

Impaired Decision-Making Capacity and Indigenous Queenslanders Final Report

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Funded by the Office of the Public Advocate Queensland



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ACKNOWLEDGEMENTS

Acknowledgement to Indigenous People

The research team would like to acknowledge the input into this research project from Indigenous Queenslanders.

Funded by the Office of the Public Advocate Queensland

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Table of Contents

Executive Summary	7
1. Background	12
2. Research Process	13
2.1 Methodology	
2.2 Ethical Considerations and Cultural Protocols	
3. Part 1: Extended Literature Review	15
4. Part 2: Data Collection	35
a) Focus Groups with Service Providers in North Queensland	
b) Focus Groups with Service Providers in Central Queensland	
c) Semi-structured Interviews with Key Stakeholders across Queensland	
5. Results and Analysis of Data	41
RQ1: What are the meanings of impaired capacity in Indigenous communities?	
RQ2: How has the issue of determining capacity for Indigenous people been addressed in Queensland, as well as within other jurisdictions in Australia?	
RQ3: How are decisions made for Indigenous adults with impaired capacity according to Indigenous cultural expectations and practices?	
RQ4: Are the requirements of the current Guardianship legislative regime appropriate for Indigenous Queenslanders? Is the legislation appropriate and advantageous for Indigenous Queenslanders with impaired capacity?	
RQ5: Are there other factors which need to be considered in	

relation to substitute decision-making practices for Indigenous Queenslanders with impaired capacity?

6. Discussion	74
7. Conclusion	78
8. Recommendations – Complete List	79
9. Recommendations – Themed List	85
References	88
 Appendix A: Table of other jurisdictions	
 Appendix B: Report for the North Queensland Region, James Cook University	
 Appendix C: Report for the Central Queensland Region, Central Queensland University	
 Appendix D: Stakeholder interviews, Griffith University	

Tables

Table: 1: Overview of Participants in Each Location in North Queensland	36
Table: 2: Overview of Participants in Each Location in Central Queensland	38
Table 3: Comparisons between Indigenous and non-Indigenous Australian worldviews	68

Figures

Figure 1: Communication issues and responses	54
Figure 2: Family and institutional relationships in the care process	58
Figure 3: Family and institutional relationships in the care process from an Indigenous perspective	59
Figure 4: Key agency criteria for services	60
Figure 5: Impacts from the historical legacy of colonisation for Indigenous Australians	7

Acronyms & Abbreviations

AHD	Advanced Health Directive
AG	Adult Guardian
CEOs	Chief Executive Officers
CQU	Central Queensland University
CQ	Central Queensland
EPA	Enduring Power of Attorney
GU	Griffith University
JCU	James Cook University
OAG	Office of Adult Guardian
OPA	Office of the Public Advocate
OPT	Office of the Public Trustee
PT	Public Trustee
RQ	Research Questions
SHs	Stakeholders
NQ	North Queensland

Executive Summary

A research project, funded by the Office of the Public Advocate (OPA), was undertaken in 2009-2011, to address a range of research questions (RQs) relating to Indigenous Queenslanders and impaired decision-making capacity (impaired capacity). Partnerships were established between the OPA, Griffith University (GU), Central Queensland University (CQU) and James Cook University (JCU) to extend previous scoping work¹ that identified that although there is considerable research in relation to disability, cognitive impairment and mental illness amongst Indigenous Australians, there is little specific research into implications for impaired capacity among this population.

However, specific issues that were identified from the literature included:

1. How Indigenous Australians make decisions about the care, finances and property of family members with impaired capacity.
2. What Indigenous peoples' knowledge and understanding about key agencies such as the Office of the Adult Guardian (OAG).
3. Whether the Guardianship and Administration system in Australia, whose role is to protect the rights and interests of adults who are unable to make decisions for themselves, is much utilised by Indigenous people, and
4. Whether the Western Guardianship and Administration system is incompatible with Indigenous peoples' because of cultural differences that result in a misfit between the legislation and Indigenous cultural concepts and the impact of obligations, such as kinship, collective ownership, reciprocity, and feelings of shame.

Therefore it was clear that a range of responses are required to engage with Indigenous persons and communities, to make the system relevant and responsive to Indigenous people.

¹ See N. Clements, J. Clapton and L. Chenoweth (2010) Indigenous Australians and Impaired Decision-Making Capacity. *Australian Journal of Social Issues*, 45 (3), 383-393.

This research, then, particularly explored issues about impaired capacity and decision-making for Indigenous people with impaired capacity in Queensland, and their engagement with the Queensland Guardianship and Administration system, as perceived by service providers and key stakeholders (SHs).

From a consultative and collaborative process between the research partners, a methodology was developed that included the following steps:

- Part 1: An expanded Literature Review
- Part 2: Data Collection
 - a) Focus groups with Service Providers with Indigenous Queenslanders in North Queensland (NQ)
 - b) Focus groups with Service Providers with Indigenous Queenslanders in Central Queensland (CQ), and
 - c) Semi-structured interviews with key SHs across Queensland

The following RQs were also developed:

1. What are the meanings of impaired capacity in Indigenous communities?
2. How has the issue of determining capacity for Indigenous people been addressed in Queensland, as well as within other jurisdictions in Australia?
3. How are decisions made for Indigenous adults with impaired capacity according to Indigenous cultural expectations and practices?
4. Are the requirements of the current Guardianship legislative regime appropriate for Indigenous Queenslanders? Is the legislation appropriate and advantageous for Indigenous Queenslanders with impaired capacity?
5. Are there other factors which need to be considered in relation to substitute decision-making practices for Indigenous Queenslanders with impaired capacity?

Ethics approval was granted through the relevant institutional Human Research Ethics Committees on completion and submission of a National Ethics Application Form that specifically addressed considerations in regard to research involving or about Indigenous Australians.

Summary of Findings

A pervasive theme of mistrust and suspicion of the Guardianship and Administration system in Queensland was strongly evident from all sources of data. Although the nature of the mistrust and suspicion did vary, nevertheless there are some common concerns. These included such aspects as trauma, fear, and remembrance of relinquishment. It is also apparent that these concerns are embedded in an intrinsic cultural incongruence between Indigenous and Western values, customs and worldviews about alternate decision-making. This incongruence appears to underpin significant confusion and lack of understanding about the roles and processes of authorities such as the Adult Guardian (AG) and Public Trustee (PT); and consequently calls into question the capacity of these authorities to provide effective alternative decision making for *all* Queenslanders.

Although some positive examples were cited, most experiences of dealing with Guardianship and Administration services for Indigenous people with impaired capacity were reported as negative. Such negativity was based upon experiences with services that reflected:

- A lack of cultural awareness and understanding of Indigenous people's history, kinship responsibilities, cultural values and beliefs and ways of working.
- A lack of transparency within processes that subsequently presented significant barriers.
- A lack, or not enough, of Indigenous people being employed by the Office of the AG and the PT, and
- The use of flawed and culturally inappropriate assessment tools.

Summary of Recommendations

Recommendations were formed from each part of the research; and are presented throughout the Report, and as a complete list at the end of the Report. The recommendations can be grouped around 4 broad themes and these are also outlined at the end of the Report.

The themes are listed below with some key aspects of each theme highlighted:

1. *Service Delivery Reform* (see Recommendations LR4, LR6, NQ 1, NQ2, CQ3, CQ4, SH6, SH1, SH2, SH3, SH4, SH8, NQ1)
 - Training and education
 - Streamlining and minimisation of bureaucracy
 - Specified positions and career pathways for Indigenous employees
 - Increased use of Indigenous services
2. *Policy and Legislative Reform* (see Recommendations NQ1, NQ2, CQ3, CQ1, LR1, LR5, LR7, SH5)
 - Indigenous input into the development of strategies to inform people of their rights
 - A Reconciliation Statement be put in place
 - Transparency of decision making and processes
 - A range of strategies be formed in regard to effective services, community engagement and Indigenous employment
 - Enhanced communication strategies to assist in navigating complex systems
 - Alternative service delivery models such as brokerage be explored
 - Wider range of alternative decision making alternatives be at hand
 - Consideration of the use of Community Guardians
 - Specific protocols be developed to ensure cultural aspects of competency are considered
 - Review of the current Legislation by Indigenous human service experts
3. *Communication with and engagement of Indigenous Queenslanders by Guardianship and Administration service agencies* (see Recommendations LR4, NQ1, CQ2, SH1)
 - Promotional material be produced in clear, culturally sensitive modes and media

- Partnerships be formed with key non Indigenous agencies such as the Elder Abuse Prevention Unit in Queensland ,and key indigenous agencies such as the Queensland Aboriginal and Islander Health Council
4. *Further research needs* (see Recommendations NQ4, LR2, LR3, SH7)
- To focus on the experiences of Indigenous Queenslanders who access the Guardianship and Administrative systems
 - Annual Reports outline the number of Indigenous Queenslanders utilising agencies and authorities
 - Identification and evaluation of culturally relevant assessment practices.

1. Background

Through funding by the OPA, a research partnership was initiated between the OPA Queensland, GU, JCU, and CQU to address a range of RQs relating to Indigenous Queenslanders and impaired capacity. Initial scoping work resulting in a literature review, has indicated that while there is a body of research in relation to disability, cognitive impairment and mental illness amongst Indigenous Australians, there is little specific research into implications for impaired capacity among this population. From reviewing the literature, it appears to be widely accepted that the incidence of acquired brain injury, alcohol and drug misuse, violence, injury and other factors is high within Indigenous communities and many Indigenous people experience vulnerability through disability, cognitive impairment or mental illness as a result of these factors. Yet relatively little appears to be known or understood about the situation of Indigenous people with impaired capacity and their interaction with the Guardianship and Administration scheme in Australia.

Therefore, further research was undertaken to explore impaired capacity and decision-making for Indigenous people with impaired capacity in Queensland, and their engagement with the Queensland Guardianship and Administration system. Although little is known there is a perception in the human services field that this area is fraught with problems and the exact nature of the problems have been difficult to define and analyse.

This research project aims to commence this process. This research sought to explore these issues by conducting focus groups and interviews with Indigenous and non-Indigenous service providers and health professionals in a range of sites across Queensland.

2. Research Process

2.1 Methodology

The overall research project included the following data collection methods, incorporated into a final report including recommendations covering associated policy and legislative issues:

- Part 1: An expanded Literature Review
- Part 2: Data Collection
 - a. Focus groups with Service Providers with Indigenous Queenslanders in NQ
 - b. Focus groups with Service Providers with Indigenous Queenslanders in CQ, and
 - c. Semi-structured interviews with key SHs across Queensland

The RQs for this Project are:

1. What are the meanings of impaired capacity in Indigenous communities?
2. How has the issue of determining capacity for Indigenous people been addressed in Queensland, as well as within other jurisdictions in Australia?
3. How are decisions made for Indigenous adults with impaired capacity according to Indigenous cultural expectations and practices?
4. Are the requirements of the current Guardianship legislative regime appropriate for Indigenous Queenslanders? Is the legislation appropriate and advantageous for Indigenous Queenslanders with impaired capacity?
5. Are there other factors which need to be considered in relation to substitute decision-making practices for Indigenous Queenslanders with impaired capacity?

2.2 Ethical Considerations and Cultural Protocols

The principles of *Reciprocity, Respect, Equality, Responsibility, Survival* and *Protection, Spirit and Integrity* as identified and described in the National Health and Medical Research Council's Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research, formed the framework for each of the studies (National Health and Medical Research Council, 2003). Local protocols were identified and observed at each site and subsequent approval sought and given.

3. Part 1: Extended Literature Review

This literature review explores indicators of the extent to which Indigenous Australians experience impaired capacity, which is a complex legal concept embedded in a statutory framework, the Guardianship and Administration system. This system is designed to provide guidance to assist people with impaired capacity for the administration of particular decisions, usually around personal, health and financial issues. The Guardianship and Administration legal framework in Australia provides for a range of substitute decision-making and supported decision-making mechanisms for people with impaired capacity. Little research has been conducted on the legal notion of impaired capacity within Australia, particularly on indicators of impaired capacity for Indigenous Australians, or on the cross-cultural relevance of this concept. Whether impaired capacity as currently understood in a Western framework is relevant for Indigenous Australians is discussed.

A search was conducted of international and Australian literature in academic literature databases relevant to the subject areas of law; health; social science; rehabilitation; criminology; psychology; mental illness and intellectual disability etc. for articles relating to relevant search terms such as impaired capacity; competency; capacity; and Indigenous communities. Additionally, publicly available documentation was sought from state/territory Guardianship agencies in Australia.

Decision-making capacity and the Guardianship and Administration system in Australia

The notion of decision-making capacity has evolved as a legal construct in liberal democracies as the means for specifying which people (usually those with an intellectual disability or mental illness) may require being taken care of by others (Silberfeld & Checkland, 1999). Legal definitions of mental capacity have moved from viewing mental capacity as a global, all embracing condition to a more specific condition restricted to particular realms of decision-making, usually around personal, health and financial types of decisions (Silberfeld & Checkland, 1999). Although

defined by legislation, capacity is usually assessed by a psychologist or psychiatrist who tests a person's cognitive abilities (Moberg & Kniele, 2006). Moberg and Kniele (2006) note that there is much debate among practitioners as to which combination of cognitive abilities comprises decision-making capacity, and therefore there is much variability in the methods and measures used to evaluate decision-making capacity in the clinical context.

Decision-making capacity is now, in general, defined in terms of functional abilities to understand information relevant to a particular decision, and to appreciate the consequences of the presenting options (Moberg & Kniele, 2006). As an example of a legislative definition of capacity, Schedule 4 of the Queensland *Guardianship and Administration Act 2000* states that *capacity*, for a person for a matter, means the person is capable of—

- (a) understanding the nature and effect of decisions about the matter; and
- (b) freely and voluntarily making decisions about the matter; and
- (c) communicating the decisions in some way.

A person with impaired capacity may have one or more of the following: an intellectual disability; an acquired brain injury; a history of drug and alcohol abuse which has impaired neurological functioning; dementia; a mental illness that impacts on the ability to make decisions; emotional and/or physical trauma (which may be past or present); or a developmental disorder such as Autism Spectrum Disorder or Asperger's Disorder.

In Australian states there are mixtures of three legislative frameworks for covering any loss of a citizen's presumed decision-making capacity (Carney, 2004). The *public planning* option, which may involve the appointment of a statutory agency as a guardian of last resort; the *private planning* option, which involves designating a private citizen as an enduring power of attorney (EPA) (for financial affairs), an enduring guardian (for personal affairs) or an enduring health power (health affairs); and the *person responsible* model, where lack of decision-making capacity is handled through a presumed appointment of family/friends.

The state based Australian Guardianship and Administration scheme, designed to protect people with impaired capacity primarily through the *public planning* option, is relatively new, having been developed over the past twenty years (House of Representatives Standing Committee on Legal and Constitutional Affairs, 2007). The Guardianship and Administration legal framework provides for a range of substitute decision-making and supported decision-making mechanisms for people with impaired capacity.

Guardianship and Administration legislation applies to certain types of decisions, usually relating to personal, health or financial issues. With supported decision-making, the presumption of capacity is always in favour of the person with a disability who will be affected by the decision, and support should enable the individual to exercise his/her legal capacity (United Nations, 2007). Substitute decision-making, which may rely on advance directives and guardians who have court authorised power to make decisions on behalf of the individual, does not have to demonstrate that those decisions are in the individual's best interests or according to his/her wishes.

Carney and Tait (1997) believe that a paradox exists for Guardianship and Administration systems in that Guardianship laws use a modern rhetoric of personal rights by promoting autonomy and fostering independence; however the main task of Guardianship forums is to take away those personal rights and entrust proxies with the exercise of legal decision-making.

Indicators of impaired capacity for Indigenous Australians

Data on the incidence of intellectual disability, mental illness, dementia, Foetal Alcohol Syndrome, acquired brain injury, petrol sniffing and other substance abuse problems may provide an indication of the levels of impaired capacity among Indigenous Australians. Unfortunately, there is a relative lack of robust data on these issues. For example, a recent federal inquiry into petrol sniffing states that the absence of statistical data and full and accurate records of petrol sniffing in Indigenous communities makes it difficult to determine the full impact of petrol sniffing (Senate

Community Affairs References Committee, 2006). Some indicators, however, are provided below.

A study on intellectual disability among the Indigenous population of Western Australia found that although comprising 3.5 percent of the population, Indigenous Australians represented 7.4 percent of all people registered for intellectual disability services (Glasson, Sullivan, Hussain, & Bittles, 2005). In the 2002 National Aboriginal and Torres Strait Islander Social Survey conducted by the Australian Bureau of Statistics, intellectual disability was estimated to affect 19,600 Indigenous people nationally. Indigenous people with intellectual disability experienced core activity limitations and restrictions more commonly, and to a greater extent, than Indigenous people with other disabilities or long-term health conditions (Australian Institute of Health and Welfare, 2007).

There is little published data on rates of acquired brain injury in the Indigenous population (Australian Institute of Health and Welfare, 1999). There is no single common point of contact in the health or welfare system at which reliable data for acquired brain injury can be collected (Australian Institute of Health and Welfare, 1999). In addition, certain types of acquired brain injury (e.g. alcohol-related brain injury) carry a level of stigma that may discourage individuals from identifying as having acquired brain injury (Australian Institute of Health and Welfare, 1999). Stanton, Jessop and Henstridge (1994) suggested, on the basis of their hospital-based study, that Indigenous people were more likely than non-Indigenous people to have acquired brain injury —Indigenous people accounted for about 8% of the data base in that study, but made up only about 2% of the population in the study region. Additionally, using data from the 1993 Australian Bureau of Statistics Survey of Disability, Ageing and Carers, the Australian Institute of Health and Welfare has estimated that 1-1.9 percent of the Australian Indigenous population has an acquired brain injury -related disability (Australian Institute of Health and Welfare, 1999).

