The potential population for systems advocacy

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

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

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

Our fact sheet series is one of the ways we share information and knowledge.

Further information Fact Sheet: Glossary of Research Terms

Potential population for systems advocacy

The concept of a 'potential population' for statutory systems advocacy developed from the need to better understand the scope, demand and focus for our work.

The potential population for systems advocacy includes all Queensland adults who may have impaired decision-making capacity. A person's capacity to make decisions may be impaired for a range of reasons including (though not limited to) dementia, intellectual disability, acquired brain injury or mental illness.

The potential population for systems advocacy is not restricted to people who receive a government-funded or government-provided specialist disability service. It is also not limited to people who are subject to a formal guardianship or administration order. The potential population for systems advocacy is much larger, as illustrated in Figure 1.





Sources: ABS 2011, AIHW 2011, OPA 2013.

January 2016 (revised)



Size of the potential population

The exact size of the potential population is not known as it is difficult to determine the number of people in Queensland who may need assistance with making decisions. However, Survey of Disability Ageing and Carers (SDAC) and population projection data can be used to reliably estimate the size of the potential population.

In 2016, we estimate that there are 118,739 adults (1 in 40 people) with impaired decision-making capacity in Queensland. Figure 2 shows that by 2026, the potential population is estimated to increase to approximately 151,566 adults (approximately 1 in 39 people).

The projected increase in the prevalence of impaired decision-making capacity in the Queensland population is attributed to Queensland's ageing population and therefore an increase in age-related conditions that can impair a person's decision-making capacity (such as dementia and stroke). Technical advances in traumatic brain injury and degenerative diseases are also a factor.





Sources: ABS 2011, ABS 2013. **Note:** The growth in population assumes that the 2009 age standardised prevalence rates remain constant over time.

Geographic profile of the potential population

The majority (66%) of the potential population live in Queensland's major city areas, while 25% live in inner regional areas (Figure 3). Compared to the general population, the proportion of people with impaired decisionmaking capacity is similar in city, regional and other areas in Queensland (2.8% - 3.1%).

Research on the geographic profile of disability highlights that disability is generally more prevalent in regional and remote areas (AIHW 2008), as well as in areas of higher socio-economic disadvantage (Bradbury et al. 2001).







Note: 'Other areas' includes outer regional, remote and very remote areas of Queensland.

Age profile of the potential population

The median age of the potential population sits in the 50-54 year old age group, which means that the majority of people with impaired capacity are over 50 years of age. People aged 80 years or older account for the largest proportion (21%) of the potential population (Figure 4).

The peak in the oldest age group is primarily attributable to the increased prevalence of age-related conditions that can specifically impair a person's decision-making capacity.



Source: ABS 2011, ABS 2013.

While the life expectancy of people with lifelong disability has been increasing, it continues to be shorter than the life expectancy of the general population (FaHCSIA 2010).

The median life expectancy of people with an intellectual disability decreases as the severity of their disability increases (FaHCSIA 2010). Research highlights that people with a mild intellectual disability have a median lifespan of 74 years, while people with severe levels of intellectual disability have a median lifespan of 59 years (Bittles *et al* 2002).

These life expectancy trends are reflected in the potential population age profile, which features a decline in the 50 to 79 years age range (Figure 4).

Disability profile of the potential population

The Office of the Public Advocate uses six broad disability categories to describe the impairment types experienced by people with impaired decision-making capacity: intellectual disability (including autism), dementia (including stroke), psychiatric disability (including mental illness), neurological, acquired brain injury and other.

These categories are based on 'disability type' and 'condition' data in the SDAC and largely align with the Disability Services National Minimum Dataset. They are not clinical definitions, but broad classifications of disability.

As shown in Figure 5, the most common 'disability' categories in the potential population are psychiatric disability (54%), intellectual disability (26%) and dementia (23%).



Source: ABS 2011.

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

Figure 6 profiles the potential population by their level of limitation with respect to the core activities of communication, self-care and mobility. The majority of the potential population (66%) have a profound or severe core activity limitation. This means that, in addition to having impaired decision-making capacity, people require assistance to undertake, or are not able to undertake, some core activities in normal daily life.

The remainder of the potential population are able to perform core activities. People with a moderate core activity limitation (12%) have difficulty with one or more core activities. Those with a mild core activity limitation (13%) are able to perform these activities using aids or equipment.



In Queensland, specialist disability services are provided for people with a profound or severe limitation in one or more core activities. While most of the potential population have a profound or severe core activity limitation, over one-third (34%) do not.

This confirms that the potential population for systems advocacy is not limited to the population that access specialist disability services.

Conclusion

The number of Queenslanders with impaired decision-making capacity is expected to grow over the next 20 years. The potential population for systems advocacy in Queensland will also grow. Accordingly, there will be increased demand for a range of mainstream and specialist disability services, including guardianship and administration services.

The profile of the potential population for systems advocacy highlights the vulnerability of this group and the increased risks for abuse, neglect and exploitation. This is not only due to impaired decision-making capacity, but also due to other disabilities and complex support needs. These observations are consistent with national (Hayes *et al* 2008; Saunders & Wong 2009) and international (Burchardt 2003) research on the significant disadvantages faced by people with a disability.

Statutory systems advocacy will become increasingly necessary to ensure the rights and interests of the growing potential population are promoted and safeguarded. Without fair access to social, economic and legal resources, the opportunity to participate in community and civic life is significantly limited.

Key concepts

Impaired decision-making capacity

The Guardianship and Administration Act 2000 is based on the 'presumption of competence'. This is a legal principle which presumes that people can make their own decisions.

Impaired decision-making capacity is the inability to follow through the process of reaching a decision and putting the decision into effect. For example, impaired decisionmaking capacity may be due to dementia, intellectual disability, acquired brain injury, or a mental illness.

There are three elements to making a decision as defined within the *Guardianship and Administration Act 2000*:

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

The Queensland Civil and Administration Tribunal determines whether a person has impaired decision-making capacity (QCAT 2011).

Potential population

The potential population for statutory systems advocacy includes all vulnerable Queensland adults who may have impaired decisionmaking capacity. The potential population is broader than those who receive a government-funded or government-provided specialist disability support service, or people who are subject to a formal guardianship or administration order.

The Office of the Public Advocate uses the SDAC to identify and profile the potential population. For this purpose, the potential population includes adults (18+ years) living in either a household or health establishment who need assistance to make decisions or think through problems due to a disability.

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