100] Australian Institute of Health and Welfare (AIHW) 2008(b), Disability in Australia: intellectual disability, Bulletin 67, Cat. No. AUS 110, AIHW, Canberra.
[101] Adult Guardian Client Profile Project, Analysis of Clients (Source: Shared client database).
[102] Organisation for Economic Co-operation and Development (OECD) 2009, *Sickness, Disability and Work: keeping on track in the economic downturn- background paper*, OECD (p12).

A key aspect of the *Shut Out* report, was the identification of community attitudes, including the beliefs and practices of medical and other clinical professionals, employers, government service providers, social workers, government service providers, carers, and the broader community in creating and perpetuating barriers for people with disability to full social inclusion and participation.

At a state level, a 2011 study by the South Australian Office of the Public Advocate of 45 people under guardianship found this group to more likely be poorer, isolated and have fewer resources than the general population.[103] The study concluded that:

> *"… this may in part be secondary to disability, it is also likely that people from a disadvantaged background who experience a disability are more likely to be brought to the attention of tribunals, than people with similar disability but who have more social advantages'…Currently with our imbalanced system we are now more focused on the state taking over people's decision-making than providing tangible assistance to help people make their own decisions, or to help families take on the private guardian role".*[104]

Overall, these findings raise concerns about the extent to which people with impaired decision-making capacity are facing social exclusion. The findings highlight gaps in policy and programs including those aimed at ensuring everyone has an opportunity to access employment, meaningful day activity and income. It is evident that discrimination based on negative stereotypes remains a powerful negative force in the contemporary experience of those living with disability, including those living who have impaired decision-making capacity.

The Office of the Public Advocate will monitor developments with the National Disability Strategy, Queensland's 10-year plan (Absolutely everybody) and departmental Disability Service Plans. These are all important facilitators to improve the social inclusion of people with impaired decision-making capacity, which is an important precursor to early intervention and prevention.

## Aboriginal and Torres Strait Islander people

The representation of Indigenous people in the guardianship system remains an area warranting further investigation. People from Aboriginal and Torres Strait Islander backgrounds accounted for a much larger proportion (13%) of Adult Guardian clients than their representation in the broader population of Queenslanders with a disability who access specialist disability services (6%).

The Australian Human Rights and Equal Opportunity Commission[105] observed that in the case of Aboriginal and Torres Strait Islander youth, the convergence of a range of factors (similar to those noted in the review of case files and listed as vulnerabilities in this report) are associated with social and economic disadvantage. This convergence reinforces the strong link that is already recognised between the higher rates of social and economic disadvantage faced by Indigenous Australians, when compared to the non-Indigenous Australian population, and the negative health outcomes including those associated with mental health conditions.[106]

The strong interconnection between social, economic and health factors is a likely contributor to entry into formal guardianship for young Aboriginal and Torres Strait Islanders in Queensland.

The almost complete absence of older Indigenous people among shared clients is likely to be influenced by the shorter life expectancy of Indigenous Australians, noting that the estimated life expectancy of Indigenous Australians is 16-17 years lower than the general Australian population.

Determining the exact number of Aboriginal and Torres Strait Islander people who are subject to guardianship is only one part of a broader issue for guardianship in Queensland.

The circumstances surrounding their entry into guardianship, their duration under guardianship, the inter-relationships between systems supporting them, and whether formal guardianship is related to avoiding or minimising the risk of abuse, neglect or exploitation are all important considerations that will assist in better understand the contributing factors to what appears to be an over-representation of Indigenous Australians within the guardianship system.

[103] The South Australia study used a randomly drawn sample and compared demographic data with census data for the general population in 2006 Social and Economic Indexes for Australia and Index of Economic Resources published by the Australian Bureau of Statistics.
[104] Office of the Public Advocate, *Annual Report 2010-11*, South Australia, p. 132.
[105] Human Rights and Equal Opportunity Commission 2005, *Indigenous young people with cognitive disabilities and Australian juvenile justice systems - A report by the Aboriginal and Torres Strait Islander Social Justice Commissioner,* Human Rights and Equal Opportunity Commission, Sydney.
[106] Australian Institute of Health and Welfare (AIHW), 2011(a), *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander People: an Overview 2011,* Cat. No. IHW 42, AIHW, Canberra.

## Other research findings

The Aboriginal and Torres Strait Islander Health Performance Framework (HPF)[107] and the Australian Indigenous Psychologists Association (AIPA)[108] identify a diverse set of health, socio-economic, behavioural, community capacity and other factors including adverse life events (such as poverty, violence, grief and loss associated with stolen generations and dispossession of land, suicide) and systemic discrimination (e.g. disproportionate numbers of notifications, investigations and substantiations of child neglect and abuse, and disproportionate numbers of young people in the juvenile justice system) as being relevant in understanding Indigenous health outcomes, including their representation in health and related service systems.

Factors that may impact on the seemingly high representation of young Indigenous Australians in the Queensland guardianship system include:

- Disability, severe mental health issues and psychological distress:
    - Aboriginal and Torres Strait Islander people are estimated to be 2.4 times more likely than non-Indigenous people to have a severe or profound disability.[109] Around 57% of Indigenous people with severe disability experience psychological and/or intellectual disability.[110]
    - Australia-wide, Aboriginal and Torres Strait Islander people are more likely to be hospitalised for mental health problems and disorders than non-Indigenous Australians,[111] [112] with mental health disorders estimated to be the second highest cause of functional impairment amongst Aboriginal and Torres Strait Islander people.[113]
    - Furthermore nearly one-third of Indigenous adults had high or very high levels of psychological distress, more than twice the rate for non-Indigenous Australians.[114]
- Limited access to specialist disability and other formal services:
    - Limited access to appropriate specialist disability services may compound existing mental health problems or symptoms associated with intellectual disability, and increase the likelihood of guardianship for adults with impaired decision making capacity.
- Child protection and juvenile justice systems as risk pathways to guardianship:
    - In Queensland, while Aboriginal and Torres Strait Islander children represent approximately 6.6% of all Queenslanders aged 0-17 years, they represented 34% of all children subject to child protection orders as at 30 June 2009.[115] There is a risk that those in this cohort who have a disability may be more likely to enter the guardianship system when they turn 18.
    - Estimates suggest that Indigenous young people are 15 times more likely to be under juvenile justice supervision than non-Indigenous children, and 24 times more likely to be detained than non-Indigenous young people,[116] with an associated risk that those with cognitive disability or mental health issues may also be more likely to enter formal guardianship at 18.
- Language and cultural barriers:
    - Language/cultural barriers, and uncertainty regarding the appropriateness of standardised tests for this cohort, may increase the risk of Aboriginal and Torres Strait Islanders being incorrectly or inappropriately assessed as having impaired decision making capacity requiring formal state guardianship.

A related qualitative research project recently commissioned by OPA on Indigenous Queenslanders and the guardianship system highlights fundamental difficulties arising from the interactions of the Queensland guardianship model and the cultural practices of Indigenous Queenslanders. The guardianship model is based on western, individualistic practices, whereas Indigenous culture is founded on collective customs. This presents the risk that the guardianship system is applied to Indigenous Queenslanders, rather than serving their needs and supporting individuals with impaired decision-making capacity within the context of their culture.[117]

[107] Australian Institute of Health and Welfare (AIHW), 2011(a),*The Health and Welfare of Australia's Aboriginal and Torres Strait Islander People: an Overview 2011*, Cat. No. IHW 42, AIHW, Canberra.
[108] Purdie, Nola, Pat Dudgeon, and Roz Walker, 2010, *Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice,* Department of Health and Ageing, Canberra, ACT.
[109] Australian Institute of Health and Welfare (AIHW), 2011(b), *Aboriginal and Torres Strait Islander people with Disability: Wellbeing, participation and support,* Cat. No. IHW 45, AIHW, Canberra.
[110] Australian Institute of Health and Welfare (AIHW), 2011(a).
[111] Australian Institute of Health and Welfare (AIHW), 2011(a).
[112] Aboriginal and Torres Strait Islander Services, Queensland Department of Communities, 2009, *Queensland Closing the Gap Report 2008/09:Indicators and Initiatives for Aboriginal and Torres Strait Islander Peoples.* Queensland Department of Communities.
[113] Australian Institute of Health and Welfare (AIHW), 2011(a).
[114] Australian Institute of Health and Welfare (AIHW), 2011(a).
[115] Queensland Closing the Gap Report 2008/09:Indicators and Initiatives for Aboriginal and Torres Strait Islander Peoples. 2009. Aboriginal and Torres Strait Islander Services. Queensland Department of Communities
[116] Australian Institute of Health and Welfare, (AIHW), 2011(c).
[117] Cadet-James D.; Cadet-James Y.; Chenoweth L.; Clapton J.; Clements N.; Pascoe V.; Radel K.; and Wallace V., 2011, Impaired Decision-Making Capacity and Indigenous Queenslanders, Final Report, School of Human Services and Social Work, Griffith University, Brisbane.

While some possible pathways into guardianship for Indigenous Queenslanders have been identified, further research would help to confirm and quantify the extent of these potential pathways as well as provide a better understanding of the mechanisms involved.

Steps to improve case management and mediation could be undertaken at the local level to allow for more informed and earlier service responses for Indigenous Queenslanders with impaired decision-making capacity. This, in turn, could lead to improved outcomes for Indigenous individuals, families and communities.

There is a need for consultation with Indigenous people about 'what works' in their communities. The perspectives of Indigenous people regarding the design and appropriateness of assessment tools and processes, communication mechanisms and service responses is vital to ensure a culturally appropriate, practical and sustainable approach.

The evidence also suggests the need for a broader and more culturally-appropriate range of decision-making support options for Indigenous Queenslanders with impaired decision-making capacity. Supported decision-making may be a more natural and culturally acceptable way to engage and empower Indigenous Queenslanders, if designed appropriately and in partnership with the Indigenous community.

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

## People from culturally and linguistically diverse (CALD) backgrounds

The percentage of people from CALD backgrounds amongst shared clients was similar to their representation amongst recipients of specialist disability services, but about half the proportion of adults with CALD backgrounds in the general Queensland population. There are a couple of contending possible explanations for these observations.

Research indicates that migrants tend to have lower death and hospitalisation rates, as well as lower rates of disability and lifestyle related risk factors.[118] This is thought to be due to two main factors: a self-selection process that includes people who are willing and economically able to migrate and excludes those who are sick or disabled, and a government selection process that involves certain eligibility criteria based on health, education, language and job skills.[119]

Nevertheless, there is evidence that the impact of this decreases the longer migrants live in Australia, i.e. the longer they live in Australia, the closer they align to health patterns of the whole population.[120]

Many people from CALD backgrounds may lack proficiency in English and access to translation services is often expensive and/or may be difficult to negotiate. These barriers to services may be compounded by an overly complex and fragmented service system[121] and may lead to difficulty in accessing health services.

Overall, it is likely that a proportion of people with impaired decision-making capacity from CALD backgrounds are falling through the service system gaps, and not accessing the health services, including mental health services, they may require.

The lower than anticipated number of people from CALD backgrounds in the guardianship system may warrant further investigation as the appointment of the Adult Guardian may afford added protection in safeguarding the rights, wellbeing and health of a vulnerable client group, who may otherwise be challenged in their attempts to access necessary supports. However, it is again necessary to ensure that guardianship options are culturally appropriate.

[118] Singh, M and de Looper, M, 2002, Australian health inequalities: birthplace. Australian Institute of Health and Welfare (AIHW) Bulletin, Cat. No. AUS 27, AIHW, Canberra.
[119] Singh, M and de Looper, M, 2002, Australian health inequalities: birthplace. Australian Institute of Health and Welfare (AIHW) Bulletin, Cat. No. AUS 27. AIHW, Canberra.
[120] Australian Institute of Health and Welfare (AIHW), 2010(a), Australia's health 2010. Cat. no. AUS 122. AIHW, Canberra.
[121] The Queensland Government has recognised the differing needs of people from CALD backgrounds and the need to reduce the complexity of service systems to enhance access by people from CALD backgrounds. For example see Multicultural Affairs Queensland, Department of Communities, 2011, A multicultural future for all of us: Queensland Multicultural Policy 2011, Department of Communities.
http://www.multicultural.qld.gov.au/resources/multicultural/media/queensland-mulilticultural-policy-a-multicultural-future.pdf

# Guardianship - Entry and Administration

## Entry into Guardianship

### Life Transitions

The peaks evidenced in the age-gender profile suggest a strong relationship to life transitions, indicating that changes in family or support network 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. This suggests that some youth may be entering guardianship from other service sectors as a short-term and possibly inappropriate solution to a complex social problem.