A recent study in the Kimberley region of Western Australia found a higher prevalence of dementia among Indigenous people than in the general population (Smith, Lo Guidice, Dwyer, Thomas, Flicker, Lautenschlager, Alemeida, & Atkinson,

2007). The prevalence of dementia in the Kimberley in those aged 45 or over was 12.4% (compared with 2.6% in the Australian population generally) (Alzheimer's Australia, 2007). Notably, the prevalence rate among the Indigenous people aged 45-59 years in the sample was 26 times the rate in the general population of that age, suggesting Indigenous people in that area develop dementia substantially earlier than other Australians (Alzheimer's Australia, 2007).

Drawing on the 2004-05 National Aboriginal and Torres Strait Islander Health Survey and the National Hospital Morbidity Database relating to the social and emotional wellbeing of Indigenous Australians, the Australian Institute of Health and Welfare (2009) reports the following key findings:

- 27 per cent of Indigenous adults reported high or very high levels of psychological distress;
- Indigenous Australians were twice as likely to report high or very high levels of psychological distress as non-Indigenous Australians, and
- In 2005-2007 mental and behavioural disorders due to psychoactive substance use were the most common type of mental health related conditions for which Indigenous Australians were hospitalised (38 per cent of hospitalisations).

Gray, Pulver, Siggers and Waldon (2006) state that substance misuse among Indigenous people in Australia, New Zealand, Canada and the United States is a major health and social problem. In Australia, there is a higher proportion of Indigenous people than non-Indigenous people who consume alcohol at harmful levels; there are higher rates of illicit drug use; and there are higher rates of volatile substance misuse. Findings from a five-year study of cannabis users in Arnhem Land, Northern Territory, were that ongoing heavy cannabis use is commonplace in the already vulnerable Indigenous communities (Lee, Conigrave, Clough, Dobbins, Jaragba, & Patton, 2009).

Only recently have data been published on Foetal Alcohol Syndrome in Australia, and they have highlighted the over-representation of Indigenous children with Foetal Alcohol Syndrome (Elliott, Payne, Morris, Hann, & Bower, 2008).

Sheldon (2010) states that there is a high incidence of cognitive decline in remote Aboriginal communities because of multiple risk factors: alcohol abuse, petrol sniffing, high incidence of head trauma, central nervous system infections and poor nutrition. From the indicators reported above, it seems fair to assume that there would be many Australian Indigenous people whose disability, disorder or condition would fit the legal definition of impaired capacity. The factors contributing to reported greater levels of disability, mental illness, dementia and acquired brain injury are likely to be linked to the extreme marginalisation and social disadvantage experienced by many Indigenous people since European settlement (Tipper & Dovey, 1991; Simpson & Sotiri, 2004; Vicary & Bishop, 2005). Important factors that have affected the social and emotional wellbeing of Indigenous Australians include the introduction of custodial care (Australian Institute of Health and Welfare, 2009) and the over-representation of Australian Indigenous children in the child welfare system (Tilbury, 2009).

Understanding of cognitive disability and mental illness by Indigenous Australians

Differences between Indigenous cultures in understandings of disability have been reported by, for example, Senior (2000), who found that there were different understandings of disabilities and disorders across different Indigenous communities. Maher (1999) also states that the understanding of disability in Indigenous communities is a dynamic and evolving phenomenon. The Western Australia Disability Services Commission (2006) highlights that taking time to understand a local Indigenous perspective to disability is an essential part of developing services or supports. Recent research has looked at Indigenous Australians' understanding, knowledge and misconceptions of dementia (Garvey, Simmonds, Clements, O'Rourke, Sullivan, Gorman, Curnow, Wise, & Beattie, 2011). The overall level of understanding of dementia was poor, and the researchers recommended that culturally appropriate awareness campaigns and targeted educational interventions be implemented to improve the general level of understanding of dementia in Indigenous communities (Garvey, Simmonds, Clements, O'Rourke, Sullivan, Gorman, Curnow, Wise, & Beattie, 2011).

Some commonalities across Indigenous cultures, in understandings of disability and/or mental illness, are able to be drawn from the available literature (Ariotti, 1999; Bostock, 1991; Brown, 2001; Tate, 1992; Disability Services Commission, 2006; Francisco & Carlson, 2002; Gething, 1994; Gething, 1995; Gilroy, 2008; O'Neill, Kirov, & Thomson, 2004; Mokak, 1997; Senior, 2000; Simpson & Sotiri, 2004; Smeaton, 1998; Swan & Raphael, 1995; Tipper & Dovey, 1991; Wolstenholme, 1996; Ziersch, 1990):

- Some Indigenous people may maintain cultural and mythological beliefs about the reasons for a disability and/or mental illness occurring.
- Disability is often perceived as part of the life cycle Indigenous families may consider themselves to be more accepting and supportive of family members who have a disability than are non-Indigenous people. People with disabilities are included within their extended families and able to assume kinship roles and responsibilities where possible.
- Indigenous Australians with disabilities may not recognise or acknowledge they have a disability as defined by legislation, and may not be regarded as a reason to access a service.
- Disability may not be seen as a stand-alone issue, but may be perceived as a factor in the whole realm of functioning (Physically, mentally, spiritually and culturally).
- Indigenous mental health issues should be considered in the social emotional context, encompassing factors such as oppression, racism, environmental factors, economical factors, stress, trauma, grief, cultural genocide.

Major barriers to Indigenous people with a disability or mental illness accessing services have been identified, such as language barriers, a lack of knowledge about disability rights and services, and the experience of shame from issues associated with privacy and confidentiality (Bostock, 1991; Gething, 1997; O'Neill, Kirov, & Thomson, 2004).

Indigenous interaction with the Guardianship and Administration system in other jurisdictions

There is a paucity of literature available on Indigenous persons with impaired capacity in international jurisdictions such as the United States of America, Canada, New Zealand that have Indigenous populations. There is no reporting in the Annual report of the number of Indigenous persons that have been involved in the Guardianship and Administration scheme in any of the Australian jurisdictions (with the exception of WA), to be able to gauge the number of Indigenous persons with impaired capacity using the system. However, the evidence provided would indicate under-representation of Indigenous people with impaired capacity accessing the system, particularly given that the previous section indicates that for most indicators, Indigenous people experience approximately at least double the rate of disability, mental illness, etc. WA and QLD are the only states to have provisions in their Guardianship and Administration Acts relating to considering a person's cultural environment, when determining the best interests of a represented person. Additionally, there is no reference to the Australian Guardianship scheme or to Indigenous Australians with impaired capacity in the Australian government's key strategy to address Indigenous disadvantage and social exclusion, the National Indigenous Reform Agreement (Council of Australian Governments 2008). In fact, no policy related to these issues could be found in any Australian jurisdiction.

Research conducted in WA, provides information on other jurisdiction's activities relating to Indigenous communities and the Guardianship and Administration system, as at 2001 (Other-Gee, Penter, Ryder, & Thompson, 2001). A summary of the report's findings from Australian jurisdictions is provided at Appendix A.

In 2001, the first Australian investigation into the relevance and appropriateness of the Guardianship and Administration system to Western Australian Indigenous people with a decision-making disability was conducted (Other-Gee, Penter, Ryder, & Thompson, 2001). The research found evidence of growing levels of decision-making disability resulting from the combined effects of severe disadvantage associated with substance abuse, early ageing, psychiatric disability, brain damage and traumatic life events such as motor vehicle (Other-Gee, Penter, Ryder, & Thompson, 2001). The

research also found that there may be ways in which the Guardianship system could better support and strengthen the informal systems and informal arrangements already in place for some Indigenous people.

Overwhelmingly, the principle areas of need for the system for Indigenous Australians reported was in terms of managing finances (Other-Gee, Penter, Ryder, & Thompson, 2001). There are two major ways in which needs were reported to be currently met: by families caring for and managing the affairs of other family members; by assistance provided, at an informal level, by other service providers (Other-Gee, Penter, Ryder, & Thompson, 2001).

Aspects of the Guardianship and Administration system that are problematic for Indigenous Australians, once access has been achieved, include (Other-Gee, Penter, Ryder, & Thompson, 2001):

- Lack of appropriate and simple information about the system's processes.
- Complexity of the paper processes, application forms, and other written material, and the overall complexity of the system. The responsibilities of Administrators are onerous and are derived from non-Indigenous standards of accountability and responsibility.
- Difficulty of establishing personal relationships with contact people, lack of personal contact and a lack of continuity of personnel.
- Formality of the system, the language used and aspects of the 'hearings' process.
- The legalistic nature of the processes, reinforced by the language of the system, and
- A perception that the system gives authority and priority to non-Indigenous medical and paramedical personnel, and to government agencies, and does not formally acknowledge the significance of Indigenous people, Indigenous service providers, and Indigenous agencies in the process.

Key principles for changing the Guardianship and Administration system's response to Indigenous persons with impaired capacity were provided ((Other-Gee, Penter, Ryder, & Thompson, 2001):

- The system should continue to make every effort to avoid the formal entry of Indigenous people into the system, at the same time, ensuring the most responsive

and appropriate intervention when formal entry and ongoing contact is unavoidable. This is consistent with the legislation and current work practices. Culturally appropriate procedures and guidelines for the management of Guardianship and Administration hearings involving Indigenous people should be developed and implemented.

- Wherever possible family and informal arrangements for managing the needs of Indigenous people are preferable to the intervention of the formal system. Support for informal arrangements should be maximised, consistent with the legislation.
- There is a need to achieve better understanding among service providers in both Indigenous and non-Indigenous organisations, to result in better information about the Guardianship and Administration system within the informal networks, and assist in establishing linkages between informal networks and service providers. There may be ways in which the Guardianship and Administration system could more effectively support and strengthen the informal supported decision-making arrangements already in place for some Indigenous people, by enabling local service providers to assist Indigenous families to meet the needs of their family members.
- Local Indigenous services and service providers are more likely to be able to assist Guardianship and Administration agencies in meeting the needs of Indigenous people, particularly in understanding factors relevant to cultural obligations.
- There is a need for a broader range of substitute decision-making alternatives for Indigenous people and Indigenous communities. For Indigenous people for whom an order has been made, or will be made, there is also a need to consider a wider range of alternatives for the management of that order.

An example of an informal arrangement for supported decision-making in an Indigenous community is available from a recent hearing in Western Australia (FS [2007] WASAT 202, p 18):

Mr S's family and his community have expressed a desire to assist Mr S in making appropriate financial decisions by using the 'old way' which is a process of meetings between Mr S, his family and the relevant elder to discuss

financial issues and to attempt to reach a consensus (with, however, Mr S having the final say on how the money is used).

Additionally, the Law Reform Commission of Western Australia (the Commission) (2006) recently reported that concerns have been raised about the application and accessibility of the Guardianship and Administration system to Indigenous people in that state, including the system's interaction with Indigenous customary laws and cultural beliefs. The Commission found that issues for the Western Australian system to address are:

- concern from agency staff about intervening in Indigenous family systems given the historical context of the effect of government policies on Indigenous people;
- understanding cultural norms, for example, communal sharing and reciprocal obligation;
- knowing who to talk to within the kinship system; and
- the system dealing with failings of other systems of care and/or services, for example, when a person is passed between the homeless service system, the criminal justice system, and the mental health system, without getting their needs addressed.

Both these investigations in Western Australia concluded that there is, to some extent, a fundamental incompatibility between the values, intentions, and operations of the Guardianship and Administration system embedded in Western philosophic traditions and the aspirations, experience, social and cultural realities for Indigenous people and that efforts to improve the system need to acknowledge this incompatibility (Law Reform Commission, 2006; Other-Gee, Penter, Ryder, & Thompson, 2001).

Cross-cultural relevance of capacity assessment

The Human Rights and Equal Opportunity Commission's (2005) review of Indigenous young people with cognitive disabilities within the Australian juvenile justice system highlighted the issues of the cultural *inappropriateness* of most cognitive assessment tools. Cognitive assessments usually use language, stimuli or

normative data with a cultural bias towards non-Indigenous people, and therefore may produce misdiagnosis among those from other cultures. Performance deficits on tasks that suggest brain dysfunction may actually arise from cultural determinants for Indigenous people such as socio-economic status, language or expectations of the assessment experience (Cairney & Maruff, 2007).

Cattarinich, Gibson, & Cave, 2001) argue that both the process by which capacity assessments are conducted and the content of the assessment instruments are problematic cross culturally. Cultural considerations for capacity assessments of Indigenous Australians include familiarity with ethnic protocols such as communication styles and taboos. As an example, due to the Indigenous preference for indirect communication (e.g. using metaphors and stories), a non-Indigenous professional may not realise when a patient has in fact answered a question, nor what the response means (Hepburn & Reed, 1995). Additionally, Shah and Heginbotham (2008) state that a successful assessment of decision-making capacity for non-white cultures is contingent upon the assessor's fluency in the subject's language, the subject's fluency in English, accuracy of interpretation services and availability of appropriate vocabulary in the subject's language for concepts discussed during the assessment.

Only recently have cognitive assessment tools for use specifically with Indigenous Australians been developed, such as *CogState* (Dingwall & Cairney, 2010; Human Rights and Equal Opportunity Commission, 2005), *Biala-II* (Shaddock, Spinks, & Esbensen, 2000), and the *Kimberley Indigenous Cognitive Assessment (KICA)* (Lo Guidice, Smith, Thomas, Lautenschlager, Almeida, Atkinson, & Flicker, 2006; Smith, Lo Guidice, Dwyer, Thomas, Flicker, Lautenschlager, Almeida, & Atkinson, 2007). Initial results showed the effectiveness of the cognitive assessment section of the tool (KICA-Cog) to detect those with dementia in populations of the Kimberley and Northern Territory. A shortened version, the KICA screen, has been evaluated in a group of people from Northern Queensland (Lo Guidice, Strivens, Smith, Stevenson, Atkinson, Dwyer, Lautenschlager, Almeida, & Flicker, 2010).

Queensland context

Queensland is projected to have the largest population of Indigenous Australians by 2021 with Queensland Government projections of about 220,000 persons by 2026 (Queensland Health, 2010). It was estimated there were 152,527 Indigenous Queenslanders in 2008, which is 3.6% of the total Queensland population (Queensland Health, 2010).

In Queensland, the Guardianship system is established by *Guardianship and Administration Act 2000* and the *Powers of Attorney Act 1998*. Both these acts provide for substitute decision-making by and for adults with impaired capacity (OPA Queensland & the Queensland Law Society, 2010). The Guardianship regime in Queensland enables various statutory Guardianship bodies and officers, private attorneys, guardians and administrators to perform functions and make decisions in accordance with prescribed rights-based principles called the General Principles of the legislation, or, for health matters, the Health Care Principle (OPA Queensland & the Queensland Law Society, 2010). The general principles include that adults are presumed to have capacity; that they have the same human rights as others, a right to have a valued role and participate in society, and a right to confidentiality; and that they should have their self reliance and judgment recognised (OPA Queensland & the Queensland Law Society, 2010).

In Queensland, as at 2001, there was reported to be considerable under-representation of Indigenous people, particularly those from rural and remote areas, in the current Guardianship and Administration system, although there have been a few cases involving Indigenous people that have highlighted the complexities involved (Other-Gee, Penter, Ryder, & Thompson, 2001). Other-Gee, Penter, Ryder and Thompson (2001) reported that there is a high degree of awareness reported to be within the system of the need to incorporate Indigenous issues into all systemic processes but the system in general, is not considered culturally inappropriate. Key issues reported included difficulties arising from family disagreement or conflict, lack of awareness of the Guardianship system, difficulties of information gathering about case-specific issues, and understanding and incorporating cultural obligations and traditions (Other-Gee, Penter, Ryder, & Thompson, 2001).

However, an earlier Queensland study by Setterlund, Tilse and Wilson (1999) of older people's knowledge of the substitute decision-making process and experiences of abuse, suggest that there are specific cultural factors that reduce access to, and the response of, the Guardianship system for Indigenous people. These include:

- cultural beliefs in the inappropriateness of taking family issues outside of the family,
- a belief that appointing an individual as a substitute decision maker for something that is viewed as a communal responsibility is inappropriate,
- language barriers, and
- lack of information and awareness about the law and civil justice remedies.

Additionally, in 2004, Queensland Advocacy consulted with representatives of Indigenous communities in Queensland about disability (Queensland Advocacy Inc, 2004). They recommended that mechanisms be identified to protect and safeguard individuals who have limited decision-making capacity, and who are in receipt of large compensation or funding, for example, by the creation of trusts, accompanied by training for community legal services and perhaps developing a Do-It-Yourself kit for community workers (Queensland Advocacy Inc, 2004).

Evidence for the Cape York Welfare trials in Queensland suggest that the empowerment of local commissions and the appointment of respected Indigenous persons or Elders as local commissioners for the Family Responsibility Commission Queensland under the terms of the trial is crucial in ensuring that the legal framework is aligned with the establishment of local authority and ownership of the social norms (Senate Select Committee on Regional and Remote Indigenous Communities, 2010). Additionally, conferences held in certain Indigenous communities are held in the local Indigenous language (Senate Select Committee on Regional and Remote Indigenous Communities, 2010). This type of local involvement may also be suitable for the Queensland Guardianship and Administration system.

Cultural differences between Indigenous perspectives and Western perspectives relevant to human service delivery

Kinship, cultural obligations and reciprocity

Pattel (2007) states that Australian Indigenous interpersonal relationships whether traditional, semi-traditional or urban, have been based on the kinship structure. An Aboriginal family consists of immediate and extended members (Pattel, 2007). Whilst some traditions have been lost due to forced colonisation, the family structure has been strongly maintained, which consist of biological kin (blood kin), affinal kin (related through marriage) and classified kin (one who has earned a particular role and stature within the family) (Pattel, 2007). Sharing is the norm among Aboriginal kin and Aboriginal people are, in general, protected by and benefit greatly from the generosity of members of broad-ranging kinships systems (Schwab, 1995).

Individuals involved with and supported by such systems consider them normal and sensible, and expectations related to the sharing of shelter, food, cash and other resources appear entirely reasonable to the participants in such kinship networks (Schwab, 1995). Saying “No”, to demands for resources has social, not just material, implications. A direct refusal of a demand for assistance is a significant act in the Aboriginal community (Schwab, 1995). To bluntly refuse a demand is a poor economic strategy since the refusal effectively denies the authenticity of the basis of the demand (Schwab, 1995). Deflecting demands is acceptable but requires strategic behaviours so as not to shame or embarrass either party (Schwab, 1995).

Schwab (1995) highlights a prominent cultural factor that affects the position of Aboriginal Australians in the wider economy: reciprocity. Reciprocity is a core element in the organisation of Aboriginal communities, and sharing remains a keystone of Aboriginal culture and identity (Schwab, 1995). While it is certainly one of the elements of the social glue that holds Aboriginal families and communities together in precarious economic and social circumstances, it is also a mechanism through which individuals may test, affirm and display their sense of community and Aboriginality (Schwab, 1995)..

Another example of cultural obligation between Indigenous Australians is 'Chuck in'. (Urbis Keys Young, 2006). 'Chuck in' is a system which enables individuals to pool their money within their family, household or community (Urbis Keys Young, 2006). It can be a formal system, where a set amount is contributed on a regular basis, or as informal as a one off collection for a particular cause such as helping a family meet the costs of an unplanned event (Urbis Keys Young, 2006). It is a way of making money go around and/or meeting community obligations (Urbis Keys Young, 2006).

Individualism vs collectivism

Vicary & Andrews (2000) cite Karpfen (1997), who identified four key areas of difference between the values held by Western people and communally based cultures such as Indigenous Australian culture: white values centre around individualism and consumerism, and are both secular and conflictual. By contrast, Aboriginal cultural is spiritual, ecological, consensual and communal.

Individualistic cultures give primacy to individual rights and boundaries, conceptualising each person as a separate entity from the group, whereas socio-centric or collectivist cultures focus on family and group membership and social role obligations (Triandis, 1995 quoted in Lefley, 2000).

Wolstenholme (1996) believes that the broad principles that much be accepted for human service delivery, is that Aboriginal family and community networks are of the utmost importance to Aboriginal well-being. Service delivery therefore must focus on strengthening Aboriginal family and agency resources and utilising Aboriginal services rather than promoting delivery of services through non-Aboriginal networks (Wolstenholme , 1996).

Historical context -'Stolen Wages'

Kidd's (2003) landmark study grounded in twelve years of investigation of primary files and correspondence generated by successive Queensland government departments relating to the Queensland Indigenous 'protection' regime during the twentieth century. Kidd (2003) found evidence of government misuse of trust monies for Indigenous Queenslanders.

Between 1897 and 1972, the government legislated to control every aspect of the life of any person of Aboriginal descent targeted for state ‘care’ (Kidd, 2003). This included where they lived, who they could marry, and Guardianship of their children. It was accomplished under powers to ‘remove’ people from their family and country, to life-long confinement on government-controlled settlements and missions (Kidd, 2003). The consequent starvation, sickness, scandalous mortality rates, substandard housing, inadequate or non-existent schooling, and non-paid or underpaid labour are the evidentiary indicators of how that duty of care was exercised (Kidd, 2003). From 1904 until the late 1960s the government used this captive labour pool to build and maintain the missions and settlements, and as raw material for the lucrative contract labour market. (Kidd, 2003). There is a body of financial data which clearly shows the massive sums of money earned by generations of Aboriginal workers did not reach them (Kidd, 2003).

More recent Queensland research looking at financial considerations for Indigenous Australians found that for some Indigenous Queenslanders, the major repercussion arising from the stolen wages, ‘as been the lack of trust that Aboriginal people experienced when dealing with institutions (Demosthenous, Robertson, Cabraal, & Singh, 2006). Drawing connections between the historical experience and financial literacy, one participant said “our money was managed by managers of properties, by organisations, shop keepers...Our people handed over their cards, their pin numbers, and they were exploited, heavily. Our people never had large lumps of money, no education whatsoever on banking, on how to make their money grow...They’ve never had people come in and do workshops on that sort of thing. We have never had that education of growing our money because our money has been managed for us.”

Cunneen (2005) notes that historically the powers under various Aborigines’ Protection Acts had instituted legal regimes that provided for the total control of Indigenous activities, and which presumed that Indigenous people had impaired capacity in general. This may, in part, explain any reluctance on the part of Indigenous Australians to utilise the Guardianship and Administration system.

Shame

Shame plays a powerful and pervasive role in traditional Aboriginal cultures and is likely to be experienced by people who act, or are forced to act, in ways that are not sanctioned by the group or are in conflict with social and spiritual obligations (Kendall & Marshall, 2004). Many non-Aboriginal service delivery principles violate such social and spiritual obligations by isolating the client from others, focusing intense attention on the client, or transferring the client to another location (Smallwood, 1996 cited by Kendall & Marshall, 2004)

Cultural differences in obligations are highlighted by a cultural consultant in FS [2007] WASAT 202 (p 14) below:

Overriding, or rather underlying [Mr S's] capacity issues is the need to recognise the nature of traditional Aboriginal culture, Aboriginal learning styles and meaning ascribed to family and community obligations. [Mr S] may indeed be 'exploited' by his family however this view would be a non-Aboriginal view and not one that has much meaning to [his] people where cultural obligations to care and support family over-rides any sense of individuation. Additionally, as these cultural obligations are reciprocal, all family members and community members are also obliged to care for [Mr S], even more so as he is considered to be more vulnerable than other community members and as such he is afforded more protection than others.

Discussion and Conclusion

There is little research into how Indigenous Australians make decisions about the care, finances and property of family members with impaired capacity. There is also little known about Indigenous peoples' knowledge and understanding about key agencies such as the OAG whose role is to protect the rights and interests of adults who are unable to make decisions for themselves.

Although the data are somewhat limited, given the numbers of Indigenous people with indicators of impaired capacity, such as intellectual disability and Foetal Alcohol Syndrome, it is reasonable to assume there are some (and perhaps a significant

number) Indigenous Australians with impaired capacity. It is unclear whether the Guardianship and Administration system in Australia is much utilised by Indigenous people, but such information would provide another indicator of the incidence of impaired capacity among Indigenous Australians, and it would be useful if agencies collected data on this. Given the increased vulnerability of Indigenous people to disability, mental illness, substance and alcohol abuse, it seems fair to assume that there would be a need for assistance to be provided for Indigenous communities, to support Indigenous people with impaired capacity in Queensland.

While there is a need for more research, early indications from this overview suggest that the Guardianship and Administration system may not be meeting Indigenous peoples' needs because of cultural barriers, such as the misfit between the legislation and Indigenous cultural concepts and obligations, such as kinship, shame, collective ownership, and reciprocity. The literature review has indicated that a range of responses are required to engage with Indigenous persons and/or communities around the issue of impaired capacity.

Recommendations

LR1. There is a need for a broader range of decision-making alternatives to be developed for Indigenous people. Some alternative approaches might be designed around involving the local Indigenous community and increasing support for informal supported decision-making arrangements, such as providing funding for community resources to aid in planning. This is consistent with Article 12 of the United Nations Convention of the Rights of Persons with Disabilities, which promotes supported decision-making (United Nations General Assembly, 2007). Service delivery must focus on strengthening Aboriginal family and agency resources and utilising Aboriginal services.

LR2. Further research is required focusing on analysis of any difficulties experienced by Indigenous Queenslanders when accessing and engaging with the Guardianship and Administration system in Queensland.

LR3. That the OAG Queensland and the OPT Queensland publish in their Annual Reports that number of Indigenous Queenslanders coming into contact with their agencies.

LR4. That brochures and fact sheets used by the agencies in the Queensland Guardianship and Administration system be redesigned in consultation with Indigenous Queenslanders, to be Indigenous friendly.

LR5. Consideration of the use of community guardians in the Queensland Guardianship and Administration system. The Northern Territory has this system, and a similar system for Family Responsibility Commissioners operates in in the Cape York Welfare Reform trials in Queensland, where respected Indigenous persons are appointed as local commissioners for the Family Responsibility Commission Queensland.

LR6. Regular dissemination of information, training and resources, to health and human service workers to disseminate amongst Indigenous communities and clients about the Guardianship system, such as to Centrelink, Home and Community Care.

LR7. That Queensland Guardianship and Administration agencies develop specific protocols to ensure that cultural aspects of competency are considered by practitioners in assessment of capacity.

4. Part 2: Data Collection

a) Focus groups with Service Providers in North Queensland

A qualitative study which utilised individual interviews and focus groups to gather data was undertaken. Organisation and community connections provided a list of potential participants who were then contacted, provided with information about the study and invited to participate. Individual interviews and focus groups were held in Townsville, Palm Island, Mt Isa and Cairns (some representatives from Yarrabah and Mossman attended the Cairns group meeting).

Information regarding the study was explained to participants who were informed that participation was voluntary and that they could withdraw from the study at any time without any repercussions. Interviews and focus groups were conducted over one to two hour periods depending on the different individuals or groups. With permission notes were taken and data tape recorded during the interviews and focus groups.

In keeping with the stated RQs, the following semi structured questions were asked of participants to generate discussion and gain an insight into their perceptions, observations and experiences:

1. What is the meaning of impaired capacity in Indigenous Communities?
2. How are decisions made for Indigenous adults with impaired capacity according to Indigenous cultural expectations and practices?
3. Are the requirements of the current Guardianship legislative regime appropriate for Indigenous Queenslanders?
4. Is the legislation appropriate and advantageous for Indigenous Queenslanders with impaired capacity?
5. Are there other factors which need to be considered in relation to substitute decision-making practices for Indigenous Queenslanders with impaired capacity?

Table 1 provides an overview of the participants involved.

Table 1: Overview of Participants in Each Location in NQ

Role	Townsville	Palm Island	Mt. Isa	Cairns/Yarrabah/ Mossman
Aged Care Worker				1
Centacare Worker			1	
Community Health Nurse	1			
Community Bus Driver		1		
Community Health Worker				1
Community Member	1	2	1	
Health Worker	1	1	1	
Hospital Domestic Worker		1		
Indigenous Health Researcher				2
Minister of Religion	1			
Nurse			1	
Parent Support Worker				2
Rep. Indigenous Org's Board Member	1			
Senior Health Aged Care Worker				1
Social Worker	1	2		
<i>Indigenous people included above:</i> Torres Strait Islanders	2	1		2
Aboriginal people	4	6	4	5

Data were analysed with manual coding of information and identification of categories and common themes. Results are provided highlighting key common findings among participants in all locations.

b) Focus groups with Service Providers in Central Queensland

Focus groups conducted with Indigenous and non- Indigenous health and human service professionals including a number of Indigenous Elders. The focus groups were conducted at various locations in CQ. The research was designed to explore the cultural bonds of Indigenous Australians to better understand decision-making practices.

The researchers approached identified stakeholder organisation Chief Executive Officers (CEOs) to explain the research and take their guidance as to how best to recruit participants. Recruitment endeavoured to protect the anonymity and minimise risk to participants. The researchers continued an ongoing consultation process regarding community and individual consent. This process was undertaken through the CEOs at their various locations. Letters of permission to access staff were sought from the organisations.

Staff were reminded that their participation in the research was entirely voluntary and would not impact on their employment in any way. CEOs were asked to forward details of the research project to appropriate staff who were asked to contact the researchers directly if they wished to participate so that their anonymity was maintained. The researchers acknowledge the diversity of Indigenous cultures and this is demonstrated by negotiating research protocols at each site guided by local community advice.

Participation involved attending a focus group for up to two hours which was audio-taped if permitted by participants. Participants were asked questions relating to their experiences and observations of: how decision-making occurs within Indigenous communities; the OAG and the Guardianship and Administrative Tribunal and associated legislation; and the meaning of impaired capacity from an Indigenous perspective. Participants were principally Indigenous and non-Indigenous

professionals from community agencies who are working with Indigenous people and communities – particularly, Indigenous people with impaired capacity. See Table 2 below.

Table: 2: Overview of Participants in Each Location in CQ

Role	R'ton	B'Berg	Mackay	Woorabinda	Emerald*
Psychologist	√ Indigenous				√ Non- Indigenous
Social Worker	√ Indigenous				√ Indigenous & Non- Indigenous
CEO Indigenous Child Safety Organisation	√				
Indigenous Project Officer, Dept of Communities	√				
Indigenous Elder/s	√ Q'ld Justice	√		2	
Director of Indigenous health centre		√			
Mental Health Nurse/s / Workers		√ Indigenous		√ Non- Indigenous and Indigenous	√ Non- Indigenous
Indigenous Community Health		√		√	

Role	R'ton	B'Berg	Mackay	Woorabinda	Emerald*
Worker/s					
CEO / staff of Indigenous health organisation including 3 Torres Strait Islanders.			√		
Director of Nursing				√ Non-Indigenous	
Nurse/s				√ Indigenous Enrolled √Non-Indigenous	
Non-Indigenous Child Safety Officer					√

* The Emerald focus group provided a significant contrast to other locations as all but one participant were non-Indigenous professionals.

(c) Semi-structured interviews with key stakeholders across Queensland

Semi-structured interviews were conducted with key Indigenous and non-Indigenous SHs from the human service sector in Queensland. Snowball sampling was used to identify seven key informants as either lawyers, advocates, practitioners, or researchers who had knowledge of, and experience in working with Indigenous Queenslanders with impaired capacity and their family and carers. Four interviewees identified as Indigenous, three interviewees identified as non-Indigenous. The SHs are significant communicators, advisers and leaders within their respective communities and hold particular knowledge, history and culturally relevant skills. The interviews were conducted within the environment of community practice.

A schedule of questions was developed to guide the interviews:

- How are decisions made within Indigenous families? By consensus; Role of elders; gender roles?
- Does the term “impaired decision-making capacity/impaired capacity” have much relevance for Indigenous persons?
- What happens when a person has an intellectual disability or mental illness which may mean they have difficulty in making personal, health and/or financial decision?
- Do you know of any Indigenous persons who have had a guardian or administrator appointed?
- What do you know about the Office of the Adult Guardian in Queensland? Have you ever used their services?
- What do you know about the Office of the Public Advocate in Queensland?
- What do you know about the Public Trustee of Queensland? Have you ever used their services? What was this about?
- How useful are any of the above agencies for Indigenous communities/persons/issues?
- Have you come across Indigenous persons who you think might require help with decision-making?
- What sort of life areas and/or issues do Indigenous persons with impaired capacity require someone to help them with: managing their money? Decisions about medical or health issues? Accommodation? Decisions about personal issues?
- Are there any other issues or factors which need to be considered for Indigenous Queenslanders, with relation to the issue of impaired capacity?

5. Results and Analysis of Data

The three data sources presented a variety of concerns. Significantly, common themes emerged across the sources in regard to the RQs; and these themes indicated deeply entrenched experiences of mistrust, suspicion, poor service delivery, confusion and misunderstandings, incongruence of values and ways of communicating, and a lack of cultural sensitivity in regard to practices, assessment tools and customs. All themes are also overcast by the often not acknowledged shadow of historical sources of trauma.

For the purposes of reporting, the responses have been clustered under the RQs; however it is highly recommended that each report of the three participant groups be read. These reports are attached as Appendices to this document.

RQ1: What are the meanings of impaired capacity in Indigenous communities?

Lack of Understanding and Alternate Thinking

There was consensus across all groups that the terms ‘impaired capacity’ and ‘impaired decision making capacity’ were neither understood nor seemed relevant to Aboriginal and Torres Strait Islander people.

If I said that to any of my clients, they would ask me what I am talking about.
(NQ participant)

People would say – what the hell does that mean? (NQ participant)

The exception to this claim is where participants or Indigenous people were familiar with the terms if there had been encounters with professional agencies or personnel where the term is used. In this context, it was perceived as a professional label. However the practices associated with the labels were seen as problematic as families struggle to relate to implicit factors such as authoritarian power which they felt powerless to question. This resulted in feelings of being disenfranchised or ‘cut off’, and are reminders of the historical legacy for Indigenous peoples as a result of their long-term relationships with governments and authority in Australia since colonisation.

Someone who is not functioning well can recover without being removed, and in a culturally appropriate way. (Stakeholder participant)

Participants in all three contexts commented that Indigenous people are more likely to think of the Western concept of ‘impaired capacity’ as mental problems or in a culturally different way. The terms *gone womba* or *a little bit Womba* were highlighted as a description of a person ‘not being quite right’ or having some mental incapacity. It was also stated that different Indigenous groups may use their own language to describe such states.

A stakeholder respondent commented that there is a need for education and awareness raising of what impaired capacity is, and what decisions are covered under the Guardianship regime for people with impaired capacity, in order to

Answer the question for Indigenous people “Why do we need to know about this?” (Stakeholder participant)

Impaired Capacity Not Necessarily a Problem

Another aspect stated across the three contexts was that even when the concept of ‘impaired capacity’ may be presented and understood, culturally it was not necessarily seen as a concern unless it was *causing* concerns.

One of the strengths of this place is that it is a very tolerant community and people are not necessarily viewed as having special needs so that can make it quite difficult and I think that some of the people do function quite well so you have to be conscious that they do need help. (NQ participant)

Stakeholder participants commented that Indigenous people have experience and understanding of cognitive impairments and impaired functioning resulting from acquired brain injury, substance misuse, dementia etc, as well as from psycho-social issues. One issue noted is an increase in car accidents and acquired brain injuries etc that was proposed is a result of people in Indigenous communities receiving Mining royalties, rushing out to buy 4WDs, and having a motor vehicle accident.