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 that 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.

The absence of an informal carer, or having an ageing carer, may be a driver for guardianship for many clients. This research found that about one-third of shared clients had an informal carer, while about one-fifth of the total population of guardianship clients was estimated to have an informal carer. These research findings suggest that without an informal support network, people with impaired decision-making capacity are highly vulnerable to entering the guardianship system.[122]

Other research into early responses and prevention 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.

If guardianship appointments are linked to life transition issues, as suggested by this research, then future demand is likely to increase, impacting on the sustainability of the current system. Further efforts may be required to ensure more appropriate case management mechanisms are accessible and/or that alternative guardianship and decision-making models are explored and implemented.

### Limited access to support services

Lack of access to necessary support services is a common experience for people subject to guardianship orders to the Adult Guardian and also for many others with impaired decision-making capacity.

This is substantiated by other secondary research recently conducted by OPA which found that 41% of adult Queenslanders with impaired decision-making capacity did not have their support needs met.[123] This means they were not receiving the level of assistance they require for daily and independent living.

A number of findings in the Adult Guardian Client Profile Project suggest that the need to access support services is a key factor driving entry into Guardianship. While a guardian can only consent to services that are available and for which a client is deemed eligible, seeking access to services was the single most common circumstance for a first-time guardianship order made to the Adult Guardian over the 10-year period covered by the Adult Guardian Client Profile Project.

Abuse, neglect, exploitation and family conflict, either singly or together, provided a set of circumstances that also prompted and order. Self-harm and/or neglect, often reflected in the adult's poor health and wellbeing, were also common triggers for guardianship.

[122] For example, as outlined in the profile section of this report, around 70% of adult clients under 65 years of age did not have an informal carer. Guardianship clients were also more likely to be living alone and less likely to be living with family than the general Queensland population.

[123] Australian Bureau of Statistics, (ABS) 2009, *Survey of Disability, Ageing and Carers (SDAC), Basic CURF 2009,Cat No.4430.0, ABS, Canberra.* This figure shows little change from the 2003 SDAC (42%), figures reported in the Office of the Public Advocate *Annual Report 2010-2011.*

## Other research findings - unmet need

The South Australian Public Advocate noted similar concerns with unmet need and its relationship to guardianship interventions in its 2010-11 Annual Report:

> *"In the current environment of significant gaps in services for vulnerable people, the Board routinely sees many people in dire circumstances who are at risk in some way. A genuine concern for human beings leads to this approach. Anecdotally, it also occurs in other jurisdictions where tribunals ask public advocates or guardians to plug the gaps between services... People with a disability of any type have a right to safety and freedom from exploitation. There is also a right to access services. It should not be necessary to lose one set of rights – in the case of guardianship, the right to make one's own decisions, and to be recognised as an adult before the law – to acquire these other rights".*[124]

Similarly, research conducted by the Victorian Office of the Public Advocate found the increase in guardianship numbers was attributed in large part to the services sector as it struggled with changes in the support needs of people with disability living in the community; a fragmented and diversified service system operating under conditions of tight fiscal constraint; and managing risk.[125]

The Office of the Public Advocate will maintain a watching brief on developments with the NDIS and its impact on the delivery of supports and services.

## Health provider practices

The Adult Guardian Client Profile Project also found that a large majority of first appointment orders were made by providers in health care or service settings, suggesting that guardianship orders made to the Adult Guardian may have been used as a part of the hospital discharge process or case management responses.

The Office of the Adult Guardian observed a noticeable increase in guardianship appointments for hospital patients in its annual report for 2010-11. The report stated that what was most needed were advocacy, case management and discharge planning, and that an accommodation decision by the Adult Guardian may be necessary only after a considerable amount of other work had occurred.[126] Participants in a workshop hosted by the OAG also observed that Queensland's comparatively higher number of interim appointments was linked to poor early intervention strategies and this included inadequate case management in hospitals.

## Accommodation issues

The findings from this project also showed that the majority of accommodation decisions made by the Adult Guardian involved moving people from private homes and hospital settings into aged care facilities. This is consistent with the finding that a high number of first order applicants were providers in health care or service settings and suggests that service providers may have been using the guardianship system to activate changes in accommodation or service provision.

It is plausible that service providers, acting under conditions of financial constraint, or in risk adverse service cultures, and with a greater knowledge of the services that are available, are more likely than friends or family to use the guardianship system as a type of brokerage tool to secure access to appropriate services.

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 were less likely to be moved in or out of group home accommodation as a result of a decision made by a guardian, however they have been moved from group home to another.

What appears pronounced from this research is that, in Queensland, the service system may be using the legal system, through guardianship, for service access and other case management responses. Further testing of this hypothesis is required.

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 (for example, service providers may be using the guardianship system to activate changes in accommodation or service provision).

Many life transitions accompany changes in accommodation, for example, moving out of the family home as a young adult or from the family home into aged care accommodation in advanced age. While these transitions can explain some of the observations in this report, none of them were directly observed in the case files. Further research could establish this link more firmly and suggest policies by which the State could better support life transitions for people with impaired decision-making capacity.

[124] Office of the Public Advocate 2011, Annual Report 2010-11, Office of the Public Advocate, South Australia, p. 125.
[125] Victorian Office of the Adult Guardian 2010, *Too Much Guardianship? Reflections on Guardianship in Victoria 1988-2008*, Office of the Adult Guardian, Melbourne.
[126] Office of the Adult Guardian 2011, *Office of the Adult Guardian Annual Report 2010-11,* Department of Justice and Attorney-General, Brisbane, p. 21.

## Administration of guardianship orders

Overall, the profile of guardianship clients referenced by this report suggests that the Queensland Civil and Administrative Tribunal (QCAT) is functioning within the legislative intent of the *Guardianship and Administration Act 2000*. This is evidenced as follows:

- Shorter first orders suggest that QCAT expects that a client's need for a guardian can be resolved quickly.
- Interim orders were almost only ever made when triggered by an imminent or actual instance of abuse, neglect or exploitation.
- Interim orders were more limited in the matters for which they were made. This embodies the general principle of minimal limitation and substituted judgment.
- Few appointment orders were plenary orders. Plenary orders are extreme measures and rightly used sparingly.

However, there remain a number of concerning issues for which further research may be warranted. These include:

- Long-term guardianship of younger clients and whether a policy of transition planning (similar to the positive behaviour support approach used for restrictive practice matters) would assist the guardianship system to meet the general principle of minimal substituted judgement.
- The use of five-year terms for guardianship. Such terms were applied to very young clients and would require the client to have both ongoing impaired decision-making capacity and an ongoing need for decision-making in order to fit the legislative intent of the *Guardianship and Administration Act 2000.*
- The frequency with which QCAT makes orders that appear to perform a case management function for clients. These orders include those where the applicants were health care and social workers and service providers.

## Reviews of orders and minimum review period

Under the *Guardianship and Administration Act 2000* (Qld) the tribunal must review an appointment of a guardian or administrator if the tribunal does not consider the impaired capacity to be permanent, in accordance with the order of the tribunal, but at least every five years.[127]

The 2010 QLRC review of Queensland's guardianship laws recommended that section 28(1) of the *Guardianship and Administration Act 2000* (Qld) should be amended to provide that (a) an initial appointment of a guardian or administrator must be reviewed every two years of the order making the appointment and (b) any other appointment of a guardian or administrator must be reviewed within five years of the order renewing or extending the appointment.[128]

This project found that most orders were for periods of 12 and 24 months, suggesting a reduction in the minimum review period is supported by current practices anyway.

The minimum review period should also be reconsidered against the principles of appointing the Adult Guardian as a last resort and exercising the least restrictive alternative in all circumstances.

It is concerning that few reviews were initiated by a party external to the Tribunal. While this has changed somewhat since the time that data for this report was extracted, the question remains as to whether there are barriers in place that discourage families, or the clients themselves, from initiating reviews or revocations.

Further research to understand the experience of family members and to measure the rates of review and revocation applications, would be beneficial in understanding the dynamics of the administration of orders, and, in particular, the low levels of revocation.

The following questions may assist in better understanding this issue:
Is there a need for better communication and support for family members seeking review or revocation of orders?
What are the rates of unsuccessful applications for review and revocation and the reasons that these were unsuccessful?

[127] *Guardianship and Administration Act 2000* (Qld), 3, Part 3, Division 2, Section 28 (1).
[128] Queensland Law Reform Commission (QLRC) 2010, *Review of Queensland's Guardianship Laws,* Report No 67, Vol 3, QLRC, Brisbane, Rec 22-4, p141.

# Sustainability

**The sustainability of the Queensland guardianship system is a significant issue.**

The most recent data available suggests that the growth in the numbers of people subject to guardianship is less than expected. Despite this, the size of the guardianship client population will increase with that of the general Queensland population.

The growth in the numbers of Queenslanders with impaired capacity is partly attributable to Queensland's ageing population and associated age-related conditions that can impair decision-making capacity, such as dementia and stroke.

There is also a possibility that social attitudes towards guardianship are an influence. The practices of health care and social workers when they make applications for guardianship are a potential example of this type of factor.

These factors may impact the growth in numbers of adults in guardianship either directly or indirectly. One way it is anticipated that the ageing Queensland population profile will indirectly contribute to more adults entering guardianship is through ageing carers. As carers age, they may no longer be able to care for their adult children with impaired capacity, thus increasing the risk of entry into guardianship by those adult children.

The increase in older Queenslanders with impaired decision-making capacity is unlikely to fully account for the rate of expected growth in Adult Guardian clients. Advances in the treatment of acquired brain injury and degenerative diseases, leading to higher survival rates and longevity, will also contribute to the overall expected growth in numbers of people with impaired decision making capacity.[129]

Other systems or process issues may also impact the expected demand for guardianship. For example, over the last three-years of the research period (i.e. 2008-2010), there was an exponential increase in the number of new guardianship clients for the Adult Guardian. This increase was attributable to the introduction in 2008 of legislative amendments to the *Disability Services Act 2006* and the *Guardianship and Administrative Act 2000* in relation to positive behaviour support and restrictive practices.[130]

Another systemic factor the project suggests may be linked to an increased risk of adults entering into guardianship by the Adult Guardian involves hospital discharge practices for patients with impaired capacity who have no or limited family or other support networks. Specifically, the project has found evidence that suggests professional health care workers in hospital settings may be using the guardianship system as a mechanism to free up hospital beds and expedite transfer to other forms of sub-acute supported accommodation.

The project has also identified that living alone and being single are associated with entering into state guardianship. The project has further suggested that these factors impact disproportionately on men and may help explain the seeming over-representation of men within the system of Adult Guardianship. The continued growth in single person households suggests the above phenomenon will continue to impact demand for Adult Guardianship services into the foreseeable future, amplified by the ageing population and the tendency for older people to live alone.

The 2009-10 Annual Report of the Queensland Civil and Administrative Tribunal (QCAT) noted that guardianship matters formed the largest component of the workload of the Human Rights Division (other matters dealt with include anti-discrimination, children and young people, and education). QCAT reported a significant increase in guardianship matters in 2009-10, which the Tribunal attributed to the ageing population and the need for formal arrangements to protect the rights of individuals.[131] This increasing trend was affirmed in the 2010-11 QCAT Annual Report.

## Experience in other jurisdictions

The growth in guardianship is common to most jurisdictions across Australia. In Victoria, which was the first jurisdiction in Australia to implement a comprehensive guardianship system, there has been a steady annual growth in the number of orders to the State. The Victorian system commenced with 225 cases in 1987-88. In its latest annual report for 2010-11, the office reports it has a total of 1,730 cases, with 905 of these being new cases (an increase of 156 from the previous year).[132]

[129] Office of the Public Advocate (OPA) 2011, The Potential Population for Systems Advocacy, Fact Sheet, OPA, Brisbane.
[130] See further discussion on the impacts of the legislative amendments later in this section.