RQ2: How has the issues of determining capacity for Indigenous people been addressed in Queensland, as well as within other jurisdictions in Australia?

This RQ was specifically addressed by the Stakeholder research and highlighted a range of **Flawed Processes** such as the assessment tools used; and also a range of professional / disciplinary inadequacies.

Tools

Respondents who had knowledge of capacity assessment and process, believed that the current assessment tools and the processes used to assess capacity are inadequate and flawed. Reasons for this view included that:

- there is no baseline measurement of a person's functioning before they lose capacity to compare to,
- capacity assessments do not allow for personality, family and locality differences, and
- there is cultural bias in that tools are determining a Western concern according to a Western framework. An example is the issue of 'gratuitous concurrence' when Indigenous people are asked questions, like in a capacity assessment, they want to please and answer the 'right' way. Another example given was education and style of communication:

It's this aspect of language and communication that underpins capacity assessments and measures of whether someone is functioning or not.

Particularly if you are measuring using the instruments they currently use, and someone is less educated, and from a more remote area. (Stakeholder participant)

Professional / Disciplinary Inadequacies

It was highlighted that professionals who are assessing, need to be able to accurately assess capacity for Indigenous people. Professionals need training around aspects like non-verbal cues.

Problem with much of the research in psychology and law on assessing functioning is that it doesn't look at the process; doesn't look at understanding the interaction between all in the assessment process. Those being assessed, the assessor, the carer, plus an interpreter. And only the best of interpreters can properly interpret, particularly in an assessment situation. So you are never going to really get what people are saying, you would need to record it and have it properly done but this would never happen in practice. So you are left with something that is flawed. (Stakeholder participant)

RQ 3: How are decisions made for Indigenous adults with impaired capacity according to Indigenous cultural expectations and practices?

There was consensus across the data sources that the processes of decision making for Indigenous adults with impaired capacity are quite problematic for quite a number of reasons.

Impact of Government Policies – Past and Present

Past government policies continue to impact Indigenous people. The removal of people from their traditional lands and the break-up of families remain painful realities for Indigenous people. Likewise the breakdown of families and traditional practices involving elders and kin affect not only the social organisation, but also capacity for alternative decision making. As a NQ participant states:

There are difficulties because there are no effective elder type roles/networks within family groups so traditionally you would expect to go to the elders within family groups or the elders within the community and they would be able to help support with those decisions.(NQ participant)

CQ participants noted that decision-making often involves lengthy processes that include utilising extended family members as well as the immediate family. As well as particular family members having particular roles, elders can also be called upon for guidance.

However, it is not unusual for family decision-making processes to be disrupted due to the unavailability of appropriate people due to previous separation. Significantly, such impact is not restricted to a single generation:

For individuals, their removal as children and the abuse they experienced at the hands of the authorities or their delegates have permanently scarred their lives. The harm continues in later generations, affecting their children and grandchildren (Human Rights and Equal Opportunity Commission, 1997, p. 4).

Social and Health Factors

The three contexts identified that the early onset of disease, substance abuse or death, along with an over-representation of Indigenous people being incarcerated in prisons etc, affect decision-making processes.

As one NQ participant commented:

There's not that many old people here because they pass away early,

Another NQ participant, referring to alcohol and drug abuse, said:

Some of our clients drink too much and take drugs so they can't help themselves let alone anyone else.

Other specific aspects of Social and Health factors were identified.

Cultural customs, family responsibilities and different ways of caring

The NQ participants highlighted how decisions are dependent on family circumstances. There was some consensus that for Aboriginal people it was mainly a matriarchal decision-making process while for Torres Strait Islanders it was more patriarchal. Caring responsibilities can also fall to the youngest or oldest family members, those geographically closer, or ones with more availability.

In my case it is the youngest child in our family who is caring for our Mum and so I suppose because she is not married or in a relationship, she's got only one child and she's not working so she's the one that is the least busy.

(NQ participant)

However some care is provided by Indigenous persons that are more attuned to the Western System. It was acknowledged that the Indigenous culture is dynamic and changes happen.

People that are more educated in the western system tend to make their own decisions or these decisions are made by a small number of people within one family instead of a traditionally larger family group. (NQ participant)

Conflict and abuse

Examples of conflict and abuse that can occur in regard to providing care and alternative decision-making were highlighted. The SHs outlined incidents of financial abuse where people with intellectual disability or acquired brain injury have their money taken by relatives on payday. People with impaired capacity are left with as little as a bit of food and a 'six pack'. It was stated that this type of abuse has been seen to occur where there has been large insurance payouts for car accidents.

Several NQ participants also commented on incidents of conflict and abuse:

1. *worked it out yeah but there is still - still have some conflict in my family like with mum's pension because we don't know where the pension goes. I don't think that my sister is the best person in the world (laughs) to budget and stuff like that. (NQ participant)*
2. *There is a conflict when a carer is picked to look after the person then there were issues when a person is appointed as the carer but another family member holds the purse strings. (NQ participant)*
3. *There are certain individuals within the community with special needs that are targeted and are used as cash commodities they are an income source for the family and they are used and abused. (NQ participant)*

RQ 4: Are the requirements of the current Guardianship legislative regime appropriate for Indigenous Queenslanders? Is the legislation appropriate and advantageous for Indigenous Queenslanders with impaired capacity?

These questions evoked some strong themes from the participants. Although some responses identified some positive experiences, most of the themes reflected significantly negative experiences. Many of the negative experiences were linked to entrenched suspicion, mistrust and fear that continue to be felt by Indigenous people. Importantly, the current Guardianship legislative regime mostly appears ineffective in countering such feelings. Unfortunately, it does appear that rather than helping, the Guardianship legislative regime may even add more negativity to the experiences of Indigenous Queenslanders with impaired capacity.

In response to RQ4, this section highlights issues of suspicion, mistrust and fear; and outlines the positive experiences and negative practices and process encountered and the factors that contribute to them.

Suspicion, Mistrust and Fear

NQ participants told how there was suspicion of any authority which was seen to have the power of control over a person, their money or their property. The participants related this ‘power’ in contemporary society to that of past government policies which resulted in removal of people from their land and children from families and abuse of power. As discussed in one focus group:

People, especially them old ones - they too frightened you know to ask for help because they think that they can still be taken away and you know locked up.

(NQ participant)

Yeah and they don’t have much money or things and they worry that that little bit of money will be stopped and how they going to live. (NQ participant)

CQ participants stated that there is a general fear of being ‘under the Guardian’. They considered such a phenomenon as akin to being “*under the Act*” and resulting in suspicion of authority controlling every aspect of people’s lives. Furthermore, the CQ participants said that this fear was further transferred to all authority figures (“*the Bully Boys*”) including doctors, trustees and police. They said that particularly for Indigenous peoples in Queensland, the historical situation centred on the Aboriginal Protection Act whereby, if someone asserted that a person was an Aborigine they could be placed “under the Act” for their protection “until the contrary was proven in court”. “The court could also decide on sight whether a person was an Aborigine under the Act or not” (Broome, 1994, p. 163).

The CQ participants also demonstrated particular mistrust of authorities in situations where family members could be at risk of removal from the family. It was stated that one participant reported the situation of a parent caring for an intellectually impaired child/adult. The parent was “*afraid*” to apply for a carer’s pension from Centrelink because they perceived they would need to provide information that would lead

authorities to take the child/adult away. This fear, they stated, could be associated with the past practice of removing Indigenous children from their families ('Stolen Generations') as previously discussed.

Similarly, the Stakeholder group expressed how there is a low level of awareness and understanding of the Guardianship and Administration system amongst Indigenous Queenslanders, and a high level of mistrust and confusion about the roles and powers of the various agencies involved. This mistrust of government services is a result of the mistreatment Indigenous people have experienced through colonisation. Additionally, the recent global financial crisis has increased mistrust of Western services by Indigenous people. It was also reported that some non-Indigenous service providers know they will be blacklisted by the Indigenous community if they place people in the Guardianship and Administration system

With Guardianship, it wasn't so long up that if a white face showed up, it was to take our children away, although that's still happening. The history in this country is of institutionalization of Indigenous people in general. Even the name, the Adult "Guardian" is paternalistic, implies oppression, it's like the old days of the "mission Manager", or "The Protector". (SH participant)

Decision-making under Guardianship - is seen as only one option every given – to move away from family and country. (SH participant)

They don't know they can appeal decisions. (SH participant)

The Stakeholder group also remarked that trust in government agencies by Indigenous Queenslanders and their families is a key issue.

The PT is not liked in general by Indigenous people. They say it's like going back to Mission Manager's days. The perception is that the PT has free range to make decisions about Indigenous' people's money. (SH participant)

People feel there is not enough transparency and accountability to do with how their money is managed – particularly around the profit that the agency would make from investing the money they hold. (SH participant)

Informants suggested that consultation and education of Indigenous Queenslanders and their families around the functions of the different agencies is key to engaging Indigenous people in the system.

The Guardianship and trusteeship may have good reasons behind it, but the communities need to know the theory behind it all and the ethics. (SH participant)

Positive Experiences

Some participants commented that there some Queenslanders with impaired capacity and / or their families have had positive experiences with the OAG and / or the OPT. NQ participants stated that positive comments they knew of seemed to be in relation to staff/officers who were more experienced and who had formed relationships with the client and family.

Yes we had really good support from that person looking after us when we had problems with Mum's stuff – it was really explained in a good way and the person took the time to get to know us. (NQ participant)

If the person has a lot of experience in doing the job then they know what they are talking about but sometimes there's a high turnover and the next person don't have a clue. (NQ participant)

CQ participants also described positive experiences. Some positive experiences were reported in cases of family conflict or where families were in situations of abuse. These descriptions are outlined below.

One participant spoke of their cousin with drug and alcohol addictions who was physically abusing their parents to gain access to their disability pension to support substance abuse habits. When the PT was awarded control of the cousin's money, this diffused the conflict as the parents were no longer in that position of responsibility and vulnerability.

Other participants reported that the independent control of a person's affairs eliminated the potential for family members and others to abuse the financial and physical situation. (For example, family members abusing the elderly.)

Two participants from Woorabinda reported good service from the PT for managing family financial affairs. One participant's family member was in care in the hospital and the other was not living locally. However, it was also noted that the financial statements provided by the Trustee were "*difficult to read*" such that they did not clearly display information in a straightforward manner. Further, questions were raised around the application of the Trustee's administration fee. Questions were also asked about interest on monies held by the Trustee – how much does the government and the Trustee benefit from use of "*my money*"?

Similarly, Stakeholder participants also could identify instances of positive interactions. For instance, when OAG has intervened to investigate a situation of abuse, the agency is useful, and sensitive in their approach – although in appointing a Guardian, the system was found to be time consuming and cumbersome.

For Guardianship however, it is a lot of paperwork, and it can take up to 12 months for the process to happen. (Stakeholder participant)

On the other hand, responses were varied about the usefulness of the OPT for Indigenous Queenslanders and their families. Some respondents thought that when the OPT has been involved as an Administrator for someone, that this was viewed both positively and negatively by Indigenous Queenslanders and their families. In certain situations it was reported that Indigenous Queenslanders have found the OPT useful – when an abusive or exploitative relationships exists within a family, the PT can be useful as it provides rules around amounts of money released and who can access it.

Indigenous people do not like the PT, because money is then not available.
(Stakeholder participant)

With paydays, the PT getting involved is good. (Stakeholder participant)

Some indigenous families are happy for the PT to get involved, as it works well to safeguard against this type of activity (abuse). (Stakeholder participant)

One respondent gave this opinion:

In the old days, disabled people would be left behind as in a hunter and gather society they couldn't afford to carry them along. Indigenous families shun these type of people, and are happy for Guardianship to take over as they would be free from making decisions. (Stakeholder participant)

Negative Processes and Practices

There was a range of negative experiences highlighted across the 3 groups. These seem to be linked to a variety of issues that emerged within the processes and practices of the OAG and the OPT; and these are outlined below.

Confusion and concern

The NQ participants stated there appeared to be some confusion about the roles of the various bodies involved with those with impaired capacity. Participants used the following terms, Adult Guardian, Health Guardian, PT, Public Advocate, Power of Attorney, the Tribunal and powers under the Mental Health Act as though they were interchangeable. They then outlined how such confusion affected practices; and this is stated below.

- A social worker commented on the confusion:

It's hard enough for professional people to understand what all them words mean - what each department does let alone just the average mob you know the workers and just people understanding that. Even if you look up on the computer you know the internet – it's hard to understand not that the average person would be doing that anyway. (NQ participant)

- From one community worker:

You know I always assumed if you come under the PT or the Health Guardian then you would do a baseline around their health issues – what does this person need for their wellbeing and the same would be done on the financial side – what

debts are outstanding what needs to happen to stop the debt collectors knocking on the door. Isn't that what they are there for? (NQ participant)

- One participant said:

People should be referred to the health guardian when there are issues and they can't look after themselves – like someone who is really into the grog and they get into such a state that they can't make decisions about themselves they need that power of attorney to take over. (NQ participant)

- Another participant stated:

A lot of our clients come under that Mental Health Act and they need that advocate Guardianship to take over to look after their affairs and things like their care and money. If there is problems then maybe the Tribunal, is that the right name? steps in to sort out. (NQ participant)

- There was concern that people would not receive the service that it was thought they were entitled to.

I wouldn't put anyone under the PT because you take away all their rights and they don't feel like anyone cares about them and with the family its all about the money as well and if you put them under the PT then they are left with nothing. (NQ participant)

- From a social worker:

I remember a few years ago I rang up the PT about one person and the PT Officer said, 'I am just fed up' so I said, why what do you mean? he said this person (the client) just rings up every week and I said well doesn't that tell you something is wrong. They don't case manage properly so there are all these gaps in understanding the help needed for the clients. (NQ participant)

- Another participant gave a lengthy report on the 'saga' of a person under the care of the PT who needed to buy new underwear. This person, who lived on an island (or the carer) had to catch the ferry to the mainland, then a taxi to the shopping

centre get three quotes from shops for the garments, then get the quotes to the PT. She then had to wait to get a cheque from the PT and finally try and cash the cheque which was a problem because there were no banks on the island.

- A community member stated that:

One old man walked an hour each week to get \$50 from the Trustee. Not only was it not enough for him to live on but he couldn't afford the bus ticket to get the money. (NQ participant)

A variety of examples showing confusion was also expressed by the CQ participants:

Generally, participants were not clear on the roles of the AG. However, participants were generally aware of the PT and felt that they were, in fact, one and the same as the 'Guardian' – they were essentially the same thing. Participants were generally unaware of the services provided by the AG or the PT. The services that participants felt the Guardian provided were reasonably nebulous such that, one participant responded *"They do wills or something?"* Added to this confusion over the Guardian's roles, another participant further highlighted the general lack of awareness of government processes and services. The participant asked the researchers if they (the researchers) could organise disabled access facilities in their home including a ramp and shower rail.

The general confusion was also tied up with Mental Health service provision and the definition of impaired capacity. It was felt that there were *"too many Acts"*. One participant questioned, *"If impaired capacity is a disability then why does the Adult Guardian not come under the Mental Health Act or disability services?"*

Participants who were health workers or mental health workers referred extensively to the Mental Health Act (processes and practices) as a template for best practice service provision. Of those participants who did know (or had previous contact with) the OAG, the PT and/or mental health services, participants generally reported negative experiences specifically of the PT.

Lack of appropriate communication and consultation

The quality of information available to Queenslanders with impaired capacity and their families was also found wanting by participants. For example, NQ participants

commented acknowledged that although there needs to be something in place to protect those with impaired capacity, there were problems with lack of appropriate information about the legislation, policies and processes. As discussed in one focus group:

Sometimes you don't even know that them things are there – how do you find out what is there to help you – and there should be help before it gets to that stage – but sometimes its only when that poor person is in real trouble that someone notices. (NQ participant)

The problem is with that Trustee business once you are under that then can you get out of it if you can look after yourself again? (NQ participant)

There is too much to take in and the family needs time – they need time to think and talk to all the family mob about it. (NQ participant)

CQ participants also all reported the need for clearer “Indigenous friendly” communication as shown in Figure 1.

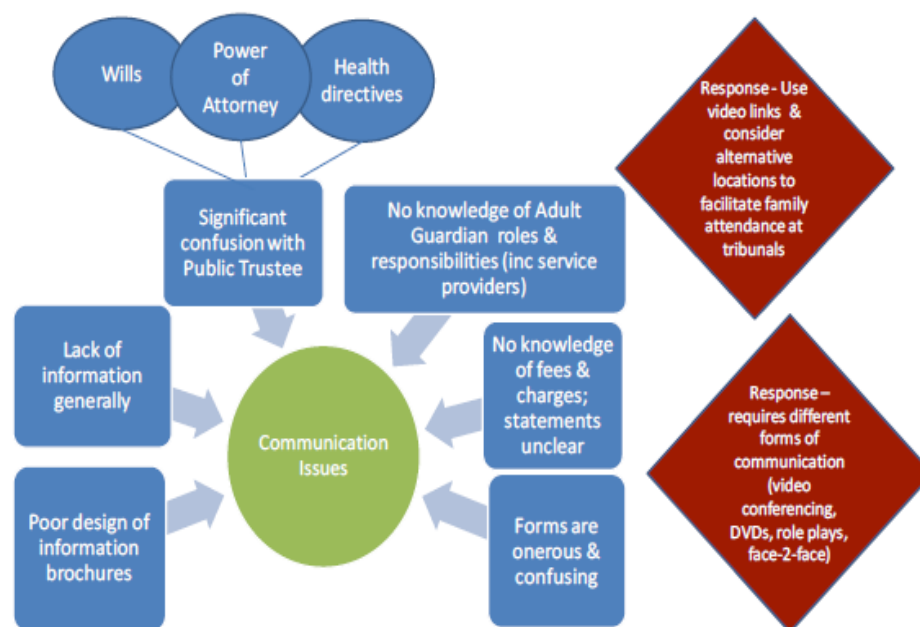


Figure 1: Communication issues and responses (Developed for this report by Pascoe and Radel, 2010)

Overwhelmingly, the CQ participants felt the brochure was unhelpful – *“it was too wordy and drab and didn’t really say who the Office were, how to contact them or what they can do for Indigenous people”*. (CQ participant)

They also offered practical solutions. For example, Health professionals felt it would be particularly useful if the OAG could conduct information sessions with staff and with community members (both face-to-face and possibly utilising video conference facilities, particularly for remote locations).

It was also suggested that ‘role play’ scenarios would be particularly beneficial to illustrate incidents where the AG could assist. It is also extremely important that the person delivering the message is appropriate – they need to be *“genuine”*. Other participants recommended the use of video links to facilitate family attendance at tribunals. Communication brochures and materials should have no legal or government jargon.

Some Stakeholder participants commented that attention needs to be paid to organisational materials. A few respondents suggested that guidelines need to be developed that address the Indigenous traditional family protocol and the interaction of the Guardianship and Administration system, for both Indigenous and non-Indigenous, human service agencies and workers, as well as the Indigenous community in general, in order to discuss incompatibilities in the system between different cultures, and to provide examples of addressing these.

Inadequate and/or inappropriate consultation was also identified as another issue with the following response from a NQ participant.

Look there are so many people – like agencies - involved in the process of assessing and monitoring someone and often the right hand don’t know what the left hand is doing and they don’t really talk to each other. Like there are doctors, nurses, health workers, aged care, community assessment teams, and what do you call all them others, physios and others – then there’s the legal side and all the Indigenous organisations that are involved. Then there is the

client and family who are sometimes left out or just told what is going to happen – well that's not consultation! (NQ participant)

Family relationships and lack of continuity of care

CQ participants expressed concern about negative experiences that emerge with the statutory authorities and family members. This was presented as a significant issue, so it is useful to show how the CQ researchers reported it in the bullet points and diagrams below.

- Participants suggested that Guardians and Trustees need to establish “*ground rules*” in conjunction with family, to understand and set boundaries in relation to financial commitments. For example, one participant mentioned a case of a child being orphaned and as a result they received an insurance pay-out. The trustee was “*only giving them \$50 at the beginning of the week and \$50 at the end*” (CQ Participant) . The participant suggested that the Trustee was concerned with the rest of the family “*ripping them off*”. However, they also felt this allowance was insufficient for covering living expenses and reciprocity.
- Other participants reported that family members who were under the Guardian often became distressed at their inability to make decisions for themselves, thereby exacerbating their conditions. Once people with impaired capacity find themselves “*under the Act*”, they find they have lost all legal capacity to make their own decisions even if they feel they can make some decisions. As a result, they become very “*apprehensive*”. Further, other participants raised issues around the Guardianship processes whereby, there is “*too much paperwork*” involved and the processes are “*too difficult*”. For example, health workers noted that increasingly they are being approached to complete paperwork for clients where “*people can't understand the forms and therefore the health service is getting requests to fill them out on their behalf*”. (CQ Participant)
- One participant commented that, in instances where,
“*a mental health service is assigned as a case manager the case manager is then designated as the contact person for the disabled person. What happens*

when that case worker moves or goes on holiday? New staff coming through don't know the process, they don't know how they can advocate for clients or how they can appeal a decision. Mental health services don't spend money on educating their staff in advocacy, so people don't know.” (CQ Participant)

- As another participant indicated:
“The continuity of care in the mental health service is appalling.” (CQ Participant)
- Participants also offered the following in terms of the care process as family members trying to maintain connection with their relative who was now ‘under the Guardian’:
- Family networks of which the client is part, *“is almost like twice removed from the actual home. Their involvement with the family is removed through the care process. Family have to always contact the case manager rather than just dealing with the family member who needs the help.” (CQ Participant)*

“The thing that I’ve found, even within my own family network is ...you’ve got the family, then you’ve got the carers, then you’ve got the agency to which the carers belong [and] then you’ve got this mob here... the advocate officers.” (CQ Participant)

“The family have to go through this whole process, but the way we deal with [family issues] does not fit with the processes of the Guardian office. ...because we’ve got the carers and their agencies and we have to now be accountable to all these other people.” (CQ Participant)

“The decision makers are not responsible to the family first they are responsible to the legislation first and not always to the one Act but to multiple Acts which makes the decision-making very murky... very, very murky...”. (CQ Participant)

- The above relationships, responsibilities and connections are represented by the following diagram:

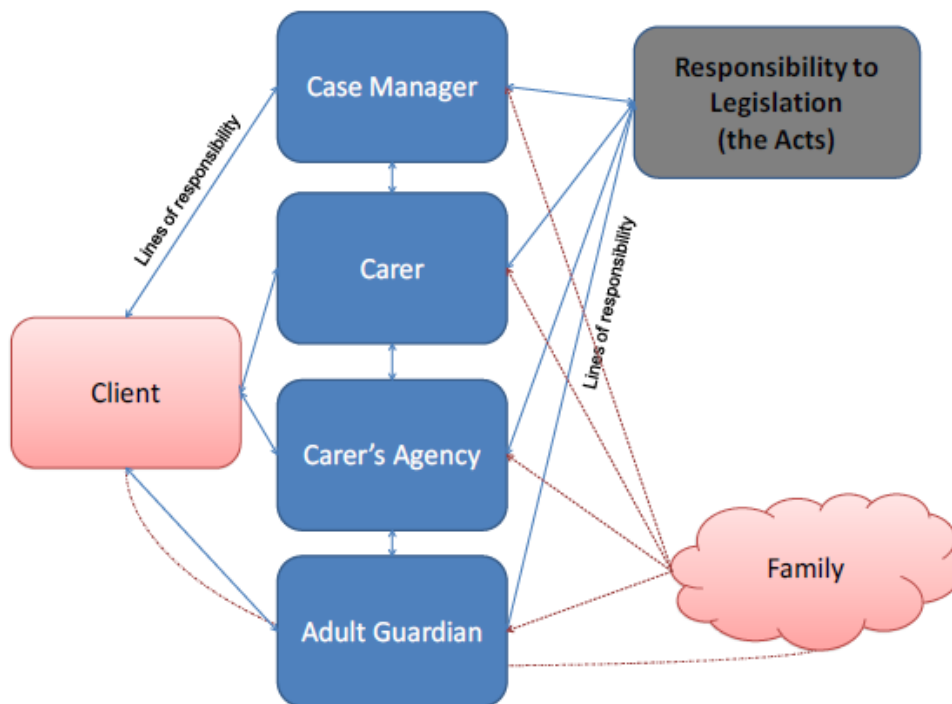


Figure 2: Family and institutional relationships in the care process
(Developed for this report by Pascoe and Radel, 2010)

- Figure 2 summarises the participants' discussions of their perceptions of the current structures and associated relationships that effectively complicate the communication and relationships between family, institutions and the person with impaired capacity. The result is to divide and disenfranchise the family.
- Alternatively, an Indigenous social worker participant discussed their perceptions of the role the AG could take with regard to their specific rural community situation. The participant stated that there are an increasing number of service providers (as indicated on the left of Figure 3 below) who have funding to intervene. In addition, the service providers also have specific criteria and key performance indicators to meet with regards to that funding. However, community and service providers cannot decide on a single course (or even a number of appropriate courses) of action. The participant explained that all of the service providers are essentially waiting on community members to make a decision about appropriate actions. The community members however, cannot agree and there is a great deal of political tension and manoeuvring involved. The tragedy is

that the resulting inaction leads to sufferers of substance abuse continuing to rapidly deteriorate.

- In the participant's opinion, the role of the Guardian would be as impartial advocate on behalf of the sufferers. The Guardian is supported by legal authority which means they have 'real' power to ensure that the sufferers have appropriate care intervention. The Guardian's involvement minimises the potential for conflict within the situation as they have no political involvement in the community – their only concern is the welfare of the sufferers.

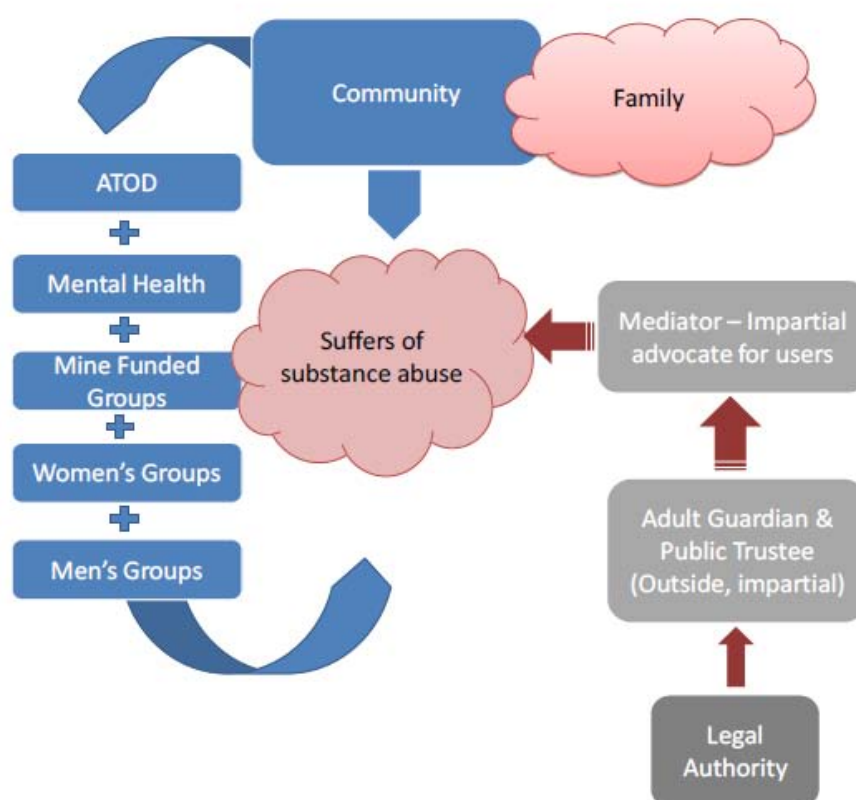


Figure 3 Family and institutional relationships in the care process from an Indigenous perspective (Developed for this report by Pascoe and Radel, 2010)

Provision of services

CQ participants considered how the AG or PT could or should intervene and provide services as outlined in Figure 4 below.

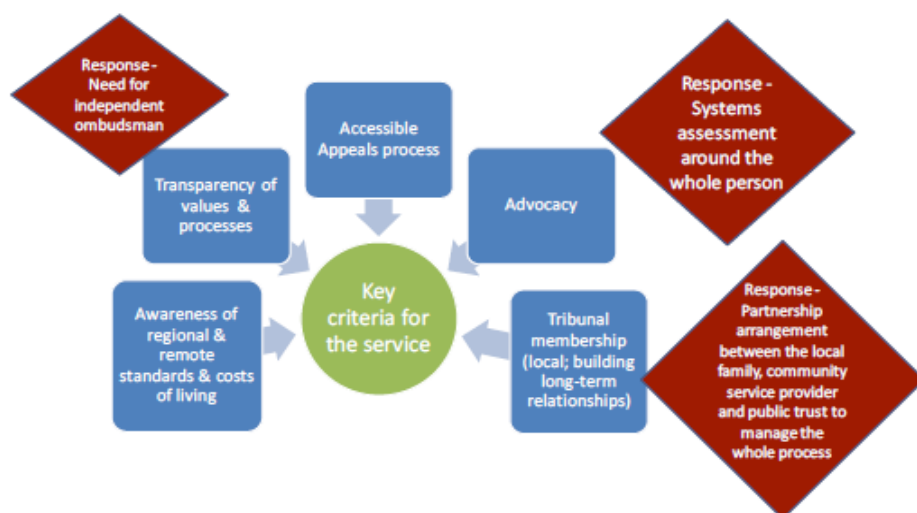


Figure 4: Key agency criteria for services (Developed for this report by Pascoe and Radel, 2010)

- A Guardian should be the last resort.
- In instances where assistance is required, families and communities need the government to provide culturally appropriate tools (“*Indigenous friendly*”), resources and information to support the family to make an informed decision.
- Where Guardians are appointed they should:
 - o consult extensively with family;
 - o be on the ground / at grass roots level;
 - o use a current Indigenous provider to be the broker of the advocacy service;
 - o develop long-term trust relationships; and
 - o acknowledge that decisions made within a family (extended) can take a great deal of discussion (up to years) and this should be understood as standard practice.

Inappropriate assessment and decision practices; and a lack of transparency

CQ participants highlighted how local people are essential to conduct assessments and case management of clients.

- For example, participants reported that when decisions were made, the decision makers were neither local nor did they appear to know anything about the local family situation. One participant discussed the “*hole in the fly screen*” where people came in to assess a person’s situation and made judgements without knowledge of the real circumstances regardless of whether the person was

“happy” in that situation or not. The living environment was considered inappropriate and clinical, Western norms and values were applied to an Indigenous context.

- With regard to local assessment, it is also important to note the differences in the costs of living for rural and remote locations and this is often not understood or taken into account by urban-based decision makers.
- Specifically in relation to people on the tribunal, another participant mentioned that they felt that “*Nobody is actually trained in advocacy*” (CQ participant) and that there is a fundamental need for decision makers to be local and an integral part of the process. In addition, it was stated that training could be beneficial for carers.
- The OAG should develop partnership arrangements between the local family, community service provider and PT to manage an integrated process.
- Considering the use of local Indigenous service providers, there should be an inclusive, multidisciplinary, skilled team as the assessment panel and there should be a “*systems assessment around the whole person*”. (CQ participant)
- Participants reported a severe lack of right of appeal once an order or decision was made and there was no clear way to exit from being ‘under the Trustee or Guardian’ (again this is mostly in regard to the Trustee).
- Participants reported that people could be placed “under the Trustee” for either 2 years or 5 years and that it was very difficult to get an appeal before the end of that time with no scheduled review periods.
- Participants reported that the Guardianship appeals process was also extremely complicated. Particularly considering those under an order already had a disability that could limit an individual’s capacity to make a successful appeal, participants

felt they needed assistance to appeal. They also needed clear decision guidelines and people trained in ‘advocacy’ to work on their behalf.

- Participants reported there was “*no transparency in the process*”. Participants felt that there was no way to know how decisions of the tribunal were being made. Also, decisions regarding ongoing care were not transparent. Many reported that Indigenous people with impaired capacity (either relatives or people under their care) were “*distressed*” by the appeals process and this stress further negatively impacted on their mental health. For example, one participant spoke of a relative who wanted a painting of a waterfall that was felt would calm and benefit their mental health. The process to access the funding was long and involved with a great deal of paperwork and the request was eventually declined as it was considered a “*non-essential item*”.
- Participants compared the AG/Trustee processes to those of Centrelink and the Mental Health Act. They indicated the Centrelink and Mental Health Act processes are more equitable and transparent. For example, one participant stated that, “*You can ask to see how and why a decision was made in Centrelink in your record*”. The Mental Health Act appeals process was considered easier to access (“*it doesn’t take nearly as long*”) and far more transparent in that all the Mental Health Act documents have the appeals process clearly included on them.
- It was also noted that the decision-making and review processes “*should be standardised for every client*”. (CQ participant)
- With regard specifically to the tribunal, there needs to be greater transparency of the representation of people on the panel. For example, the panel should include an advocacy person and a human rights commissioner and clients need to know who these people are and their backgrounds. Again this was compared to the mental health process as an exemplar.
- A number of participants also raised the issue of needing an ombudsman or independent person to arbitrate in cases of dispute.

Lack of cultural congruence

The stakeholder participants highlighted significant cultural issues that they think need to be addressed in regard to the Guardianship and Administration system for Queenslanders with impaired capacity. They commented that in instances where the system is used to support and protect Indigenous Queenslanders with impaired capacity and their families in a cultural appropriate way, the system is reported to work well. However, as the system has been designed around a Western cultural framework, the system does not allow for different cultural practices.

All informants replied that the Guardianship and Administration system is very complex for white people, without even introducing cultural differences. An example is the Indigenous cultural concept of ‘shame’, particularly about telling your business to someone else, particularly a non-Indigenous person.

There is a stigma for indigenous people about having other people making their decision, particularly white people. (SH participant)

The process can be extremely damaging, they feel shame and humiliation. (SH participant)

The stakeholder participants also identified that another key cultural difference relevant for the system is that the framework is predicated on the individualistic nature of a culture, versus a cultural that is based on the collective. Indigenous cultural norms are based on group decision-making and the concept of reciprocity, whereas the Guardianship and Administration system designates an individual for particular types of decisions, and does not allow for collective responsibilities, such as people sharing the financial responsibility for one person’s debt. This is complicated when purchasing things such as cars and boats, where there is often collective ownership in Indigenous families and communities.

This type of functional interdependence between family and community members is not catered to in the Guardianship and Administration system.

Reflects the values for mainstream Australia – that the material is valued far above the emotional and the spiritual. Western people may see saving as

important, Indigenous people may prefer to have their money spent sometimes.
(SH participant)

Western/white people need to ask themselves, why are our cultural values better? (SH participant)

Inadequate education

The stakeholder participants stated that agencies within the Guardianship and Administration system need to substantially increase their education initiatives to Indigenous Queenslanders, particularly by developing and using culturally appropriate documents and other formats, such as workshops and DVDs .