[131] Queensland Civil and Administrative Tribunal 2010, *Annual Report 2009-10,* The State of Queensland, Brisbane.
[132] Office of the Public Advocate 2011, *Office of the Public Advocate Annual Report 2010-11,* Office of the Public Advocate, Victoria, p. 6.

The Victorian Office of the Public Advocate has argued that this trend is due to an 'over reliance on guardianship to fill the gaps where other less restrictive supports like case management and coordination, mediation, advocacy and community education, more accessible health care and housing would have addressed the identified issue'.[133] The Victorian Office of the Public Advocate has cautioned that the legislative reforms did not intend for State guardians to be responsible for the majority of guardianship – rather, it was the intention that the 'community take responsibility for guardianship'.[134]

Similarly the 2011 South Australian Annual Report reports a regular growth in its guardianship system over the previous five years:

> *In 2006-07 there were 499 clients and by 2010-11, this increased to 793 clients (an increase of 59% over 5 years). The increase in active cases over the 5-year period was 50% (from 401 in 2006-07 to 602 in 2010-11).*[135]

The South Australian Public Advocate attributes this steady increase in guardianship to predominantly demographic changes however also notes the impact of policy and practice such as legal interpretations of the need for guardianship; changing practices within the Guardianship Board [the 'tribunal' that appoints guardians]; and contemporary risk-management concerns by service provider organisations.[136]

In light of this pattern of growth, and considering the trends appear to also be evident in other jurisdictions, the sustainability and efficiency of the current guardianship system in Queensland is a significant issue for further examination.

## Impact of restrictive practices

As noted earlier, the exponential increase in State guardianship in Queensland over the period 2008–2010 may be partially attributable to the introduction of amendments to both the *Disability Services Act 2006* (Qld) and the *Guardianship and Administration Act 2000* (Qld) in relation to restrictive amendments in 2008.

The Queensland Civil and Administrative Tribunal (then the Guardianship and Administrative Tribunal) reported that in 2008-09, the Adult Guardian was appointed in 75% of guardianship cases for restrictive practices (i.e. in 49 cases of the 65 appointments). The relatively high number of cases placed a huge challenge on the resources of the OAG.[137]

A previous review of restrictive practices by OPA considered that the reasons for the high number of Adult Guardian appointments for restrictive practice matters may be due to:

- some adults not having a support network and therefore no one else is available
- some family members may not wish to accept appointment
- some family members find the regime too complex
- some family members may wish to support the adult in other ways rather than be substitute decision-maker
- some family members may not be appropriate decision-makers with respect to restrictive practice matters.

The former Queensland Public Advocate noted that this outcome was a matter for concern since 'those close to a particular adult will usually be better placed, given their intimate knowledge of the person concerned, and greater accessibility than a statutory officer, to make decisions for their family member. They will usually know the adult well, see them regularly and be able to frequently and informally monitor implementation by service staff.' It was suggested that greater support should be given to families if complexity is an issue and noted that reforms were underway by service providers, the then Department of Communities, the Tribunal and the Adult Guardian to implement strategies to assist families more when appointed as a guardian for a restrictive practice matter.[138]

Research and related literature on challenging behaviour and the use of restrictive practices also highlights the strong relationship between a person's communication capacity, the ability of others to understand them, and associated frustration levels.[139] 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 antisocial behaviour, a breakdown in services and isolation, further exacerbating the situation and potentially leading to restrictive practice interventions.

As the initial backlog from the new legislative requirements are redressed and with the continued promotion of 'less restrictive' alternatives and greater support for families and clients, it is anticipated that guardianship appointments made to the Adult Guardian for restrictive practice matters will gradually decelerate.

The impact of restrictive practices on the guardianship system and people with impaired decision-making capacity bears close monitoring. Further research into the support needs for families (such as respite) and clients (for example, augmentative and alternative communication options) is needed.

[133] Office of the Public Advocate 2010, *Too much guardianship? Reflections on Guardianship in Victoria 1988-2008,* Office of the Public Advocate, Victoria, p. 2.
[134] Office of the Public Advocate 2010, *Too much guardianship? Reflections on Guardianship in Victoria 1988-2008,* Office of the Public Advocate, Victoria, p.6.
[135] South Australian Office of the Public Advocate 2011, *Annual Report 2011,* Office of the Public Advocate, Collinswood, p. 141.
[136] South Australian Office of the Public Advocate 2011, *Annual Report 2011,* Office of the Public Advocate, Collinswood, p. 143.
[137] Office of the Public Advocate (OPA) 2009, *Annual Report 2008-09*, OPA, Brisbane, p. 79.
[138] Office of the Public Advocate (OPA), *Annual Report 2008-09,* OPA, Brisbane, pp. 79-80.
[139] See for example, The Australian Psychological Society Ltd (APS) 2011, *Evidence-based guidelines to reduce the need for restrictive practices in the disability sector,* APS, Melbourne.

## Alternatives to guardianship

This research suggests that guardianship in its current form is unsustainable, not only as a case management tool, but because of the steady growth in guardianship appointments.

Queensland's ageing population is likely to have a significant impact on the demand for guardianship orders made to the Adult Guardian. There will possibly be an increase in orders due to increasing numbers of people experiencing age-related conditions that 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.

Investment in providing appropriate, 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.

The initiation of formal guardianship has always been based on the premise of 'last resort'. Informal arrangements through support networks should be the favoured practice. Equally important is the need for people to plan for the risk of impaired decision-making capacity and to be proactive about putting in place their own arrangements based on their decisions about who would be the most appropriate substitute decision-maker (i.e. a living will).

## Early intervention and prevention

This research has highlighted the importance of investing in education, cultural awareness and appropriate communication tools in the guardianship system. Every effort must be made to encourage and maintain family and community involvement in decision-making.

From a social policy perspective, the presence of an extended support network could help mitigate some of the risk associated with reduced access to the informal support provided by families, especially parents, as carers age and caring responsibilities become more challenging.

Investment in providing appropriate and sustainable supports to maintain family and informal support networks is likely to be a key factor in managing future demand for guardianship services. It is essential that last resort legal interventions, like guardianship, seek to promote and maintain existing family relationships, whilst upholding the principle of the least restrictive alternative in all circumstances. Those individuals who have family and informal networks are at less risk of requiring the services of the Adult Guardian.

In particular, early response programs to improve communication and address challenging behaviours must be a priority for people who experience difficulties with communication.

## Case management

Greater attention could also be given to building collaborative and seamless services for adults with impaired decision-making capacity incorporating, for example, a set of basic service standards in regards to communication, referral, and case management responsibility. The integrity of the last resort principle would be better safeguarded if these standards were met before an application for guardianship was decided.

Alternative models of decision-making support could also reduce pressure on the guardianship system. For example, one model that could be considered is the one currently used for health care consents whereby OAG may have the potential to provide considered, one-off consent for transitions in accommodation matters without applying a full guardianship order.

To gain a better understanding of access to services and the level of unmet need, 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.

## Other research findings

The Victorian Law Reform Commission (VLRC) has made similar recommendations in its recent guardianship report (2012), noting a preference for personal appointments and recommending the process be simplified and more accessible in order to facilitate this.

The VLRC also supported the submission made by the Victorian Public Advocate, which argued that:

> *"…personal appointments provide greater autonomy for many people whose capacity is impaired, because a trusted person is well placed to know and implement the wishes of the person when it becomes necessary for someone else to make decisions."*[140]

[140] Victorian Law Reform Commission (VLRC) 2012, *Guardianship, Final Report 24,* VLRC, Melbourne, p. 56.

A community education campaign to educate the public about the guardianship system and advance planning options is vital. The education campaign must be tailored to suit the needs of the range of potential users, including all types of clients; families and carers; service and support providers; health care and medical professionals; and police organisations. The need for further community information was supported by both the QLRC (Recommendation 32-21) and the VLRC in their respective reviews of guardianship systems.

It will also 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 these instruments unless there are strict revocation standards. The 2010 QLRC Review made a number of recommendations to improve the use and application of enduring powers of attorney and advance health directives.[141]

Both OPA and OAG are also monitoring the investigation of new models, including statutory individual advocacy, supported decision-making and community guardians, some of which are being trialled in other Australian jurisdictions. The OAG has noted in its Annual Report for 2010-11 that there may be scope to integrate these into the Queensland model in the future.[142]

South Australia has been conducting a trial of a supported decision-making model, with the final independent evaluation report completed in late November. The pilot trials a new decision-making model that establishes supported decision-making agreements for people with impaired decision-making capacity. This model enables the person to still have control over their decision-making authority through an agreed support arrangement. Assistance is provided to support all people participating in the agreements and their support team. A 'monitor' helps with the process and identifies any problems if they occur. The South Australian trial covers decision-making in the areas of accommodation, lifestyle and health.

The NSW Public Guardian's Office is also considering a supported decision-making project with the NSW Office of Ageing, Disability and Home Care.

The recent VLRC guardianship review (2012) has also investigated supported decision-making alternatives and has made several recommendations for broader decision-making models (such as supported decision-making and co-decision-making arrangements):

> *…by introducing a wider range of decision-making arrangements – and by encouraging people to consider decisions that the assisted person would make – the Commission believes that guardianship laws can be seen as a positive means of promoting the participation of people whose decision-making ability is impaired, rather than solely as a protective mechanism that restricts freedom of decision and action.'*[143]

Alternative dispute resolution, mediation, supported decision-making or other contemporary options like community guardianship should also be given consideration in Queensland. These avenues could potentially reduce the need for guardianship appointments to the Adult Guardian, and may enhance the sustainability of the guardianship system overall.

Article 12 of the United Nations' Convention on the Rights of Persons with Disabilities specifically refers to the right for persons with disabilities to be supported in order to exercise their legal capacity.

The Office of the Public Advocate will give priority to research into alternative models to guardianship.

[141] See Queensland Law Reform Commission (QLRC) 2010, *A Review of Queensland's Guardianship Laws*, Report No. 67 QLRC, Brisbane (Vol 1-Chapter 8 and Vol 2- Chapter 9).
[142] Office of the Adult Guardian, *Annual Report 2010-11*, Office of the Adult Guardian, Brisbane, p. 22.
[143] Victorian Law Reform Commission (VLRC) 2012, *Guardianship, Final Report 24*, VLRC, Melbourne, p. xxv.

# Summary

The Adult Guardian Client Profile Project has provided new insights into the Queensland guardianship system and the circumstances of Queenslanders subject to guardianship orders made to the Adult Guardian. This research has also identified a range of potential systems issues requiring further investigation.

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 in cases where family members or other support networks exist.

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, 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 (whether intentional or otherwise) falls outside Parliament's original intention and undermines the integrity of guardianship as a mechanism of social justice and rights protection.

The guardianship system may benefit from promoting a mutual understanding of the goals of shared case management responsibility as being core to effective service delivery and outcomes for clients. It may also be useful to have clear guidelines for dispute resolution and crisis management when multiple agencies are involved in complex individual matters.

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.

The Office of the Public Advocate supports the need for an agreed set of performance criteria against which the Queensland guardianship system should be monitored. Progress towards the achievement of performance criteria should be reported and widely disseminated.

The findings from this research will be used by the Office of the Public Advocate to support an evidence-based approach to systems issues relating to the legal intervention of guardianship. It is hoped that this research will generate debate about how best to promote inclusive and sustainable policies, programs and practices that improve life-outcomes for people subject to a guardianship order made to the Adult Guardian.

Research such as this is often a starting point in understanding the business of an agency and its client groups. It provides an evidence base to progress issues and pursue improvements. It also tends to raise a number of questions that require further investigation. Investigating the issues flagged in this research may lead to a more sophisticated evidence base and more informed decision-making. The Office of the Public Advocate will seek further opportunities to engage with the OAG and other key agencies in partnerships that will advance positive change for people with impaired decision-making capacity.

Through systems advocacy and links with government, non-government organisations and other key stakeholders, and drawing on the evidence presented in this report and other contemporary research, the Office of the Public Advocate will continue to urge reform in key areas to help ensure adults with impaired decision-making capacity are protected, their quality of life improved, and the risks of prematurely or unnecessarily falling into State guardianship reduced.

# Appendix 1 - General principles and health care principle

This is an extract from the *Guardianship and Administration Act 2000* (Qld), schedule 1 [Reprint 6A effective 23 February 2012, Office of the Parliamentary Counsel] and is not an official copy of the legislation. The official or authorised versions of Queensland legislation can be found in hard copy versions printed by the Government Printer.

## Presumption of capacity

An adult is presumed to have capacity for a matter.

## Same human rights

The right of all adults to the same basic human rights regardless of a particular adult's capacity must be recognised and taken into account.

The importance of empowering an adult to exercise the adult's basic human rights must also be recognised and taken into account.

## Individual value

An adult's right to respect for his or her human worth and dignity as an individual must be recognised and taken into account.

## Valued role as member of society

An adult's right to be a valued member of society must be recognised and taken into account.

Accordingly, the importance of encouraging and supporting an adult to perform social roles valued in society must be taken into account.

## Participation in community life

The importance of encouraging and supporting an adult to live a life in the general community, and to take part in activities enjoyed by the general community, must be taken into account.

## Encouragement of self-reliance

The importance of encouraging and supporting an adult to achieve the adult's maximum physical, social, emotional and intellectual potential, and to become as self-reliant as practicable, must be taken into account.

## Maximum participation, minimal limitations and substituted judgment

An adult's right to participate, to the greatest extent practicable, in decisions affecting the adult's life, including the development of policies, programs and services for people with impaired capacity for a matter, must be recognised and taken into account.

Also, the importance of preserving, to the greatest extent practicable, an adult's right to make his or her own decisions must be taken into account.

So, for example—

- the adult must be given any necessary support, and access to information, to enable the adult to participate in decisions affecting the adult's life; and
- to the greatest extent practicable, for exercising power for a matter for the adult, the adult's views and wishes are to be sought and taken into account; and
- a person or other entity in performing a function or exercising a power under this Act must do so in the way least restrictive of the adult's rights.

Also, the principle of substituted judgment must be used so that if, from the adult's previous actions, it is reasonably practicable to work out what the adult's views and wishes would be, a person or other entity in performing a function or exercising a power under this Act must take into account what the person or other entity considers would be the adult's views and wishes.

However, a person or other entity in performing a function or exercising a power under this Act must do so in a way consistent with the adult's proper care and protection.

Views and wishes may be expressed orally, in writing or in another way, including, for example, by conduct.

# Maintenance of existing supportive relationships

The importance of maintaining an adult's existing supportive relationships must be taken into account.

# Maintenance of environment and values

The importance of maintaining an adult's cultural and linguistic environment, and set of values (including any religious beliefs), must be taken into account.

For an adult who is a member of an Aboriginal community or a Torres Strait Islander, this means the importance of maintaining the adult's Aboriginal or Torres Strait Islander cultural and linguistic environment, and set of values (including Aboriginal tradition or Island custom), must be taken into account.

***Editor's notes—***
*1 Aboriginal tradition has the meaning given by the Acts Interpretation Act 1954, section 36.*
*2 Island custom has the meaning given by the Acts Interpretation Act 1954, section 36.*

# Appropriate to circumstances

Power for a matter should be exercised by a guardian or administrator for an adult in a way that is appropriate to the adult's characteristics and needs.

# Confidentiality

An adult's right to confidentiality of information about the adult must be recognised and taken into account.

# Health care principle

The health care principle means power for a health matter, or special health matter, for an adult should be exercised by a guardian, the Adult Guardian, the tribunal, or for a matter relating to prescribed special health care, another entity—

- in the way least restrictive of the adult's rights; and
- only if the exercise of power—
  - is necessary and appropriate to maintain or promote the adult's health or wellbeing; or
  - is, in all the circumstances, in the adult's best interests.

***Example of exercising power in the way least restrictive of the adult's rights—***
*If there is a choice between a more or less intrusive way of meeting an identified need, the less intrusive way should be adopted.*

In deciding whether the exercise of a power is appropriate, the guardian, the Adult Guardian, tribunal or other entity must, to the greatest extent practicable—

- seek the adult's views and wishes and take them into account; and
- take the information given by the adult's health provider into account.

***Editor's note—***
*See section 76 (Health providers to give information).*

The adult's views and wishes may be expressed—

- orally; or
- in writing, for example, in an advance health directive; or
- in another way, including, for example, by conduct.

The health care principle does not affect any right an adult has to refuse health care.

In deciding whether to consent to special health care for an adult, the tribunal or other entity must, to the greatest extent practicable, seek the views of the following person and take them into account—

- a guardian appointed by the tribunal for the adult;
- if there is no guardian mentioned in paragraph (a), an attorney for a health matter appointed by the adult;
- if there is no guardian or attorney mentioned in paragraph (a) or (b), the statutory health attorney for the adult.

# Appendix 2 - National standards of public guardianship

Australian Guardianship and Administration Committee
7 October 2009

## Introduction

The National Standards of Public Guardianship were initially endorsed by the Australian Guardianship and Administration Committee in 2001. The standards provide the minimum expectations of guardianship staff in making substitute decisions on behalf of people with decision-making disabilities whose guardian is the Public Guardian/Advocate.

The standards have provided a baseline benchmark and framework that has informed the development of standards by each jurisdiction.

## Preamble

The ratification by Australia of the *United Nations Convention on the Rights of Persons with Disabilities* on 17 July 2008 has informed the 2009 review of the minimum standards for public guardianship.

The convention promotes, protects and ensures the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. The convention defines these rights in each area of life and includes, amongst others, access to justice, freedom of expression, independent life in the community, education, work, standard of living, health care, rehabilitation, and participation in political and public life.

In particular Article 12 *Equal recognition before the law* provides that:

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

Accordingly for all people there is a presumption of capacity and all possible efforts should be made to assist a person exercise their own capacity. When a person does not have full legal capacity, such incapacity is decision specific, and therefore a person's decision-making capacity needs to be considered for each and every decision.

## The Standards

The following nine standards set out the principles for a guardian to observe when making decisions on behalf of a person. The standards complement policies, practice standards, and procedures as well as complaint and review mechanisms for people affected by the decisions, and a range of government requirements relating to areas such as appropriate professional behaviour, privacy and confidentiality, conflict of interest and ethical work practices. The standards are:

- Provide information
- Seek views
- Advocacy
- Protection
- Make decisions
- Record information
- Participate in guardianship reviews
- Professional development
- Privacy and confidentiality

## Provide Information

Agencies with a statutory mandate of guardianship decision-making will ensure information about their vision or mission, their services and the legislative and ethical principles and policies underlying their services are accessible to all consumers, stakeholders and staff.

Staff making guardianship decisions will ensure that:

- Information is made available to the represented person[144] and other key people in their life about:
    - The role of the office
        - The principles of the legislation

[144] Represented person is the person who is the subject of a current Order made by a Board, Tribunal or Court in Australia

- The authority of the guardian in relation to the represented person
- Customer services standards
- Appointment of an interpreter
- How to request reasons for a decision
- How to make a complaint or have a decision reviewed
- How to apply for a review of an Order
- Other complaints processes
- Freedom of Information provisions

- Information about substitute consent and the guardian's authority in respect of the represented person is provided to all relevant service providers, including medical and dental practitioners providing services to the represented person
- Information is made available on request in appropriate formats to ensure it is accessible.

# Seek Views

Staff making guardianship decisions will:

- Seek and consider the views of the represented person, giving effect to the wishes of the represented person where possible
- Make personal contact with the represented person a minimum of one visit each year
- Seek and consider the views of key parties involved with the represented person in regard to any proposed significant decisions
- Seek and consider the views of relevant medical and other professionals, as the proposed decision requires
- Consider the strengths and weaknesses of advice from service providers, and if there is reason to consider the advice inadequate in some way, seek a second opinion on behalf of the represented person
- If the represented person objects to the proposed decision, make reasonable attempts to ascertain the reasons for their objection and consider ways to achieve their wishes or resolve the dispute if possible
- If any key person objects to the proposed decision, make reasonable attempts to ascertain the reasons for their objection and consider these prior to making a decision
- Consider and advocate for the least restrictive alternative that meets the needs of the represented person.

# Advocacy

Represented persons have a right to access housing or accommodation, health care, support services, and assistance to participate in the community.

Staff making guardianship decisions will:

- Assess whether all options have been presented to the decision maker by service providers, and seek to recognise when a preferable option has not been presented
- Make all possible attempts to advocate for the best option so that a decision can be made between meaningful options that improve both quality of life and opportunity for the represented person.

# Protection

Guardianship can serve an adult protection function for represented people at risk of harm by third parties. People with a decision making disability may be vulnerable to physical, sexual, emotional and financial abuse, as well as exploitation and neglect.

Staff making guardianship decisions will:

- In both the initial assessment and subsequent reviews, consider whether a person is safe, and if they have experienced abuse, exploitation and/or neglect
- Further investigate and take action including the referral of the represented person to an appropriate authority where there is any reasonable suspicion that a represented person has experienced abuse, exploitation and/or neglect, taking into account their wishes.

# Make Decisions

Staff making guardianship decisions will:

- Make decisions according to the legislative provisions and principles and the authority of the current Order
- Make decisions according to the authority delegated to them
- Make decisions following agency policy and procedures
- Communicate decisions to the represented person and key parties in a manner meaningful to the person
- Provide written reasons for decision on request of the represented person or a key party
- Review their decision making on a regular basis with their manager.

# Record Information

Staff making guardianship decisions will:

- Record guardianship decisions including the views of the represented person and other relevant parties, timeframes, conditions and the reasons for them
- Record significant information obtained
- Record significant details of contacts made and decisions taken.

# Participate in Guardianship Reviews

Staff participating in guardianship reviews will:

- Request a review of the current Order by the Board, Tribunal or Court if at any time there is a need to extend, review or revoke the powers given under the Order or where the Order is not working in the best interests of the represented person
- Recommend continuation of the Order for the shortest time possible and only when there is evidence that the represented person lacks legal capacity and needs decisions to be made for them in those areas
- Consult with the represented person as far as possible to ascertain their views
- Consult with relevant key parties and professionals and include their comments in the report
- Provide a written or verbal report detailing their assessment and recommendation regarding the continuing need for a guardianship order to the Board, Tribunal or Court.

# Professional Development

Agencies with the statutory mandate of guardianship decision making will ensure:

- All staff have access to individual supervision, support and guidance in the performance of their guardianship role
- The case of each represented person will be reviewed on a six monthly basis either in individual supervision or in professional team meetings
- All staff have access to professional development opportunities in every year of their employment.

Staff making guardianship decisions will:

- Engage in meetings on a regular basis with their manager or colleagues to discuss issues in their decision making and professional development needs
- Undertake continuing professional development in areas relevant to their role.

# Privacy and Confidentiality

Agencies with the statutory mandate of guardianship decision making will:

- Develop policies and procedures that protect the privacy and confidentiality of the represented persons and the key people in their lives and comply with legislative requirements.

All staff making guardianship decisions will ensure:

- That only information relevant to the performance of their statutory authority and in the best interests of the represented person is released
- That they comply with other relevant government requirements including Codes of Conduct.