Because of the demographic and geographic spread of Indigenous people around Queensland, education can't just be the Government putting out a leaflet. (SH participant)

Education about Guardianship and trusteeship should be part of chronic disease management in the health system, but isn't. (SH participant)

The biggest area of need for education to be directed at Indigenous Queenslanders, as reported by informants, was to do with EPA and Advanced Health Directives (AHD). Another key area was around a person's rights and responsibilities once they are part of the system.

EPA's are raised quite a lot. Needs to be more education about EPA's etc, especially for young people. (SH participant)

Increased education and engagement by key agencies in the Guardianship and Administration system *about* the system, such as the OAG and the OPT, of Indigenous and non-Indigenous human service agencies and workers, particularly Indigenous health workers, Indigenous Health Councils, Indigenous doctors, Indigenous legal services, hospices, hospitals, respite services and the Elder Abuse Prevention Unit Queensland.

The Indigenous legal services are another area that could be utilised – they mostly see their services are providing for criminal matters. (SH participant)

RQ5: Are there other factors which need to be considered in relation to substitute decision-making practices for Indigenous Queenslanders with impaired capacity?

A range of factors were identified that impact substitute decision-making practices for Indigenous Queenslanders with impaired capacity. The factors either expanded or reiterated concerns expressed previously in RQ4; and in regard to this question, included strategies for improved community engagement through engagement, education and employment. It was also identified that particular barriers, such as the dominance of Western frameworks and the accessibility to services by Indigenous people, lack of cultural awareness including the impact of trauma, literacy and numeracy issues, privacy concerns and a lack of transparency in processes, need to be addressed.

Community Engagement

Engagement

NQ participants perceived a lack of engagement from the statutory bodies with groups, organisations and communities. It was felt that there is a disconnect between the agencies and Indigenous people and this results in many (negative) issues being experienced.

Yes if there was more contact and engagement with our people then there would be more understanding. If we could work together then we could help them put into place strategies to improve services. (NQ participant)

It is more difficult in towns but in like rural and remote communities, those agencies (OAG and PT) should do some work with the key SHs in the communities so that they are aware of the roles and responsibilities and how agencies can work together. Good to involve the elders too and get their advice. Even in towns there are Indigenous bodies and elders who can be engaged. (NQ participant)

Education

Again, the need for various forms of education activities was highlighted across all areas. Like the SHs in RQ4, participants also highlighted the need to educate Indigenous people about the importance of a Will or the value of a Power of Attorney or a Health Directive. While not necessarily the domain of the AG, it was felt that the importance of such documents needs to be presented. One CQ participant asked:

What if you (a service provider) are in a position of trust with an individual who has no other family left? Can you take over? Who decides? What are the boundaries around power of attorney? (CQ participant)

Therefore, it was suggested that more training and information needs to be provided for communities regarding the importance of these documents. There needs to be more preparatory work done before the Guardian or Trustee is required as a ‘last resort’.

Employment

The need for Indigenous people to be employed within statutory bodies such as the OAG and the OPT was identified. It was suggested by NQ participants that Indigenous people could work as liaison officers or community workers.

Yes they need someone like health workers but call them something else to be like a liaison person to work between the services and the community and the family – someone who knows our ways and also knows what goes on in the community. (NQ participant)

What qualifications do these people need to have to work in these positions – see this is an area where Indigenous people wouldn’t think to work so they should be encouraged to do that. (NQ participant)

Some SH participants made similar suggestions. They also advocated the need for specified positions, including the development of a career pathway, for the employment of Indigenous people within key agencies in the Guardianship and Administration system. This was seen as key to progressing the engagement of Indigenous Queenslanders and their families and carers with Guardianship and Administration agencies.

CQ participants highlighted the need for a preparedness for services to be able to take on new staff with no skills to provide employment and training opportunities for rural and remote communities.

Addressing Barriers

Dominance of Western Frameworks and Accessibility to Services by Indigenous People

The dominance of Western frameworks for practice was seen as a significant barrier. The fact that the established, statutory guardianship and proxy-decision practices have their roots in Western systems was seen as problematic. For CQ participants, this was seen as a legacy of colonisation whereby the dominant Western framework of operating and the capacity to respond to the needs of Indigenous communities do not dovetail together, as evidenced in Table 3.

Table 3: Comparisons between Indigenous and non-Indigenous Australian

worldviews (Adapted from Sterling, 1986 cited in Hughes, More, & Williams, 2004)

INDIGENOUS AUSTRALIAN SOCIETY	NON-INDIGENOUS SOCIETY
History is timeless	History is quantified and specified
Engage in holistic or 'big picture' thinking	Engage in observation and experimental thinking
Concept of time is circular, past continuous, without boundaries	Time is linear, referenced to points, future oriented
Spiritual views are not questioned	Spiritual views are debated and questioned
Being rather than doing is important-fit into the existing circumstances	Try to change existing circumstances
Immediate gratification important	Deferred gratification important
Indigenous society acceptable as it is	Society needs to change
Group oriented – everything is for all group members	Individual oriented – acquisitions are for you
Kinship important in family/extended family unit. A person can go from home to home	Kinship far less important
Spontaneous lifestyle – do what you want when you want to	Structured lifestyle – must plan and be stable if you want to succeed
Often uncritical due to respect	Critical – everyone is judged
Basically listeners – do not speak unless it is important	Basically verbalisers – think out loud, must speak
Use symbolic language	Literate – use books, and very verbal
Little eye contact – it is impolite to do so	Lots of eye contact – it is impolite not to do so
Indirect questioning – talk around the point	Direct questions – very to the point
Non-legislative – laws are morals and are to support the group, not to isolate anyone (reintegration)	Legislative – laws are written and offenders are isolated
Accepting of others following separation for wrongdoing	Not accepting of others following separation for wrongdoing
A non-market economy – money not important	Market oriented – money important and complex
Age is respected	Youth is respected
Giving is important	Saving is important

Hence, the CQ researchers make the following observations:

The table reflects differences that may influence decision-making in Australian Indigenous communities and families. As a result, communities are evolving in response to Western frameworks but are not fully acculturated. Communities are mediating different worldviews in relation to property ownership, wealth and possessions where Indigenous worldviews and traditions often assert common ownership. However, this common ownership is not comfortably mediated through individualised Western legislation.

Furthermore, the CQ participants highlighted issues in regard to physical accessibility, especially in regard to location and the diversity of Indigenous communities. They commented how services are not necessarily locally based and service providers often do not travel to remote communities, with the that clients located remotely must travel

to attend tribunals or to access services and this is often not possible or very expensive and time consuming.

The SH participants highlighted specific issues in regard to Aged Care services; where they stated that a related issue to substitute decision-making is the availability of places and suitability of the Western aged care system. The informants reported that Indigenous Queenslanders did not always agree with Guardianship and Administration agencies or human service providers that the available aged care facilities are a suitable option for Indigenous Queenslanders with impaired capacity.

If there was more aged care funding to support people in the home, Indigenous people wouldn't need to be sent away to a nursing home etc. (SH participant)

Lack of cultural awareness including the impact of trauma

Concerns were raised about a lack of cultural awareness shown by OAG or OPT officers when working with Indigenous people. NQ participants commented:

You know those officers who work in those places (Government and other agencies) should have things like cultural awareness programs so they understand what has happened to our mob and how this has affected them. (NQ participant)

They (authorities) just don't understand about our culture eh! You know about kinship and things and responsibilities and who looks after who and what works for our people is not the same as what works for white people. (NQ participant)

That's why some of our clients are a little bit frightened you know a bit reluctant to go under them (the PT) as power of attorney because they are too hard on our people - we need someone who understands community. There's an example of one person - for her to move into the family home she had to come with her own TV and DVD player - then the PT said, 'no we just brought her a TV and DVD 12 months ago', but what they didn't understand was that that TV and DVD belonged to everyone in that other house even though she paid for it - so she couldn't just up and take it. (NQ participant)

Similarly, there was general consensus with the NQ participants that people employed in the services need to understand about history, kinship, cultural values and beliefs and contemporary issues for Indigenous people. Significantly, all Indigenous CQ participants also commented how this lack of cultural awareness demonstrated a continuing trauma that is experienced because of Indigenous people's historical relationships with government and authority in Australia. This is outlined in Figure 5 below.



Figure 5: Impacts from the historical legacy of colonisation for Indigenous Australians (Developed for this research by Pascoe and Radel, 2010)

Literacy and numeracy issues

NQ participants highlighted how literacy and numeracy issues impact clients and families. They stated the example that if people can't read and write or understand financial statements, they don't want to say that they don't understand. Two NQ practitioners stated:

A lot of them can't read and that is a barrier for them, everything is related to reading, they feel shame, they don't want to talk to people.

The need to make them things (information) better to understand – have a video of the information or something.

There is so much paper work and people have to sign off but they really don't know what they are signing.

Privacy Concerns (CQ)

All CQ participants spoke of the issue of privacy/confidentiality laws. In the bullet points below, it is worth noting how the CQ researchers reported the issue, and the implications that emerge:

- Participants suggested that these laws actually impede the transfer of relevant information between service providers. For example, relevant client information is not transferred between: mental health institutions, child safety services, local Home and Community Care (HACC) and other service providers. Ideally, there should also be a seamless transition between child and adult services.



- As one participant noted, if the HACC referred a client to a mental

health service then no information was passed back to the HACC service to enable case management when the client returned to the local area. Local service providers are then unable to follow up on outcomes and family needs. As one participant indicated, *“we have trouble referring people to mental health and then can’t continue in our care role because the privacy act says we can’t get any information about our clients”*. This links with the previous observations about the continuity of care in mental health service provision.

- Each service provider has an independent charter and due to the privacy laws they cannot communicate with other service providers to ensure continuity of care. As one participant noted, *“we don’t want to know all the details of the mental health issues but we don’t get even relevant information”*.
- Another participant told of a tragic event where as a direct result of the privacy/confidentiality issues, a young man committed suicide.
- These privacy conditions actually support and further reinforce one-way relinquishment. This therefore prohibits ongoing quality care, support and continuity to sense of community.

Lack of Transparency

Some NQ participants were concerned about the lack of transparency of the process involved with making decisions about the future care of people with impaired capacity. The researchers state that this concern included how decisions were made and whether the people making the decisions actually had access to all the information or understood the family’s position. They comment how one discussion revealed that:

Sometimes family are confused because they (staff) come and talk about one thing and then they go away and then come back again and there is nothing laid out that this is the whole process and this is how we are making the decisions. (NQ participant)

Yeah – and if the family don't agree with something about the decisions they are too shame to talk up or they are too frightened in case it makes it bad for the person. (NQ participant)

That's true eh but the other thing is that they don't really know what it means at the end of the day to not be in control of making your decisions until its all happened – then they are stuck with it. (NQ participant)

6. Discussion

On analysis of the data, a number of themes were common across all research conducted, as presented below in response to the RQs.

RQ1: What are the meanings of impaired capacity in Indigenous communities?

It was clear that the term impaired capacity had little meaning for Indigenous Queensland. However cognitive impairment and a lack of functioning, usually as a result of dementia, acquired brain injury, mental illness, and/or substance misuse, Indigenous Queenslanders understood as “going back to spirit”, and as requiring traditional treatments.

RQ2: How has the issue of determining capacity for Indigenous people been addressed in Queensland, as well as within other jurisdictions in Australia?

Informants who had knowledge of capacity assessment believed current tools are flawed and inadequate, for a variety of reasons, such as due to the underlying western cultural framework of most of the tools and the process of assessment itself.

RQ3: How are decisions made for Indigenous adults with impaired capacity according to Indigenous cultural expectations and practices?

Decisions made within Indigenous families and communities for Indigenous people with impaired capacity are usually made according to the traditional family protocols, where the eldest in the family makes decisions. However, there are instances where the traditional family protocols are ignored, resulting in exploitation and abuse of Indigenous people with impaired capacity. People with impaired capacity were vulnerable to exploitation of their rights, money and property. Abuse of money was reported in several cases. Conflict within families regarding decision-making and control over money was evident.

It was apparent that Indigenous decision-making practices were adversely influenced by fear and suspicion of authority. Participant responses revealed evidence of continuing trauma which could be attributed to ongoing ramifications as a result of colonisation. Participants still referred back to “living under the Act”.

Decision-making for families of those with impaired capacity varied depending on family expectations, who was available, who had the least responsibilities and the physical location of the person in relation to family members.

RQ4: Are the requirements of the current Guardianship legislative regime appropriate for Indigenous Queenslanders? Is the legislation appropriate and advantageous for Indigenous Queenslanders with impaired capacity?

Significant differences remain between Indigenous and Western world views based on individual versus collective ownership. There is considerable incongruence between individualised Western legislation around property ownership and individual rights and Indigenous family decision-making patterns.

Family and kinship roles and responsibilities and the associated decision-making practices and processes do not dovetail well with Western individualised legislation.

There was a clear lack of understanding and some confusion around the role of authorities (OAG and the PT) and other agencies responsible for the care of people with impaired capacity.

Overwhelmingly the perceptions of the roles of the AG were either unknown or misunderstood. Often the AG roles were confused with the PT. Further, the lengthy appeals processes and lack of transparency within the processes were raised as significant barriers to accessing the services. Participants reported both positive and negative experiences of their dealings with the AG.

Communication about the roles and services of the AG was considered particularly unhelpful. For example, printed brochures were considered unclear and were not

provided in “Indigenous friendly” language. Further, the Office was not considered to be effectively communicating what they do with appropriate service providers.

Participants indicated a lack of general knowledge of wills, health directives and powers of attorney. There also appeared to be a number of legislation and services with overlapping responsibilities but ineffective information sharing. Further, there appeared to be unclear guidelines as to which legislation or service might apply in specific situations. Participants also noted that privacy and confidentiality laws impeded continuity of care and client follow-up between service providers. The location and diversity of Indigenous communities may impact on the provision of services due to lack of recognition of heightened costs of living for rural and remote communities.

The result of Government policies continues to impact on the decision-making process for some families and communities regarding individuals with impaired capacity. History has made people suspicious and fearful of authorities who are seen to have the power to take control over others.

Local knowledge of community dynamics and family decision-making patterns was seen as imperative to service provision and making ‘good’ decisions.

Experiences with dealing with services for those with impaired capacity were mostly reported as negative. A need for legislative bodies to care for the rights of those with impaired capacity was seen as necessary but with improved processes such as access to appropriate information and adequate consultation.

There was general consensus that there was a lack of understanding of Indigenous people’s history, kinship responsibilities, cultural values and beliefs and ways of working. A need for better community engagement was identified along with the promotion of Indigenous people to work in agencies dealing with people with impaired capacity and their families along with the introduction of new Indigenous liaison officer positions to work in this field.

There is a low level of awareness and understanding of the Guardianship and Administration system amongst Indigenous Queenslanders, and a high level of mistrust and confusion about the roles and powers of the various agencies.

In instances where the Guardianship and Administration system is used to support and protect in culturally appropriate ways, it works well for Indigenous Queenslanders. However the system is also culturally biased, and does not allow for different cultural practices.

RQ5: Are there other factors which need to be considered in relation to substitute decision-making practices for Indigenous Queenslanders with impaired capacity?

Participants recommended that all services need to be able to take on new unskilled staff from the community to provide locally-based employment and training opportunities for rural and remote areas. A related issue raised by informants included the lack of Indigenous people employed within the Guardianship and Administration system as a contributing factor to Indigenous Queenslanders lack of knowledge and mistrust of the system.

7. Conclusion

This Report has presented a variety of research findings exploring the relevance of the concept of impaired capacity and the relevance of the Guardianship and Administration system in Queensland, for Indigenous Queenslanders. This research suggests the Guardianship and Administration system in Queensland may not be meeting Indigenous peoples' needs because of a lack of awareness and understanding of the system, as well as the cultural misfit between the Western legal framework of the Guardianship and Administration system and Indigenous cultural concepts such as reciprocity. Future investigation of the issues outlined in this paper will need to involve Indigenous Queenslanders with impaired capacity and their families and carers, and Indigenous health and human service providers, in order to design and deliver relevant and responsive services.

Additionally, considering the historical context in Queensland and Australia, where important life decisions for Indigenous Australians were made by the State, the Guardianship and Administration system may be seen by some Indigenous Queenslanders as a contemporary form of the previous "protectionist" legislative framework.

8. Recommendations - Complete List

Literature Review

LR1. There is a need for a broader range of decision-making alternatives to be developed for Indigenous people. Some alternative approaches might be designed around involving the local Indigenous community and increasing support for informal supported decision-making arrangements, such as providing funding for community resources to aid in planning. This is consistent with Article 12 of the United Nations Convention of the Rights of Persons with Disabilities, which promotes supported decision-making (United Nations General Assembly, 2007). Service delivery, therefore must focus on strengthening Aboriginal family and agency resources and utilising Aboriginal services.

LR2. Further research is required focusing on analysis of any difficulties experienced by Indigenous Queenslanders when accessing and engaging with the Guardianship and Administration system in Queensland.

LR3. That the OAG Queensland and the OPT Queensland publish in their Annual Reports the number of Indigenous Queenslanders coming into contact with their agencies.

LR4. That brochures and fact sheets used by the agencies in the Queensland Guardianship and Administration system be redesigned in consultation with Indigenous Queenslanders, to be Indigenous friendly. Material developed by other government agencies that are good examples of Indigenous friendly resources are : the resource kit “A journey into the Queensland forensic mental health system Indigenous resource kit”, developed by the Queensland Centre for Mental Health Learning, the “Taking care of business – Planning ahead in Aboriginal and Torres Strait Islander Communities”, developed by the New South Wales Department of Ageing, Disability and Home Care, and the “Looking out for Dementia” resources developed by Alzheimer’s Australia. Other forms of communication and engagement should be considered, including alternative formats such as: a DVD demonstrating

role play of the roles and services of the OAG and the OPT; video conferencing with local service providers; and face-to-face meetings with Indigenous Queenslanders. Particular topics to address through informational resources, directed at areas of need and misunderstanding, are: the interaction of the different legislation underpinning the Guardianship and Administration system in Queensland; definitions and explanations of impaired capacity; people's rights when coming into contact with the system; pathways through the system; and EPA and AHD's.