# Appendix 3 - List of acronyms, general definitions and project terms

The following acronyms, general definitions and project terms are used throughout this report.

| Term | Definition |
|---|---|
| The Act | The Act refers to the *Guardianship and Administration Act 2000* (Qld). |
| Active case/client | A client case file of an Adult Guardian client where a current order was ongoing at the time of review for this research project (i.e. as at 30 December 2010). |
| Adult Guardian client | An adult for whom the Adult Guardian has been appointed by the tribunal as their personal guardian at least once (on a full or interim order) between the 10-year period 2000 and 2010. This means that a client may be an active or closed client of the Adult Guardian. |
| Adult Guardian client database | The database of Adult Guardian clients created by the Office of the Public Advocate for the Adult Guardian Client Profile Project (n=2,978). |
| Appointment order | An order issued by the tribunal, after a hearing, that appoints a guardian (in the context of this work, the Adult Guardian) as substitute decision maker for an adult with impaired decision-making capacity (excludes interim orders). (s. 12 *Guardianship and Administration Act 2000).* |
| Closed case/client | A client case file of an Adult Guardian client where there was no current order at the time of the review for this research project (i.e. as at 30 December 2010). |
| Disability service user | A Queensland resident who accessed specialist disability support services funded under the National Disability Agreement, during the 2008-09 financial year. |
| DS NMDS | The Disability Services National Minimum Data Set (DS NMDS) is a consistent set of data items collected in all Australian jurisdictions under the National Disability Agreement. Information is collected on the people who accessed disability support services provided under the National Disability Agreement, and the agencies that provided the services. |
| Duration of guardianship | The total estimated period of time to which a guardianship client was subject to guardianship. |
| Employment | The Australian Bureau of Statistics defines employment as paid work of at least one hour per week. This is an international definition of employment and is used throughout this report. |
| First order | Is the chronologically first guardianship order to which a person has been subject. |
| GAA 2000 | *Guardianship and Administration Act 2000* |
| GAAT | Guardianship and Administration Tribunal - see Tribunal. |
| Guardianship orders | An umbrella term that includes both interim and appointment orders (for this project, limited to the appointment of the Adult Guardian). |
| Initial client information management system | The initial database system used by the Office of the Adult Guardian to manage its client records. |

Continued

| | |
|---|---|
| Interim order/s | An order issued by the tribunal, without a hearing that appoints a guardian (in the context of this work, the Adult Guardian) as substitute decision maker for an adult with impaired decision-making capacity (s12 *Guardianship and Administration Act 2000).* |
| Labour force participation | The Australian Bureau of Statistics defines the labour force as the total number of people in Australia who are willing and able to work. It includes everyone who is working or actively looking for work - that is, the number of employed and unemployed together as one group. The percentage of the total population who are in the labour force is known as the labour force participation rate. |
| New client | Adults who become an Adult Guardian client for the first time at any point during the 10-year period 2000 to 2010. |
| OAG | Office of the Adult Guardian. |
| OPA | Office of the Public Advocate. |
| QCAT | Queensland Civil and Administrative Tribunal - see Tribunal. |
| Sample case files | The representative case files analysed by the Office of the Public Advocate for the Adult Guardian Client Profile Project (n=68). |
| Shared client | Common adult clients (aged 18-65 years) who were under a guardianship order (full or interim) to the Adult Guardian during the period January 2000 to November 2010 AND who accessed a specialist disability service funded or provided by the state government through the National Disability Agreement during the financial year 2008-09. |
| Shared client database | The database of shared clients created by the Office of the Public Advocate for the Adult Guardian Client Profile Project (n=1,019). |
| Subsequent order | Is any guardianship order, other than the first guardianship order, to which a person has been subject. |
| Term of a guardianship order | Is the length of time for which the tribunal has stated that an order will remain current. An order must be reviewed at the end of its term. |
| Tribunal | The term 'tribunal' refers to the entity established to independently determine guardianship appointments. The Queensland Civil and Administrative Tribunal (QCAT) has been instituted since 1 December 2009 to decide matters about guardianship appointments. QCAT replaced the Guardianship and Administration Tribunal (GAAT) which was established in 2000 under the *Guardianship and Administration Act 2000* (Qld). |
| Trigger for guardianship | An act or event that initiated the guardianship process that resulted in an adult first becoming subject to a guardianship order made to the Adult Guardian. |

# Appendix 4 - Methodology and data sources

## Data sources

The primary research for the Adult Guardian Client Profile Project involved the collation and detailed examination of key data sources to create the following three project databases:

| Data source | Number of records |
|---|---|
| The Adult Guardian client database was constructed from data that was extracted from the Office of the Adult Guardian (OAG) Adult Guardian System (AGS) which records broad information on Adult Guardian clients for the project period 2000-2010. | 2,978 clients |
| A shared client database that matches clients from the Adult Guardian client database with clients in the 2008-09 Disability Services National Minimum Data Set data (DS NMDS ) managed by the then Department of Communities. | 1,019 clients |
| The sample of Adult Guardian client case files provided additional rich information from case files held by the OAG. The sample was determined to be representative of the overall population of guardianship clients (2000-2010) for age, gender, active status of the case and year of entry into the guardianship system. | 68 clients<br>146 orders |

Each project database is explained in detail below.

## Adult Guardian client database

The Adult Guardian client database was primarily used to inform the age and gender profiling.

The OAG operated a client information management system called the Adult Guardian System (AGS) to maintain and manage client and guardianship order details. The AGS was identified for replacement in 2009 due to the need for more sophisticated reporting and record keeping functions.

In August 2011, a new client information management system called OAG Resolve was implemented by the OAG.[145] Once fully operational, OAG Resolve will lead to more streamlined administrative functions and deliver improved reporting capabilities for the work of the office.[146]

Despite some shortfalls, the AGS was the source of information on people who received services from the OAG, including those with guardianship orders made to the Adult Guardian. This source of information forms the first component of the evidence base for the Adult Guardian Client Profile.

The structure and reporting functions of the initial client information management system were not designed to export data in a form suitable for profiling the client population. As a result, a database analyst from the Information Technology Services branch within the Department of Justice and Attorney-General provided assistance to extract the necessary data.

Complex Structured Query Language (SQL) queries were written and implemented to extract the relevant fields for client records over the 10-year period (2000 to 2010). The data was extracted in two phases in late November and early December 2010. Approximately 21,300 client records were extracted from the AGS for the period 2000-2010. Data cleaning and the elimination of duplicates reduced this figure to 6,684 individual client records. After excluding records for services other than guardianship, a database was created of 2,978 unique clients who had been subject to a guardianship order made to the Adult Guardian as at 31 October 2010. The Adult Guardian client database used for this project represents 45% of the total clients of the OAG.[147]

The data extracted from the AGS featured significant errors including duplicate records for individual clients, multiple identification numbers for clients, inconsistent spelling of names and missing data. These issues were addressed in the data cleaning process.

To clarify, this database comprised 2,978 unique individuals (adults) who had been subject to at least one guardianship order (made to the Adult Guardian) between January 2000 and December 2010. This included persons aged 18 years or older, for whom the Adult Guardian has been appointed by means of a guardianship order made by the tribunal.

The Adult Guardian client database was used to identify shared clients in the DS NMDS and to select the sample of case files.

[145] The Office of the Public Advocate has provided information to the OAG in relation to the recording and data quality issues that were identified during the course of this project. This may assist with its future decision-making and practices in this area, particularly as the new client information management system is being embedded.
[146] Office of the Adult Guardian 2011, *Annual Report 2010-11*, Department of Justice and Attorney-General, Brisbane.
[147] The remaining 55% represented individuals who had never been subject to a guardianship order but who had received another type of the other services provided by the OAG.

## Data limitations

Analysis based on the Adult Guardian client database is only as accurate as the quality & completeness of client details in the AGS.

The data that was used to develop the Adult Guardian client database was current as at November 2010, when it was extracted from the AGS. The OAG maintains a 'live' information system to manage its clients, meaning that information about guardianship orders and clients is continually updated. The client profile is therefore accurate only for the time of extraction.

# Shared client database

The shared client database was primarily used to inform the profile of clients subject to a guardianship order made to the Adult Guardian.

The Adult Guardian client database contained a ten-year collection of client records, however it did not contain detailed client information. To obtain a greater depth of client information, client data from the AGS was matched against client data from the Disability Services National Minimum Data Set (DS NMDS) held by the Department of Communities.

The DS NMDS is a specialist disability data collection held by the Department of Communities.[148] Under the National Disability Agreement (previously the Commonwealth State and Territory Disability Agreement), States and Territories collate agreed data items in relation to specialist disability services on an annual basis. The information in the DS NMDS is published in the Report on Government Services produced by the Productivity Commission as well as other publications produced by the Australian Institute for Health and Welfare.

To be eligible for these specialist disability services in Queensland, applicants must:

- Be a Queensland resident
- Have a severe or profound limitation in communication, mobility or self care
- Be under 65 years of age at the time of onset of the condition for which the service is being sought.

At the time of the analysis, the most recently available DS NMDS data for Queensland was the 2008-09 collection. The 2009-10 data was preliminary at the time and unavailable for use. The 2008-09 collection included approximately 15,850 adult disability service users (18-64 years).

The outcome of the data linkage process between these two data sets was the shared client database.

## Data limitations

The shared client database is not representative of the overall population of guardianship clients due to a number of factors. Specifically, specialist disability services are:

- In high demand and are delivered on a priority basis. This means that those people who access them tend to have the highest level of need.
- Not intended to support aged clients. As such the age profile of DS NMDS clients is heavily skewed towards people under 65 years of age.

The shared client database only represents the overlap between ten years of guardianship clients and a single year of specialist disability services. A guardianship client may have accessed these disability services years before, or after, their period of guardianship.

## The data linkage process

Data linkage is a method used to combine data from more than one administrative or statistical dataset. It provides a means of maximising the potential of existing government datasets, particularly where a shared client base is known to exist. It has been used successfully at the national and state level. See the following for more information on data linkage:

- National Community Services Information Management Group 2004, Statistical Data Linkage in Community Services Data Collections, Australian Institute of Health and Welfare, Canberra.
- Cross Portfolio Statistical Integration Committee 2010, High Level Principles for Data Integration Involving Commonwealth Data for Statistical and Research Purposes, Cross Portfolio Statistical Integration Committee Secretariat, Australian Government, Canberra.

The Adult Guardian Client Profile project assumed that a significant proportion of guardianship clients would also access specialist disability services provided under the National Disability Agreement (NDA). Using this assumption, an exploratory data linkage exercise was undertaken using the administrative datasets of the OAG and the Department of Communities. This exercise showed that there was sufficient information present in both data sets to allow full scale data linkage to be undertaken.

[148] As of April 2012, the Department of Communities has been renamed as the Department of Communities, Child Safety and Disability Services. For ease of reference, the former title is maintained in the report.

## Data sources

The data linkage process involved two data collections:

- the Adult Guardian client database and
- the DS NMDS .

The Adult Guardian client database holds 10 years of guardianship client records while the DS NMDS is a collection describing a single year (2008-09).

The broad characteristics of the two data collections are summarised in Table 8:

***Table 8*** **Characteristics of the data sources used in the data linkage process**

| Adult Guardian client database 2000-2010 | Disability Services National Minimum Data Set 2008-09 |
|---|---|
| 2,978 records for clients subject to guardianship orders made to the Adult Guardian | 22,544 records for clients accessing specialist disability services |
| Live client information management system | Annual reconciliation of services received |
| Seven variables describing clients | Forty one variables describing clients |
| Ten year collection period (2000 to 2010) | One year collection period (2008-09) |

## Linking the Adult Guardian Client Database with the DS NMDS

The Office of the Public Advocate collaborated with the then Department of Communities to match de-identified client data in the Adult Guardian client database with DS NMDS data. This was used to develop the shared client database used for the project.

The two data collections were linked by matching a statistical linkage key (SLK). A SLK is a pseudo-unique identifier used to identify individual records within a database without relying on personal information like a person's name.

The SLK used in the DS NMDS combines elements from three components: name; date of birth and gender.[149] These components are used to create a 14 character SLK unique identifier.[150] [151] This SLK algorithm was applied to the records in the Adult Guardian client database.

The then Department of Communities was provided with the SLK for the 1,739 guardianship clients for whom there was sufficient information to construct a useful SLK. The remaining 1,239 records were deemed unsuitable for matching because:

- The record lacked a reliable date of birth that would make the likelihood of achieving a match extremely low
- The client was deceased prior to the DS NMDS collection year (2008-09) and hence unable to access a service during the collection
- The client was over the age of 65 in the DS NMDS collection year (2008-09). Persons over the age of 65 are highly unlikely to access a DS NMDS as they are intended for persons aged under 65.

The then Department of Communities returned two data sets correlating to those clients with whom a match was found in the DS NMDS, and the DS NMDS services they accessed. Of the 1,739 OAG client identifiers provided to the then Department of Communities, 1,019 were matched to DS NMDS service records for 2008-09. These clients collectively had 3,264 records of DS NMDS services accessed.[152]

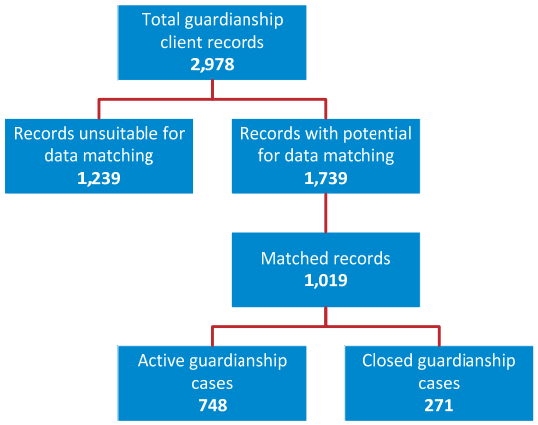
Within the Adult Guardian Client Profile Project, the 1,019 clients identified in the data linkage with the DS NMDS are referred to as "shared clients". A shared client is an adult who was subject to a guardianship order at least once between 2000 and 2010, and who accessed specialist disability services in 2008-09 funded or provided by the then Department of Communities.

[149] Australian Institute of Health and Welfare & Queensland Government 2009, *Disability Services National Minimum data Set Collection Data Guide (Queensland Edition)*, Department of Communities, Brisbane.
[150] Australian Institute of Health and Welfare (AIHW) 2009, Disability Services National Minimum Data Set Collection Data Guide: Data Items and Definitions 2009-10, AIHW, Canberra.
[151] Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) 2011, *Disability Services Census 2011*, FaHCSIA, viewed 30 June 2011, <http://www.fahcsia.gov.au/sa/disability/progserv/providers/infocollection/Pages/services-census.aspx#8>.
[152] Service access records in the DS NMDS are not episodic but rather indicate only that a particular type of service was accessed at least once in the collection year.

# Data linkage outcome

The data linkage process allowed the 1,019 shared clients to be profiled by the DS NMDS services they accessed. These shared clients included 748 active guardianship cases and 271 closed guardianship cases (see Figure 35).

***Figure 35*** **Guardianship client records and data linkage outcome**




Only 59% of the 1,739 records that were supplied to the then Department of Communities were matched against the 2008-09 DS NMDS. This is not unexpected for a number of reasons:

- Specialist disability services are neither appropriate nor necessary for many guardianship clients (based on client age and type of severity of need)
- A portion of the guardianship client population were deceased prior to the collection period
- A portion of the guardianship client population did not enter the guardianship system until after the collection period.

It is likely that some guardianship clients were in receipt of other services such as those provided by the Home and Community Care programme (HACC) or community mental health services. These data collections were not available for inclusion in this project.

The 720 guardianship client SLKs that were submitted to the then Department of Communities but that remained unmatched were analysed during the data linkage process. These unmatched clients tended to be older and less likely to have an intellectual disability. This is not surprising considering the provision of specialist disability services tends to be skewed towards younger adults and people with an intellectual disability.[153] [154]

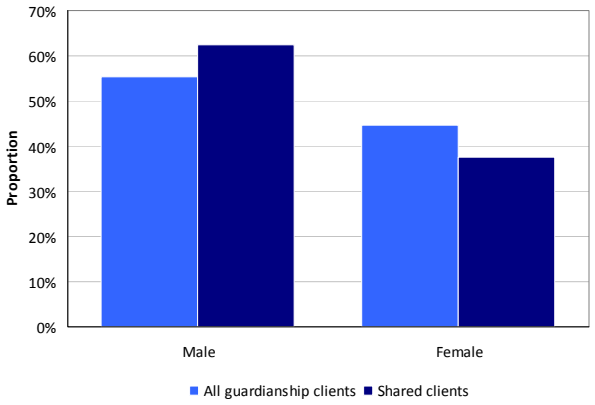
# Evaluation of the shared client database

The shared client database was tested to ascertain its ability to represent the Adult Guardian client population. Due to the limited amount of personal information about clients contained in the Adult Guardian client database, testing was limited to variables for age, gender and primary disability variables.

Based on the available data, the profile of shared clients was determined to be representative of the Adult Guardian client population only for age and gender and only for those clients under the age of 65 years.

A comparison of the gender balance of shared clients and all guardianship clients is presented in Figure 37. The gender balance shows marked disparity between the two populations.

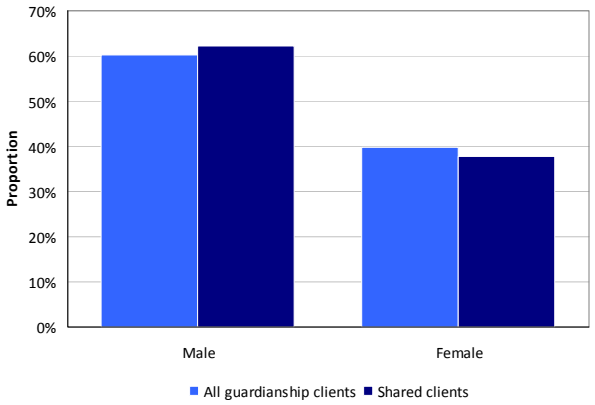
***Figure 36*** **Gender comparison of the guardianship client and shared client populations**




**Source:** Adult Guardian client database n= 2,866 and shared client database n=1,019.

A comparison of the gender balance of shared clients and all guardianship clients under 65 years is presented in Figure 3. The gender balance from each population is comparable when limited to those under the age of 65 years.

***Figure 37*** **Gender comparison of all and shared clients under 65 years of age**

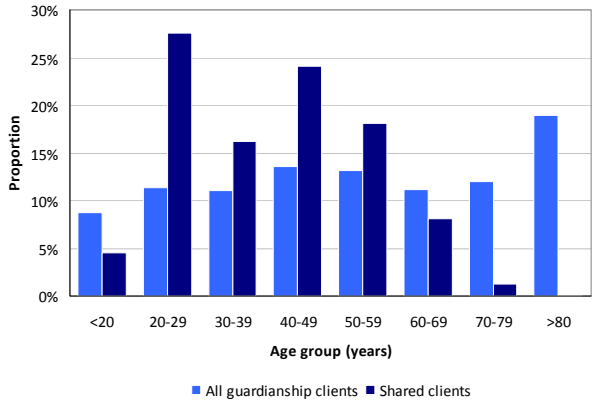



**Source: Adult Guardian client database, n=1,820 and shared client database n=978.**

[153] Australian Institute of Health and Welfare (AIHW) 2011, Disability Support Services 2008-09: Report on Services Provided under the Commonwealth/State Disability Agreement and the National Disability Agreement, Cat No. DIS 58, AIHW, Canberra.
[154] Department of Communities 2010, Customised Data Request, November 2010, Disability Services National Minimum Data Set 2008-09, Department of Communities, Brisbane.

The comparison of the age profile of guardianship clients and the shared client populations reveals significant disparity. The guardianship client population is substantially older with over 20% of guardianship clients being over 80 years of age.

***Figure 38*** **Age profile comparison of the guardianship client and the shared client populations**

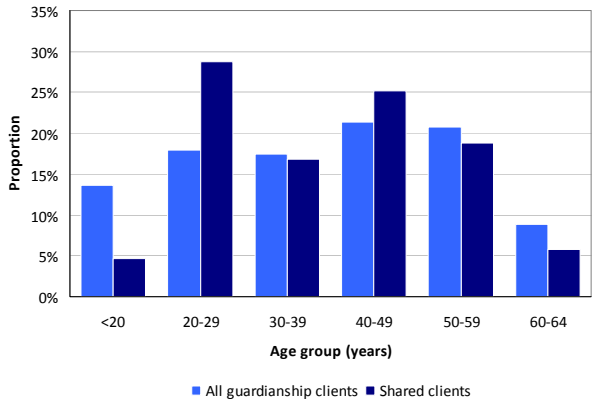



**Source:** Adult Guardian client database n= 2,866 and shared client database n=1,019.

The disparity in age profiles is greatly reduced when comparing only the under 65 year component of each population. As seen in Figure 5, the age profile of shared clients more closely reflects that of all guardianship clients under 65 years. This is still a significant bias towards the older age groups.

The age profile of people subject to a guardianship order made to the Adult Guardian is discussed further in the report.

***Figure 39*** **Age comparison of all and shared clients**

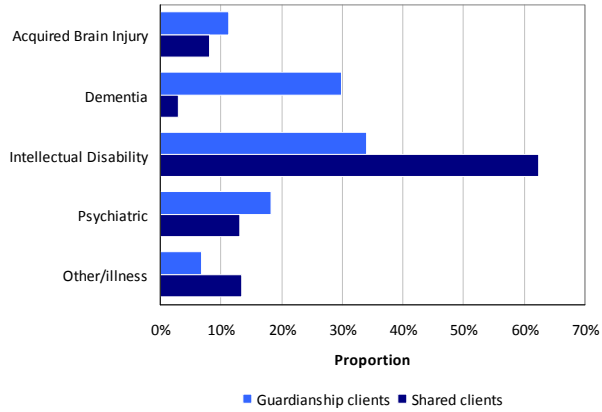



**Source:** Adult Guardian client database n=1,820 and shared client database n=978.

Figure 6 shows that the shared client population was not representative of the guardianship client population for disability types. This is likely due to the strong correlation between age and conditions that impair an individual's decision-making capacity (such as dementia). The late onset of these conditions means that clients are much less likely to access specialist disability services. The reverse is true for conditions resulting in intellectual disability, which tend to be either life-long or manifest at an early age.

Caution should be exercised when comparing proportions in Figure 6 as the method of recording disability types for clients of the Adult Guardian lacked the definitional rigour found in the DS NMDS.

***Figure 40*** **Primary disability type comparison of all and shared clients**




**Source:** Adult Guardian client database, n=2,675 (303 missing) and shared client database n=1,011 (8 missing).

# Sample case files

The sample case files were primarily used to inform the demographic profile of guardianship clients and the administrative aspects relating to their guardianship orders.

The Adult Guardian Client Profile Project included a detailed examination of a small sample of Adult Guardian clients. The intention was to collect extensive information on a small number of clients to build an in-depth understanding of the Adult Guardian client base. This information was intended to cover topics for which there was no information available in any other data source.

To compensate for the relatively small size of the sample, care was taken to ensure that the sample was representative of:

- the age and sex distribution
- the balance of active and closed cases
- the year of entry into the guardianship system.

This allows the findings from the sample to be reliably applied to the broader population of people subject to guardianship.

Stratified random sampling was chosen as the sample selection method, meaning each Adult Guardian guardianship client had an equal probability of being selected based on the representativeness of their demographics. A sample of 75 cases was selected from the AGS, representing 3% of the total guardianship client population. The unavailability of a small number of the randomly selected files meant that 68 out of 75 cases were examined.

A data collection tool was developed by OPA to gather socio-demographic information on guardianship clients. The tool also collected information on the guardianship orders made by the Queensland Civil and Administrative Tribunal for guardianship clients. This information included the length of orders, the matters for which they were made, and triggers and applicants for guardianship orders.

The data collection tool was a database of information from the case files. The majority of variables were direct extractions from case file forms and notes. Where possible, variables were adapted from existing frameworks such as the 2009 Survey of Disability, Ageing and Carers, the 2006 Census of Population and Housing or the International Classification of Disability and Functioning. Some variables were constructed anew. This is noted throughout the report where applicable and is reported in Appendix 6.

Similarly to the extraction of data from the OAG's client information management system, the collation of case file information was a time and resource-intensive process. The collection of data from the sample of case files was undertaken between March and April 2011. The large majority of case files were collected and recorded by a single staff member thereby reducing the risk of variation in assessment and recording of variables.

Many client cases were complex and comprised of several files, some of which were not kept in order. Some closed files were retrieved from archive and a number were couriered from the Adult Guardian's Townsville office.

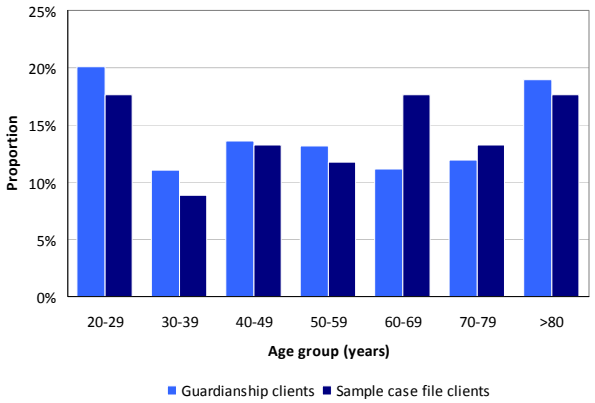
Prior to sampling, the sample cases were tested to determine if they were representative of the guardianship client population. Representativeness was determined by comparison of the sample to the Adult Guardian client database. The comparison covered the following variables:

- age at entry to guardianship,
- gender,
- time of guardianship order, and
- active status of the case.