LR5. Consideration of the use of community guardians in the Queensland Guardianship and Administration system. The Northern Territory has this system, and a similar system for Family Responsibility Commissioners operates in the Cape York Welfare Reform trials in Queensland, where respected Indigenous persons are appointed as local commissioners for the Family Responsibility Commission Queensland.

LR6. Regular dissemination of information, training and resources, to health and human service workers to disseminate amongst Indigenous communities and clients about the Guardianship system, such as to Centrelink, Home and Community Care.

LR7. That Queensland Guardianship and Administration agencies develop specific protocols to ensure that cultural aspects of competency are considered by practitioners in assessment of capacity.

North Queensland research

NQ1. Clarification of the Role of Agencies and Promotion of the OAG:

NQ1.1 That Indigenous people have input into the development of appropriate strategies, resources and material to inform people of their rights and available services to assist them.

. NQ1.2 That strategies include the provision of a transparent process with potential outcomes and implications clearly evident.

NQ1.3. That relevant Indigenous and other organisations are approached to form partnerships with the OAG to form a more coordinated approach to

addressing the needs of Indigenous people with impaired capacity and their families.

NQ2. Workforce and Professional Development:

NQ2.1. Provide all staff at all levels of those agencies dealing with Indigenous people with impaired capacity undertake a suitable program which provides them with an understanding of history, kinship, cultural values and beliefs, governance and decision-making and effective means of communication.

NQ2.2. Ensure that agencies dealing with Indigenous people with impaired capacity have in place a reconciliation statement, a strategy to provide effective services for Indigenous people, a community engagement strategy and an Indigenous employment strategy.

NQ3. Monitoring and Review:

NQ3.1. That strategies have key performance indicators which are used to measure the effectiveness of the strategies over time.

NQ4. Further Research:

NQ4.1. That further research be conducted regarding the needs of Indigenous people with impaired capacity and their families in relation to legislative requirements.

Central Queensland research

CQ1. Brokering services at a local, community level

CQ1.1. It is recommended that the OAG enter into brokerage arrangements or agreements with local Indigenous service providers. This would enable assessment to take place on a 'grass roots level' utilising local community knowledge and relationships.

CQ2. Better communication and promotion of the OAG and its services

The OAG needs to

CQ2.1. Review their information brochures. It is recommended to produce brochures and other promotional materials in clear language which is more readily accessible by Indigenous peoples.

CQ2.2. Consider other forms of communication including a DVD demonstrating role plays of the roles and services of the AG.

CQ2.3. Consider also, video conferencing with local service providers (for example the Woorabinda and Emerald Hospitals).

CQ2.4. Incorporate participants expressed a desire to “*sit down and yarn face-to-face*” with people from the Office to better understand what they do.

CQ3. Appeals Processes and Transparency

CQ3.1. It is recommended that the OAG and the OPT collaborate whenever possible to streamline their processes and minimise bureaucracy particularly for the tribunal and appeals processes.

CQ3.2 The membership and processes of the tribunal require greater transparency.

CQ3.3. Particularly, individuals under the AG require access to their information regarding the decision-making processes of the tribunal and all subsequent decision processes. Individuals need to know the information around why and how a decision was made and then clarity and transparency in the appeals process.

CQ3.4. Individuals also require more frequent, standardised review periods for the reassessment of their circumstances.

CQ4. Clarification of the “Acts”

CQ4.1. Individuals demonstrated there was a great deal of misinformation around the OAG and their services, particularly in regard to the application and limitations of the various “Acts” (the Mental Health Act, the Adult Guardian Act, PT Act, etc).

Stakeholder research

SH1. Increased education and engagement by key agencies in the Guardianship and Administration system about the Guardianship and Administration system, such as the OAG and the OPT, of Indigenous and non-Indigenous human service agencies and workers, particularly Indigenous health workers, Indigenous Health Councils,

Indigenous doctors, Indigenous legal services, hospices, hospitals, respite services and the Elder Abuse Prevention Unit Queensland.

SH2. Increased education and engagement by key agencies in the Guardianship and Administration system about what impaired capacity is and the Guardianship and Administration system, such as the OAG and the OPT, of Indigenous Queenslanders, particularly those with impaired capacity and their families and carers. This should be conducted in culturally appropriate ways, and directed at areas of need and misunderstanding, such as EPA and AHD's.

SH3. Guidelines should be developed that explain the system, and that address the interaction of the traditional family protocol and other cultural differences, with the Guardianship and Administration system, targeted at both Indigenous and non-Indigenous human service agencies and workers, as well as the Indigenous community in general, in order to discuss incompatibilities and to provide examples of addressing these.

SH4. Training is needed for both Indigenous and non-Indigenous human service agencies and workers, as a key source of information dissemination and support to Indigenous Queenslanders.

SH5. A review of the key legislation by Indigenous human service experts and the Indigenous community, to identify cultural incompatibilities in the legislation and to explore options for reform.

SH6. Creation of specified positions and a career pathway for Indigenous people within key agencies in the Guardianship and Administration system.

SH7. Further research to identify current assessment practices used by health practitioners in Queensland, and to evaluate these for cultural relevance to Indigenous Queenslanders.

SH8. Training for all workers in the Guardianship and Administration system by Indigenous experts in the interaction of the system with Indigenous culture.

9. Recommendations - Themed List

The following brief summary is drawn from the detailed recommendations (see pg80) resulting from a meta-analysis of the three studies and literature review. Similar themes and recommendations emerged from all studies:

1. Service delivery reform

- Staff at all levels of Guardianship and Administration agencies undertake a suitable training and education program in Indigenous history, kinship, cultural values and beliefs, governance and decision-making and effective means of communication.
- The OAG and the OPT collaborate whenever possible to streamline their processes and minimise bureaucracy for Indigenous clients and family.
- Specified positions with a career pathway be created for Indigenous people within all agencies in the Guardianship and Administration system.
- Service delivery should utilise Aboriginal services rather than promoting delivery of services through non-Aboriginal networks.

2. Policy and legislative reform

- Indigenous people have input into the development of appropriate strategies, to inform people of their rights and available services to assist them. That strategies include the provision of a transparent process with potential outcomes and implications clearly evident. That strategies have key performance indicators which are used to measure the effectiveness of the strategies over time. That all agencies dealing with Indigenous people with impaired capacity have in place a Reconciliation statement, a strategy to provide effective services for Indigenous people, a community engagement strategy and an Indigenous employment strategy.
- Guidelines should be developed that explain the Guardianship and Administration system in Queensland, and provide guidance for the interaction of the system and Indigenous cultural differences, targeted at clients and provide ways to discuss and address incompatibilities.
- The Queensland Civil and Administrative tribunal membership and processes require greater transparency particularly for individuals under the OAG who

require access to their information. That the OAG enter into brokerage arrangements or agreements with local Indigenous service providers to best utilise 'grass roots' local community knowledge and relationships.

- There is a need for a broader range of decision-making alternatives to be developed for Indigenous people including approaches involving the local Indigenous community and increasing support for informal decision-making arrangements, such as providing funding for community resources to aid in planning.
- Consideration of the use of community guardians in the Queensland Guardianship and Administration system (as in the Northern Territory and similarly the system for Family Responsibility Commissioners the Cape York Welfare Reform trials in Queensland), where respected Indigenous persons are appointed as local commissioners for the Family Responsibility Commission Queensland.
- That Queensland Guardianship and Administration agencies develop specific protocols to ensure that Indigenous cultural aspects of competency are considered by practitioners in assessment of capacity.
- A review of the key legislation by Indigenous human service experts and the Indigenous community, to identify cultural incompatibilities in the legislation and to explore options for reform.

3. Communication with and engagement of Indigenous Queenslanders by Guardianship and Administration system agencies

- Brochures, fact sheets, and promotional material be produced in clear and accessible language, by the agencies in the Queensland Guardianship and Administration system. There are a number of good examples of Indigenous friendly resources (see detailed recommendation pg 80). Regular dissemination of information, training and resources occur to both Indigenous and non-Indigenous health and human service workers in Queensland, as they are key local sources of information. Indigenous health workers, Indigenous Health Councils, Indigenous doctors, Indigenous legal services, hospices,

hospitals, and respite services are particularly relevant for dissemination of information to Indigenous Queenslanders.

- Relevant Indigenous organisations, such as those listed above, and non-Indigenous organisations, such as the Elder Abuse Prevention Unit in Queensland, are approached to form partnerships with the OAG and the OPT to form a more coordinated approach to addressing the needs of Indigenous people with impaired capacity and their families.

4. Further research needs

- Further research focusing on analysis of needs and difficulties experienced by Indigenous Queenslanders in relation to the Guardianship and Administration system in Queensland is required.
- The Annual Reports of OAG Queensland and the OPT Queensland include the number of Indigenous Queenslanders coming into contact with their agencies.
- Identification and evaluation be undertaken of the cultural relevance of current cognitive assessment practices and tools used by health practitioners in Queensland.

References

- Ariotti, L. (1999). Social construction of Anangu disability. *Australian Journal of Rural Health*, 7 (4), 216-22.
- Alzheimer's Australia. (2007). *Dementia, a major health problem for Indigenous people*. Scullin: Alzheimer's Australia.
- Alzheimer's Australia Northern Territory. (2002). *Indigenous dementia project report*. Nightcliff: Alzheimer's Australia Northern Territory.
- Australian Institute of Health and Welfare. (1999). *The definition, incidence and prevalence of acquired brain injury in Australia*. Canberra: Australian Institute of Health and Welfare.
- Australian Institute of Health and Welfare (2007). Intellectual disability in Australia's Aboriginal and Torres Strait Islander peoples. *Journal of Intellectual and Developmental Disability*, 32, 222-5.
- Australian Institute of Health and Welfare. (2009). *Measuring the social and emotional wellbeing of Aboriginal and Torres Strait Islander peoples*. Canberra: Australian Institute of Health and Welfare.
- Bostock, L. (1991). Access and equity for the doubly disadvantaged. *Aboriginal and Islander Health Worker Journal*, 15(4), 10-15
- Broome, R. (1994). *Aboriginal Australians – Black responses to white dominance 1788-1994*. St Leonards: Allen and Unwin.
- Brown, R. (2001). Australian Indigenous mental health. *Australian and New Zealand Journal of Mental Health Nursing*, 10 (1), 33-41.
- Cairney, S., & Maruff, P. (2007). Computerised tests of brain function for use with Indigenous people. In L. E. Dyson, M. Hendricks & S. Grant (Eds.), *Information technology and Indigenous people*. Hershey: IDEA Group Inc.
- Carney, T. (2004). Aged capacity and substitute decision-making in Australia and Japan. *Law Asia Journal*, 2003/04, 1-21.
- Carney, T. & Tait, D. (1997). *The adult Guardianship experiment: Tribunals and popular justice*. Sydney: Federation Press.
- Cattarinich, X., Gibson, N., & Cave, A. J. (2001). Assessing mental capacity in Canadian Aboriginal seniors. *Social Science & Medicine*, 53(11), 1469-1479.

- Clements, N, Clapton, J., & Chenoweth, L. (2010). Indigenous Australians and Impaired Decision-Making Capacity. *Australian Journal of Social Issues*, 45 (3), 383-393.
- Council of Australian Governments. (2008). *National Indigenous Reform Agreement (Closing the Gap)*. Canberra: Council of Australian Governments.
- Cunneen, C. (2005). Colonialism and historical injustice. *Social Semiotics*, 15(1), 59-80.
- Demosthenous, C., Robertson, B., Cabraal, A., & Singh, S. (2006, October). Cultural identity and financial literacy: Australian Aboriginal experiences of money and money management. Paper presented at the Financial Literacy, Banking and Identity Conference, Melbourne
- Dingwall, K. M., & Cairney, S. (2010). Psychological and cognitive assessment of Indigenous Australians. *Australian and New Zealand Journal of Psychiatry*, 44 (1), 20-30.
- Disability Services Commission. (2006). *Aboriginal people with disabilities [kit]: Getting services right*. West Perth: Disability Services Commission.
- Elliott, E. J., Payne, J., Morris, A., Hann, E., & Bower, C. (2008). Foetal alcohol syndrome: a prospective national surveillance study. *Archives of Disease in Childhood*, 93(9), 732-737.
- Francisco, I., & Carlson, G. (2002). Occupational therapy and people with intellectual disability from culturally diverse backgrounds. *Australian Occupational Therapy Journal*, 49 (4), 200-211.
- Garvey, G., Simmonds, D., Clements, V., O'Rourke, P., Sullivan, K., Gorman, D., Curnow, V., Wise, S., & Beattie, E. (2011). Making sense of dementia: understanding amongst Indigenous Australians. *International Journal of Geriatric Psychiatry*, 26(6), 649-656.
- Gething, L. (1997). Sources of double disadvantage for people with disabilities living in remote and rural areas of New South Wales. *Disability & Society*, 12 (4), 513-531.
- Gething, L. (1995). A case study of Australian Aboriginal people with disabilities. *Australian Disability Review*, 2, 77-88.
- Gething, L. (1994). Aboriginality and disability. *Aboriginal and Islander Health Worker Journal*, 18 (3), 29-34.

- Gilroy, J. (2008). Service delivery for Aboriginal people with a disability and their Families. *Disparity*, 5 (1), 24-27.
- Glasson, E.J., Sullivan, S.G., Hussain, R., & Bittles, A.H. (2005). An assessment of intellectual disability among Indigenous Australians. *Journal of Intellectual Disability Research*, 49 (8), 626-34
- Gray, D., Pulver, L. J., Saggars, S., & Walson, J. (2006). Addressing Indigenous substance misuse and related harms. *Drug and Alcohol Review*, 25(3), 183-188.
- Hepburn, K., & Reed, R. (1995). Ethical and clinical issues with Native-American elders: End of life decision-making. *Clinics in Geriatric Medicine*, 11(1), 97-111.
- House of Representatives Standing Committee on Legal and Constitutional Affairs. (2007). *Older people and the law*. Canberra: The Parliament of the Commonwealth of Australia.
- Hughes, P., More, A. J., & Williams, M. (2004). *Aboriginal ways of learning*. Adelaide: Flinders Press.
- Human Rights and Equal Opportunity Commission. (1997). *Bringing them Home – Report of the national inquiry into the separation of Aboriginal and Torres Strait Islander children from their families*. Canberra: Human Rights and Equal Opportunity Commission.
- Human Rights and Equal Opportunity Commission. (2005). *Indigenous young people with cognitive disabilities and Australian juvenile justice systems*. Sydney: Human Rights and Equal Opportunity Commission.
- Hunter, E. (2007). Disadvantage and discontent: A review of issues relevant to the mental health of rural and remote Indigenous Australians. *Australian Journal of Rural Health*, 15(2), 88-93.
- Kendall, E., & Marshall, C. A. (2004). Factors that prevent equitable access to rehabilitation for Aboriginal Australians with disabilities: The need for culturally safe rehabilitation. *Rehabilitation Psychology*, 49 (1), 5-13.
- Kidd, R. (2003). Abuse of Trust: The Government as banker in Queensland and the United States. *Indigenous Law Bulletin*, 5(26), 13-16.

- Law Reform Commission of Western Australia. (2006). *Aboriginal customary laws: The interaction of Western Australian law with Aboriginal law and culture*. Perth: Law Reform Commission of Western Australia.
- Lee, K.S., Conigrave, K.M., Clough, A.R., Dobbins, T.A., Jaragba, M.J., & Patton, G.C. (2009). Five-year longitudinal study of cannabis users in three remote Aboriginal communities in Arnhem Land, Northern Territory, Australia. *Drug and Alcohol Review*, 28, 623-30.
- Lefley, H. P. (2000). Cultural perspectives on families, mental illness, and the law. *International Journal of Law and Psychiatry*, 23(3), 229-243.
- Lo Guidice, D., Strivens, E., Smith, K., Stevenson, M., Atkinson, D., Dwyer, A., Lautenschlager, N. T., Almeida, O. A., & Flicker, L. (2010). The KICA Screen: The psychometric properties of a shortened version of the KICA (Kimberley Indigenous Cognitive Assessment). *Australasian Journal on Ageing*, doi: 10.1111/j.1741-6612.2010.00486.x
- Lo Guidice, D., Smith, K., Thomas, J., Lautenschlager, N. T., Almeida, O. A., Atkinson, D., & Flicker, L. (2006). Kimberley Indigenous Cognitive Assessment Tool (KICA): Development of a cognitive assessment tool for older Indigenous Australians. *International Psychogeriatrics*, 18 (2), 269-280.
- Maher, P. (1999). Disability in the Australian Aboriginal population. *Australian Journal of Primary Health – Interchange*, 5 (3), 10-20.
- Moberg, P.J., & Kniele, K. (2006). Evaluation of competency: Ethical considerations for neuropsychologists. *Applied Neuropsychology*, 13(2), 101-14.
- Mokak, R. (1997) Aboriginal people and disability: what are the issues and where do we go from here? *Aboriginal and Islander Health Worker Journal*, 21(5), 14-15
- National Health and Medical Research Council. (2003). *Values and ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research*. Canberra: Commonwealth of Australia.
- O'Neill, M., Kirov, E., & Thomson, N. (2004). A review of the literature on disability services for Aboriginal and Torres Strait Islander peoples. *Australian Indigenous Health Bulletin*, 4 (4), 1-29.