The sample was determined to be representative of the guardianship client population for all of these variables. This means that the findings based on the sample case file data can be applied to the overall guardianship population where the Adult Guardian is appointed as the guardian.

Figure 7 and Figure 8 illustrate a comparison of the age and gender profile of the sample case files with the total Adult Guardian client database. In terms of age at entry to guardianship, the sample closely matched the total client population from which it was drawn.

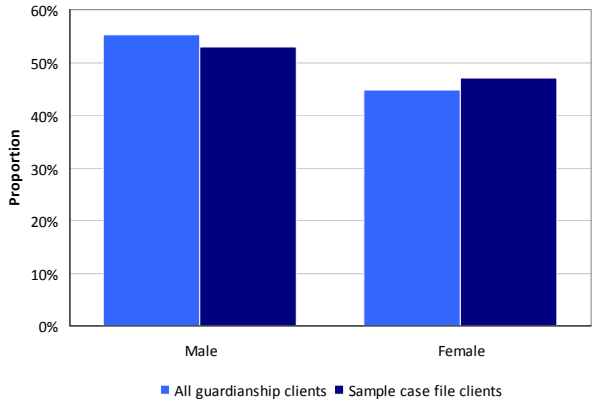
***Figure 41*** **Age at entry to guardianship comparison of all and sample case file clients**




**Source:** Adult Guardian client database, n=2,866 (112 missing cases); Sample case files, n=68.

The sample had a similar proportion of males and females than the total client population.

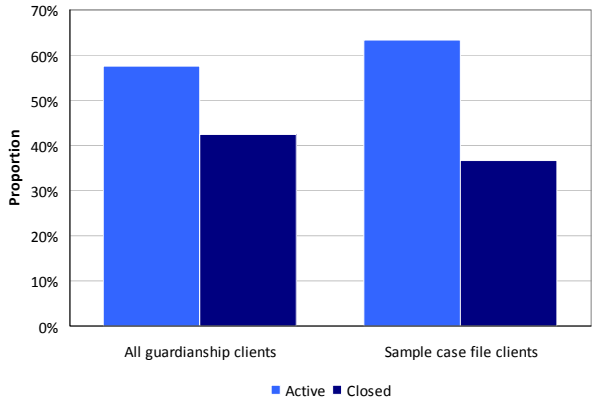
***Figure 42*** **Gender comparison of all and sample case file clients**




**Source:** Adult Guardian client database, n=2,978; Sample case files, n=68.

Active cases accounted for a slightly higher proportion in the sample compared to the population from which it was drawn (Figure 9). This may be partially attributable to the unavailability of a number of closed files that had been archived and were not able to be located.

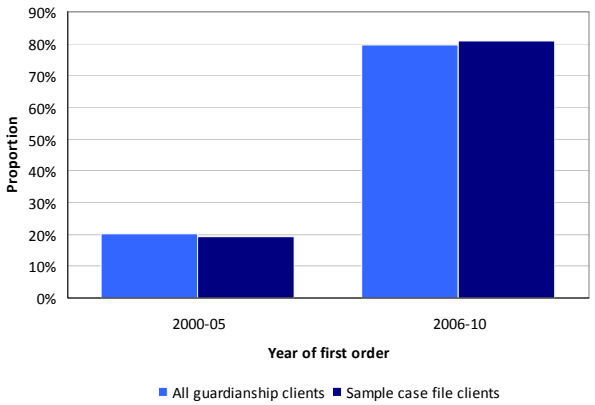
***Figure 43*** **Active status comparison of all and sample case files**




**Source:** Adult Guardian client database, n=2,978; Sample case files, n=68

Client case files from the period 2006-2010 accounted for 81% of the sample case files. This reflected the proportion of total guardianship clients during that period (Figure 10).

***Figure 44*** **Time comparison of all and sample case file clients**




**Source:** Adult Guardian client database, n=2,978; Sample case files, n=68. Note: Data is based on the date of first guardianship order.

## Data limitations

The sample of guardianship client case files represents a relatively small proportion of the guardianship client population. This restricts the statistical accuracy of findings where there is a small number of case files involved. This has been taken into account in the analysis presented in this report.

The sample methodology relied on the operationalisation of a number of variables. Where possible, these variables were aligned to national or local standards, such as those provided by the ABS. To assist with the interpretation of this data, this report includes details about how the sample variables were defined and applied in Appendix 6.

Information from the sample case files was extracted over three months from February to April 2011. Personal information and administrative data pertaining to guardianship orders was accurate as at the time of the latest update provided in the files.

# Appendix 5 - Disability Services National Minimum Dataset data definitions

## Support needs

In the DS NMDS the support needs question records information about the need for help or supervision in the overall life of a person who is in receipt of services provided through a National Disability Agreement (NDA) funded service provider.

A need for help or supervision in a particular life area may, or may not, be directly relevant to the service being provided.

As well as this, a particular life area may not be relevant to a service user aged 15 years and over but would be an estimated assessment of what level of support the service user would need to participate in that particular life area.

The need must be due to the person's disability, and should be ongoing (have lasted or be expected to last for 6 months or more). It must relate to the extent of need over and above that which would usually be expected due to their age, i.e. it should be evaluated in relation to a person of the same age without a disability.

### Question:

How often does the service user need personal help or supervision with activities or participation in the following life areas?

### Life areas

**Self-care** – activities such as washing oneself, dressing, eating and/or toileting

**Mobility** – moving around the home and/or moving around away from home (for instance, using public transport), getting in or out of bed or a chair

**Communication** – making self understood by strangers/family/friends/staff, in own native language or most effective method of communication if applicable, and understanding others

**Interpersonal interactions and relationships** – including, for example, actions and behaviours that an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions

**Learning, applying knowledge and general tasks and demands** – understanding new ideas, remembering, solving problems, making decisions, paying attention, undertaking single or multiple tasks, carrying out daily routines

**Education** – for example, the actions, behaviours and tasks an individual needs to perform at school, college or any educational setting

**Community (civic) and economic life** – for example, participating in recreation and leisure, religion and spirituality, human rights, political life and citizenship, and economic life such as handling money

**Domestic life** – undertaking activities such as shopping, organising meals, cleaning, disposing of garbage, housekeeping, cooking and home maintenance (this does not include care of household members, animals and/or plants)

**Working** – for example, undertaking the actions, behaviours and tasks needed to obtain and retain paid employment.

### Frequency of need for support

The person can undertake activities or participate in this life area with this level of personal help or supervision:

1. Unable to do or always needs help or supervision in this life area.
2. Sometimes needs help/supervision in this life area.
3. Does not need help or supervision in this life area but uses aids and/or equipment.
4. Does not need help or supervision in this life area and does not use aids and/or equipment.
5. Not applicable—only use where the need for support or assistance is due to the person's age, not their disability.

## Service type definitions

### Definition

The funded support activity that has been provided to the client under the NDA.

### Service types

**Accommodation support**

Services that provide accommodation to people with a disability and services that provide support needed to enable a person with a disability to remain in their existing accommodation or to move to more suitable or appropriate accommodation.

Accommodation support services includes the following sub-categories:

- Large residential/institution (>20 places)—24-hour care
- Small residential/institution (7–20 places)—24-hour care
- Hostels—generally not 24-hour care
- Group homes (<7 places)
- Attendant care/personal care
- In-home accommodation support
- Alternative family placement
- Other accommodation support.

**Community support**

Services that provide the support needed for a person with a disability to live in a non-institutional setting. Support with the basic needs of living such as meal preparation, dressing, transferring etc. are included under accommodation support.

Community support services includes the following sub-categories:

- Therapy support for individuals
- Early childhood intervention
- Behaviour/specialist intervention
- Counselling (individual/family/group)
- Regional resource and support teams
- Case management, local coordination and development
- Other community support.

**Community access**

Services designed to provide opportunities for people with a disability to gain and use their abilities to enjoy their full potential for social independence. People who do not attend school, or who are not employed full-time mainly use these services.

Community access support includes the following sub-categories:

- Learning and life skills development
- Recreation/holiday programs
- Other community access.

**Respite**

Respite services provide a short-term and time-limited break for families and other voluntary care givers of people with disabilities to assist in supporting and maintaining the primary care giving relationship, while providing a positive experience for the person with a disability.

Respite support includes the following sub-categories:

- Own home respite
- Centre-based respite/respite homes
- Host family respite/peer support respite
- Flexible respite
- Other respite.

# Informal Carer arrangements – additional information

The Disability Services National Minimum Data Set, Data Guide: Data Items and definitions 2009-10 recognises that more than one person may provide informal care, however information about carer attributes is only collected for the main carer.

The main carer is defined as the person who provides the most significant care and assistance related to the service user's capacity to remain living in their current environment.

Where two or more people equally share the caring role (eg. mother and father) characteristics are only requested for one of these carers.

It is also recognised that the roles of parent and carer, particularly in the case of children, are difficult to distinguish. Carers of children may consider they are a carer (as well as a parent) if they provide more care to their child than would be typical of the care provided to a child of the same age without a disability.

This data item is purely descriptive of a service user's circumstances. It is not intended to reflect whether the carer is considered by the funded agency capable of undertaking the caring role.

# Residential Setting

## Question

What is the service user's usual residential setting? ('usual' means 4 or more days per week on average)

## Definition

The type of physical accommodation in which the person usually resides ('usually' being 4 or more days per week on average).

## Classification

- Private residence (e.g. private or public rental, owned, purchasing etc.)
- Residence within an Aboriginal/Torres Strait Islander community (e.g. rented private residence, temporary shelter)
- Domestic-scale supported living facility (e.g. group homes)
- Supported accommodation facility (e.g. hostels, supported residential services or facilities)
- Boarding house/private hotel
- Independent living unit within a retirement village
- Residential aged care facility (nursing home or aged care hostel)
- Psychiatric/mental health community care facility
- Hospital
- Short-term crisis, emergency or transitional accommodation facility (e.g. night shelters, refuges, hostels for the homeless, halfway houses)
- Public place/temporary shelter
- Other (includes situations such as a child under a court/guardianship order with no usual address).

# Appendix 6 - Sample case file definitions and explanatory notes

## Rationale

This project collected information from a random sample of case files of adults with impaired decision-making capacity who were subject to guardianship by the Adult Guardian between 2000-10.

The case files were of the working files that guardians used while performing their function and included a mix of formal documents associated with QCAT hearings, applications for guardianship, communications with service providers and family members, as well as case notes written by the guardians themselves.

During the initial scoping of the project, five case files were used to identify variables that could be used to profile the guardianship client population. Some variables were based on information recorded on official forms, such as the date of order, marital status of a client or matters of appointment. Other variables were operationalised using conceptual frameworks from related data sources such as the ABS Survey of Disability, Ageing and Carers.

The following forms were frequently used to collect data from the sample case files:

- Form 10 - Application for administration/guardianship appointment or review
- Form 41 - Application for interim order or injunction
- Form 11 - Application for a declaration about capacity
- Form 12 - Application for miscellaneous matters

The project was designed to report on a number of variables for which there was either no existing conceptual framework or for which the existing frameworks were considered unsuitable. These variables, such as the triggers for guardianship applications, were operationalised anew. They are not intended to describe all possible responses, but rather to provide insight into the frequency with which responses of interest occurred.

The following table describes the rationale used to classify and record groups of variables that were used in the sample of guardianship client case files.

***Table 9*** **.Rationale for variables collected in the sample of case files**

**Variables describing individual characteristics**

| Variables | Rationale |
|---|---|
| Carer demographics | The variables and categories used to describe carers were based on those used in the DS NMDS and the 2003 SDAC. |
| Disability classification | Three separate disability classifications were recorded to enhance comparability with other data sources. The data collection tool recorded the OAG primary impairment, the International Classification of Functioning and Disability (ICF) broad activity limitation and the level of core activity limitation.<br><br>No formal definitions are used to assess categories for OAG primary impairment. Without any basis on which to perform independent validation, the OAG primary impairment was copied from the file without change.<br><br>The ICF broad activity limitations were based on the International Classification of Functioning and Disability. This classification system is based on comprehensive definitions and has international recognition. Previous work undertaken by the OPA has enabled the ICF broad activity limitations to be compared to the 2003 SDAC disability types.<br><br>The level of core activity limitation was based on the definitions used in the 2003 SDAC. This same system of classification is also used in the DS NMDS. |
| Communication | The variables “communication method” and “need for a translator” were adapted from variables used in the DS NMDS. The adaptation made these variables more appropriate an entirely adult population. |
| Income | The income categories were based on those used in the 2003 SDAC. |
| Health and medical conditions | The health variables were developed independently based on an initial reading of five case files. The variables were intended to identify known issues in the population (such as drug or alcohol abuse, medication for sexual disinhibition etc) or record the presence of specific events related to guardianship (such as an ITO or forensic order). |
| Accommodation | The accommodation variables were based on the 2003 SDAC and the 2006 Census.<br><br>Accommodation type and tenure categories were copied from the 2003 SDAC.<br><br>The variables “Whether living at same address 5 years ago” and “Whether living at same address 1 year ago” were copied from the 2006 Census. |
| Participation | The participation variables were adapted from the 2003 SDAC categories. |
| Safety and risk | The safety variables were developed independently based on issues that were identified as significant during the conception phase of the project. The variables were intended to correspond to issues known to be significant in the guardianship population such as family conflict, crime, poverty etc. |
| Support needs and assistance received | The support needs and assistance received variables were based on need for, and access to, human services. |

| Variables describing characteristics of orders | |
|---|---|
| **Variables** | **Rationale** |
| Matters of appointment | The matters of appointment variables were based on the written orders made by QCAT. These in term were operationalised from the GAA 2000. |
| Person making the application for guardianship | The applicant variable was developed independently based on an initial reading of five case files. Further categories were coded based on likely applicants such as family members or service providers. |
| Restrictive practices | The restrictive practices variables were based on the 2008 restrictive practices amendments to the DSA 2006. |
| Triggers for the application for guardianship | The trigger variable was developed independently based on an initial reading of five case files. |

# Definitions

The table below lists all of the variables used in the sample of guardianship client case files and their responses.

***Table 10*** **List of variables used in the sample of guardianship client case files**

| Name | Definition | Categories |
|---|---|---|
| Id no | Case identification | Number |
| Date entered | Data entry original date | Date |
| Date revised | Data revision last date | Date |
| Date last entry | Date of most recent entry in file | Date |
| File ref no | OAG file reference number | Number |
| Surname | Client first name | Text |
| First name | Client surname | Text |
| Sex | Sex | 1 = Male<br>2 = Female |
| Birth date | Date of birth | Date |
| Death date | Date of death | Date |
| Marital status | Current marital status (married includes de facto) | 1 = Married<br>2 = Widowed<br>3 = Divorced<br>4 = Separated<br>5 = Never married<br>9 = Unknown or not stated |
| Children | Number of children (including step children) | Number |
| Carer presence | Whether there is a carer (paid or unpaid) at time of entry to guardianship system - if adult is temporarily in hospital, and there is normally an the informal carer, that person is denoted | 1 = Paid carer<br>2 = Unpaid carer<br>3 = Cares for self<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Carer age | Informal carer's age category estimate | 1 = Under 35<br>2 = 35-64<br>3 = 65 and over<br>9 = Unknown or not stated |
| Carer sex | Informal carer's sex | 1 = Male<br>2 = Female |

**Continued**

| | | |
|---|---|---|
| Carer relationship | Relationship of informal carer to client | 01 = Husband<br>02 = Wife<br>03 = Father<br>04 = Mother<br>05 = Son<br>06 = Daughter<br>07 = Brother<br>08 = Sister<br>09 = Grandson<br>10 = Granddaughter<br>11 = Grandfather<br>12 = Grandmother<br>13 = Other relative<br>14 = Friend<br>15 = Other<br>99 = Unknown or not stated |
| Carer residence | Residential location of informal carer | 1 = Resides with adult<br>2 = Resides nearby<br>3 = Resides elsewhere<br>9 = Unknown or not stated |
| Country birth | Whether main English speaking country other than Australia (NZ, UK, Ireland, USA, Canada, South Africa & Zimbabwe) | 1 = Australia<br>2 = Main English speaking<br>3 = Non-English speaking<br>9 = Unknown or not stated |
| Main language | Whether main language spoken at home is English | 1 = English<br>2 = Language other than English<br>9 = Unknown or not stated |
| Indigenous | Whether aboriginal and/or Torres Strait Islander | 1 = Non-indigenous<br>2 = Aboriginal<br>3 = Torres strait islander<br>4 = Both aboriginal & Torres Strait Islander<br>6 = Unable to be determined |
| ICF learn | Needs assistance with ICF activity learning and applying knowledge<br>Purposeful sensory experiences<br>Basic learning<br>Applying knowledge | Yes/No |
| ICF communication | Needs assistance with ICF activity communication<br>Communicating – receiving<br>Communicating – producing<br>Conversation and use of communication devices and techniques | Yes/No |
| ICF mob | Needs assistance with ICF activity mobility<br>Changing and maintaining body position<br>Carrying, moving and handling objects<br>Walking and moving<br>Moving around using transportation | Yes/No |

**Continued**

| | | |
|---|---|---|
| ICF self care | Needs assistance with ICF activity self-care<br>Washing oneself<br>Caring for body parts<br>Toileting<br>Dressing<br>Eating<br>Drinking<br>Looking after one's health | Yes/No |
| ICF domestic | Needs assistance with ICF activity domestic life<br>Acquisition of necessities<br>Household tasks<br>Caring for household objects and assisting others | Yes/No |
| ICF interpersonal | Needs assistance with ICF activity interpersonal interactions and relationships<br>General interpersonal interactions<br>Particular interpersonal relationships | Yes/No |
| ICF education | Needs assistance with ICF activity major life areas<br>Education<br>Work and employment<br>Economic life | Yes/No |
| ICF CSCL | Needs assistance with ICF activity community, social and civic life<br>Community life<br>Recreation and leisure<br>Religion and spirituality<br>Human rights<br>Political life and citizenship | Yes/No |
| OAG impair ABI | OAG primary impairment ABI | Yes/No |
| OAG impair ID | OAG primary impairment intellectual disability | Yes/No |
| OAG impair psyc | OAG primary impairment psychiatric | Yes/No |
| OAG impair dementia | OAG primary impairment dementia | Yes/No |
| OAG impair illness | OAG primary impairment illness | Yes/No |
| OAG impair other | OAG primary impairment other | Yes/No |
| Communication method | Main method of communication | 1 = Speech with gestures<br>2 = Makaton / other non-verbal devices<br>3 = Gestures only<br>4 = Looks and gazes only<br>5 = Other<br>9 = Unknown or not stated |
| Communication translator | Whether a need for a translator (language or speech) | 1 = Yes<br>2 = No |
| Communication ability | Whether ability to communication is compromised due to impairment / disability | 1 = Yes<br>2 = No<br>9 = Unknown or not stated |

**Continued**

| | | |
|---|---|---|
| Income DSP | Disability Support Pension recipient | Yes/No |
| Income DVA | Dept of Veterans' Affairs recipient | Yes/No |
| Income age pension | Australian govt age pension recipient | Yes/No |
| Income rental assist | Commonwealth rental assistance recipient | Yes/No |
| Income wage | Wage or salary earner | Yes/No |
| Income other | Other main source of income | Yes/No |
| Income no record | An income source unable to be determined | Yes/No |
| Disability need | Whether has need for assistance with core-activity due to disability, long term health condition or old age (similar to ASSNP in census) | 1 = Yes<br>2 = No<br>3 = Unable to be determined<br>9 = Unknown or not stated |
| Disability status | Level of core activity limitation (refer to core activity limitation in the SDAC) | 1 = Profound<br>2 = Severe<br>3 = Moderate<br>4 = Mild<br>5 = Schooling restriction<br>6 = Employment restriction<br>7 = No limitation<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Accommodation arrangements | Whether currently lives alone or with others | 1 = Lives alone<br>2 = Lives with family<br>3 = Lives with others |
| Accommodation type previous | Previous type of accommodation when application for guardianship was made | 01 = House/unit<br>02 = Caravan<br>03 = Shed<br>04 = Tent<br>05 = Hospital (general)<br>06 = Residential aged care<br>07 = Group homes<br>08 = Prison<br>09 = Hospital (psychiatric/ forensic unit)<br>10 = Boarding house /hostel<br>11 = Other<br>12 = Sleeping rough<br>13 = Shelter<br>15 = Other<br>99 = Unknown or not stated |

**Continued**

| | | |
|---|---|---|
| Accommodation type current | Current type of accommodation at closure of case or as at date of recording data | 01 = House/unit<br>02 = Caravan<br>03 = Shed<br>04 = Tent<br>05 = Hospital (general)<br>06 = Residential aged care<br>07 = Group homes<br>08 = Prison<br>09 = Hospital (psychiatric/ forensic unit)<br>10 = Boarding house /hostel<br>11 = Other<br>12 = Sleeping rough<br>13 = Shelter<br>15 = Other<br>99 = Unknown or not stated |
| Accommodation address same 5yr | Whether living at same address 5 years ago | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Accommodation address same 1yr | Whether living at same address 1 year ago | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Participation activity | Current main activity undertaken. People of retirement age are coded ‘retired’ rather than 'disability' | 1 = Working or looking for work<br>2 = Working in unpaid voluntary job<br>3 = Home duties<br>4 = Studying<br>5 = Retired<br>6 = Own illness/injury<br>7 = Own disability<br>8 = Caring for ill/disabled/aged person<br>9 = Unknown or not stated |
| Participation volunteer previous | Whether ever undertaken unpaid volunteer or community work (not household) | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety isolation | Whether isolated from friends or family | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |

**Continued**

| | | |
|---|---|---|
| Safety family conflict | Whether at risk due to family conflict | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety DVO | Whether subject to DVO | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety medication | Whether at risk due to failure to appropriately medicate | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety drug/alcohol | Whether at risk due to drug or alcohol abuse | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety physical | Whether at risk of physical abuse | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety self harm | Whether at risk of self harm | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety financial | Whether at risk of financial exploitation | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety accommodation | Whether under threat of eviction, end of lease, change of address | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |

**Continued**

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|---|---|---|
| Safety crime | Whether at risk of participating in criminal activity | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety crime victim | Whether at risk of being a victim of criminal activity | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety justice | Whether at risk of interaction with justice system | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety investigate | Number of investigations ever undertaken | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety alimentation | Whether at risk of poor nutrition or starvation | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety neglect | Whether at risk of neglect by others through omission or commission | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety harm others | Whether at risk of causing harm to others | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |
| Safety self neglect | Whether at risk of neglect by self through omission or commission | 1 = Yes<br>2 = No<br>7 = NA<br>8 = Unable to be determined<br>9 = Unknown or not stated |

# Supported accommodation

The following accommodation types were conflated to "supported accommodation" when analysing the sample case files.

## Domestic-scale supported living facility

Community living settings in which services users reside in a facility that provides support in some way by staff or volunteers. This category includes group homes, cluster apartments where a support worker lives on site, community residential apartments, congregate care arrangements, etc. Domestic-scale supported living settings may or may not have 24-hour supervision and care.

## Supported accommodation facility

Refers to larger supported facilities (usually 7 or more people) in which service users reside in an accommodation facility that provides board or lodging for a number of people and that has support services provided on what is usually a 24-hour basis by rostered care workers. Supported accommodation services facilities include hostels for people with disabilities. Aged care hostels are included in residential aged care category.

## Psychiatric/mental health community care facility

Refers to community care units that provide accommodation and non-acute care and support on a temporary basis to people with mental illness or psychological disabilities.

## Office of the Public Advocate

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|---|---|
| **Website** | **www.publicadvocate.qld.gov.au** |
| **Email** | **public.advocate@justice.qld.gov.au** |
| **Write to** | **Office of the Public Advocate**<br>**GPO Box 149**<br>**BRISBANE QLD 4001** |
| **Telephone** | **(07) 3224 7424** |
| **Fax** | **(07) 3224 7364** |


Queensland Government