- Office of the Public Advocate Qld and the Queensland Law Society. (2010). *Elder abuse: How well does the law in Queensland cope?* Brisbane: Office of the Public Advocate Qld and the Queensland Law Society.
- Office of the Public Advocate Western Australia. (2005). *Mistreatment of older people in Aboriginal communities project: An investigation into elder abuse in Aboriginal communities*. East Perth: Office of the Public Advocate Western Australia.
- Other-Gee, B., Penter, C., Ryder, L., & Thompson, J. (2001). *Needs of Indigenous people in the Guardianship and Administration system in Western Australia*. Perth: Office of the Public Advocate Western Australia.
- Pattel, N. (2007). Aboriginal families, cultural context and therapy. *Counselling, Psychotherapy, and Health*, 3(1), 1-24.
- Queensland Advocacy Inc. (2004). *Weaving our magic through connectedness*. Brisbane: Queensland Advocacy Inc.
- Queensland Health. (2010). *The health of Queenslanders 2010*. Brisbane: The State of Queensland (Queensland Health)
- Schwab, R. G. (1995). *The calculus of Reciprocity: Principles and implications of Aboriginal sharing*. Canberra: Australian National University, Centre for Aboriginal Economic Policy Research.
- Scott, M. (2007, March). Understanding and engaging Aboriginal communities in the Guardianship and Administration system. *Paper presented at the Australian Guardianship and Administrative Committee Conference, Melbourne*.
- Senate Community Affairs References Committee. (2006). *Beyond petrol sniffing: renewing hope for Indigenous communities*. Canberra: Commonwealth of Australia.
- Senior, K. (2000). *Testing the ICIDH-2 with Indigenous Australians: Results of field work in two Aboriginal communities in the Northern Territory*. Canberra: Australian Institute of Health and Welfare, ICIDH Collaborating Centre and the Department of Health and Family Services.
- Setterlund, D., Tilse, C., & Wilson, J. (1999). *Substitute decision-making and older Australians*. Canberra: Australian Institute of Criminology.

- Shaddock, A. J., Spinks, A. T., & Esbensen, A. (2000). Improving communication with people with an intellectual disability: The content validation of the Biala-II profile. *International Journal of Disability, Development & Education*, 47(4), 383-395.
- Shah, A., & Heginbotham, C. (2008). The Mental Capacity Act: some implications for black and minority ethnic elders. *Age and Ageing*, 37(3), 242-243.
- Sheldon, M. (2010). Reviewing psychiatric assessment in remote Aboriginal communities. In N. Purdie, P. Dudgeon & R. Walker (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice*. Barton: Commonwealth of Australia.
- Senate Select Committee on Regional and Remote Indigenous Communities. (2010). *Second report 2009*. Canberra: Commonwealth of Australia.
- Silberfeld, M., & Checkland, D. (1999). Faulty judgment, expert opinion, and decision-making capacity. *Theoretical Medicine & BioEthics*, 20, 377-93.
- Simpson, J. & Sotiri, M. (2004). *Criminal justice and Indigenous people with cognitive disabilities: a discussion paper*. Canberra: Aboriginal and Torres Strait Islander Services.
- Smeaton, T. (1998). *Family dreaming: support programs for Aboriginal and Torres Strait Islander People with disabilities*. Sydney: Ageing and Disability Department
- Smith, K., Lo Guidice, D., Dwyer, A., Thomas, J., Flicker, L., Lautenschlager, N. T., Almeida, O. P., & Atkinson, D. (2007). ‘Ngana minyarti? What is this?’ Development of cognitive questions for the Kimberley Indigenous Cognitive Assessment. *Australasian Journal on Ageing*, 26(3), 115-119.
- Stanton, J, Jessop, M., & Henstridge, J. (1994). *Acquired brain injury accommodation and support needs*. Perth: Bureau for Disability Services.
- Swan, P., & Raphael, B. (1995). *Ways forward: National consultancy report on Aboriginal and Torres Strait Islander mental health. Part 1*. Canberra: Australian Government Publishing Service.
- Tate, B. (1992) Aboriginal disabilities. *Aboriginal and Islander Health Worker Journal*, 16(1), 8-9

- Tilbury, C. (2009). The over-representation of indigenous children in the Australian child welfare system. *Internal Journal of Social Welfare*, 18, 57-64.
- Tipper, D., & Dovey, S. (1991) *Bringing the Act together: The Disability Services Act and the support needs of Aboriginal people: Case studies of service provision in Western New South Wales*. Sydney: Planning and Research Unit, New South Wales Technical and Further Education Commission.
- United Nations General Assembly. (2007). *Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly*, 24 January 2007, A/RES/61/106, available at: <http://www.unhcr.org/refworld/docid/45f973632.html> [accessed 18 May 2011]
- United Nations. (2007). *From exclusion to Equality: Realizing the rights of persons with disabilities handbook for parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol*. Geneva: United Nations.
- Urbis Keys Young. (2006). National Indigenous money management agenda: Community consultations. Final report. Sydney: Urbis Keys Young.
- Vicary, D., & Andrews, H. (2000). Developing a culturally appropriate psychotherapeutic approach with Indigenous Australians. *Australian Psychologist*, 35(3), 181-185.
- Vicary, D.A., & Bishop, B.J. (2005). Western psychotherapeutic practice: Engaging Aboriginal people in culturally appropriate and respectful ways. *Australian Psychologist*, 40(1), 8-19.
- Wolstenholme, R. (1996). Caring for Aboriginal people with disabilities. *Australian Disability Review*, 3, 3-14.
- Ziersch, T. P. (1990). The reintegration of Aboriginal children with significant physical disabilities into remote communities. *Australian Disability Review*, 7(3), 24-30.

Appendix A Table of other jurisdictions

State	Issues	Strategies
NSW	In NSW, addressing the needs of Indigenous people with the Guardianship system is identified as a major systems challenge. There is reported to be significant under-representation of Indigenous people currently in the system. Two distinct challenges for the NSW Guardianship system are: The need to have available appropriate alternatives to Guardianship and administration so that Indigenous people do not need to use the system, and The need to make the system better for those Indigenous people who choose to, or have to, use the system.	The Public Guardian in NSW has implemented a number of strategies to improve responsiveness to Indigenous people. These include: Developing a pamphlet for Koori people, Developing closer links with Indigenous Health Workers, particularly those in community controlled organisations, and with specialist Indigenous support workers in court liaison roles, Having an Indigenous representative on the Advisory Board to the Public Guardian. This person is also a member of the Guardianship Tribunal; and Employing regional staff who deal with individual Indigenous clients at the local level.
VIC	The Victorian jurisdiction has not dealt with many cases involving Indigenous people. Indigenous people are seen to be under-represented, although the exact reasons for this are not known. The jurisdiction has undertaken no specific initiatives to understand Indigenous people's need for, or use of the system. No data is currently collected on the Indigenous status of applicants. The Victorian Tribunal has heard a number of applications involving Indigenous people, which have been challenging for the system. Challenging aspects mentioned include that of understanding and responding to complete cultural and family obligations, and of responding to Indigenous people in a respectful way. Administration orders are most commonly made. There are features of the system which are said to be problematic for Indigenous people and people of other diverse cultures. In particular, the difficulty of not compromising the dignity of elderly people, the potential for intrusion into the family domain, and the fact that people of Indigenous background can be deeply mistrustful of 'state intervention'.	n/a
SA	The current response of the system to Indigenous people in South Australia is described as "piecemeal" and there are no Indigenous specific policies or protocols within the jurisdiction. However, Indigenous people have been appointed as Board Members. Cases involving Indigenous people were reported to present considerable challenges and to be fraught with inherent difficulties. It was reported that there is hesitancy about intervening in Indigenous families in a way that disempowers and replicates the paternalism of the 'white' system. Some issues that arise in respect to Indigenous people include: Lack of suitable facilities (e.g. lack of accommodation for Indigenous people with brain damage resulting from substance abuse). This means that some orders are initiated because there is no	n/a

	other resource or facility or once an order is made there is often no available facilities; Difficulty of dealing with complex kinship structures and relationships Difficulty of understanding the nature of financial sharing in Indigenous families Prevalence of substance abuse related brain damage; and Responding to the different needs of Indigenous people in urban, rural and remote communities.	
NT	In the Northern Territory, approx 30% of the population is Indigenous and, while the system is used by large numbers of Indigenous people, Indigenous people are under-represented in the total number of cases. In many cases involving Indigenous people, a family member, or someone with cultural authority, would be appointed to act as a Guardian. This person may live in the same community. The arrangements could involve: Shared Guardianship. This may involve shared management between a Public Guardian or the PT, in the case of financial management, and an Indigenous community guardian; or Family/Community Guardian. This may involve a member of the family or community being appointed as a guardian. No significant problems have been reported, with inappropriate management of orders, to benefit family members or others, when Indigenous or Community Guardians have been appointed. There are some administrative problems with these orders, particularly when they are managed over large distances. Adult Guardians employed by Northern Territory Health Services manage cases at a local level and may be some distance from the community guardian. A (2002) study looked at the issue of dementia in Indigenous communities in the Northern Territory (Alzheimer's Australia NT, 2002). Reported neglect and financial abuse and Guardianship issues also received some mention in relation to: • who decides what is best for the client • who decides whether clients should remain in care or be returned to communities.	n/a
QLD	In Queensland, as at 2001, there was reported to be considerable under-representation of Indigenous people in the current Guardianship and Administration system. There have been a few cases involving Indigenous people that have highlighted the complexities involved. There have been few if any case involving Indigenous people from rural and remote areas and it is assumed that these cases will be much more challenging. There is a high degree of awareness reported to be within the system of the need to incorporate Indigenous issues into all systemic processes but the "system", in general, is not considered culturally	n/a

	inappropriate. Some of the key issues reported include: Difficulties arising from family disagreement or conflict Lack of awareness of the Guardianship system Difficulties of information gathering about case-specific issues, and Understanding and incorporating cultural obligations and traditions.	
WA	Other-Gee et al. (2001) found that there was an under-representation of Indigenous people in the Western Australian Guardianship and Administration system. They suggested the following reasons for this finding: • a lack of awareness of the system and its function by Indigenous people; • a lack of cultural relevance of the system; and • the inherent difficulties of a statutory system in the Indigenous context, when many past and present government policies have had a negative effect on Indigenous people and communities.	The focus of the overall strategy is to enable local service providers, in contact with Indigenous people and their families, to assist Indigenous families to meet the needs of their family members. Scott (2007) states that in response to this research, the WA OPA began to address this by: • The development of inter-agency protocols and work with Indigenous people, • Cultural awareness training for staff, including capacity assessment within a cultural context, • Indigenous psychological services and cultural consultants have been employed to advise on the above, and • Raising awareness about the role of the Public Advocate to Indigenous communities and service providers, through their community education program.



Indigenous Queenslanders and Impaired Decision Making Capacity

Report for the North Queensland Region

Yvonne Cadet-James
Val Wallace

School of Indigenous Australian Studies
James Cook University

October 2010



Indigenous Queenslanders and Impaired Decision Making Capacity

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EXECUTIVE SUMMARY

This pilot study was commissioned by the Queensland Office of the Adult Guardian. A literature review conducted by Griffith University revealed that there was little known about Indigenous Australians expectations and experiences with the care of family members with impaired decision making capacity. This research aimed to provide an insight into the issues and the implications for Indigenous Australians.

This report provides the findings from the pilot study for the North Queensland region component of the larger collaborative partnership between Griffith University, Central Queensland University and James Cook University.

Summary of the Key Findings:

- The result of Government policies continues to impact on the decision making process for some families and communities regarding individuals with impaired decision making capacity.
- There was a clear lack of understanding and some confusion around the role of authorities (Office of the Adult Guardian and the Public Trustee) and other agencies responsible for the care of people with impaired decision making capacity.

- Decision making for families of those with impaired decision making capacity varied depending on family expectations, who was available, who had the least responsibilities and the physical location of the person in relation to family members.
- Experiences with dealing with services for those with impaired decision making capacity were mostly reported as negative.
- A need for legislative bodies to care for the rights of those with impaired decision making capacity was seen as necessary but with improved processes such as access to appropriate information and adequate consultation.
- There was general consensus that there was a lack of understanding of Indigenous people's history, kinship responsibilities, cultural values and beliefs and ways of working.
- A need for better community engagement was identified along with the promotion of Indigenous people to work in agencies dealing with people with impaired decision making capacity and their families along with the introduction of new Indigenous liaison officer positions to work in this field.

KEY RECOMMENDATIONS

Clarification of the Role of Agencies and Promotion of the Office of the Adult Guardian:

- That there is clarification of the role of agencies dealing with Indigenous people with impaired decision making capacity and promotion of the Office of the Adult Guardian through input from Indigenous people, organisations and communities.
- That strategies include the provision of a transparent process with potential outcomes and implications clearly evident.

Workforce and Professional Development:

- That all staff at all levels of those agencies dealing with Indigenous people with impaired decision making capacity undertake a suitable program which provides them with an understanding of history, kinship, cultural values and beliefs, governance and decision making and effective means of communication.
- That all agencies dealing with Indigenous people with impaired decision making capacity have in place a reconciliation statement, a strategy to provide effective services for Indigenous people, a community engagement strategy and an Indigenous employment strategy.

Monitoring and Review:

- That strategies have key performance indicators which are used to measure the effectiveness of the strategies.

Further Research:

- That further research be conducted regarding the needs of Indigenous people with impaired decision making capacity and their families in relation to legislative requirements.

THE RESEARCH REPORT

BACKGROUND

A literature review conducted by Griffith University revealed that there is little research into how Indigenous Australians make decisions about the care, finances and property of family members with impaired decision making capacity. There is also little known about Indigenous peoples' knowledge and understanding about the Office of the Adult Guardian whose role is to protect the rights and interests of adults who are unable to make decisions for themselves.

Anecdotal evidence from Indigenous people who work in the area of health and social services suggested that the term 'impaired decision making capacity' did not have very much meaning or relevance for Indigenous people. They also felt that there was some confusion around what constitutes 'impaired decision making capacity'.

This pilot project was commissioned to provide an insight into these issues.

AIM OF THE RESEARCH

The aim of the research was to gain an understanding of:

- Aboriginal and Torres Strait Islander Peoples' understanding of and perception of the role of the Office of the Adult Guardian; and
- How Aboriginal and Torres Strait Islander People make decisions about the care, finances and property of family members with impaired decision making capacity.
- The issues and implications for Indigenous Australians with impaired decision making capacity and their families.

HUMAN RESEARCH ETHICS

Ethics approval for this component of the larger study was obtained from James Cook University Human Research Ethics Sub Committee.

METHODOLOGY:

Type of Study

This was a qualitative study which utilised individual and focus group interviews to gather data.

Ethical Considerations and Cultural Protocols

The principles of Reciprocity, Respect, Equality, Responsibility, Survival and Protection, Spirit and Integrity as identified and described in the National Health and Medical Council Values and Ethics document formed the framework for the study (NHMRC 2003). Local protocols were identified and observed at each location.

Recruitment

Organisation and community connections provided a list of potential participants who were then contacted, provided with information about the study and invited to participate.

Data Collection

Individual interviews and focus groups were held in Townsville, Palm Island, Mt Isa and Cairns (some representatives from Yarrabah and Mossman attended the Cairns group meeting).

Overview of Participants in Each Location

Townsville

One community health nurse, one health workers, a minister of religion, one social worker, one retired person with past employment in the Aboriginal Legal Service and current representation on several boards of Indigenous organisations, one community member. (2 Torres Strait Islanders and 4 Aboriginal People).

Palm Island

Two social workers, one health worker, a hospital domestic worker, the community bus driver and two community members (1 Torres Strait Islander and 6 Aboriginal People).

Mt Isa

One health worker, one community member, one nurse, one Centacare worker. (4 Aboriginal people)

Cairns/Yarrabah/Mossman

One community health worker, one senior community health aged care worker, one aged care worker, two parent support workers, two Indigenous health researchers.

(2 Torres Strait Islanders and 5 Aboriginal people).

Interviews and Focus Groups

Information regarding the study was explained to participants who were informed that participation was voluntary and that they could withdraw from the study at any time without any repercussions. Interviews and focus groups were conducted over one to two hour periods depending on the different individuals or groups. With permission notes were taken and data tape recorded during the interviews and focus groups.

Research Questions

The following semi structured questions were asked of participants to generate discussion and gain an insight into their perceptions, observations and experiences.

1. What is the meaning of impaired decision making in Indigenous Communities?
2. How are decisions made for Indigenous adults with impaired decision making capacity according to Indigenous cultural expectations and practices?
3. Are the requirements of the current guardianship legislative regime appropriate for Indigenous Queenslanders?
4. Is the legislation appropriate and advantageous for Indigenous Queenslanders with impaired capacity?
5. Are there other factors which need to be considered in relation to substitute decision making practices for Indigenous Queenslanders with impaired decision making capacity?

Data Analysis and Results

Data were analysed with manual coding of information and identification of categories and common themes. Results are provided highlighting key common findings among participants in all locations.

Analysis

What is the meaning of impaired decision making in Indigenous Communities?

There was general consensus across all locations and with both Aboriginal and Torres Strait Islander people that most people would not understand and/or relate to the term 'impaired decision making capacity'. The exception was some participants who were familiar with the term due to their professional backgrounds and/or the nature of their work.

As two participants said:

If I said that to any of my clients, they would ask me what I am talking about.

People would say – what the hell does that mean?

Participants reported that there were different ways that people referred to those with 'impaired decision making capacity'. These included, the person is not quite right, they are 'womba', they are a different kind or they have a mental problem. Some participants said that different groups used their own language names to describe people with impaired decision making capacity.

There was a general notion that people with impaired decision making capacity were not seen as a great concern in the community unless they were causing problems which impacted on others. As one participant said:

One of the strengths of this place is that it is a very tolerant community and people are not necessarily viewed as having special needs so that can make it quite difficult and I think that some of the people do function quite well so you have to be conscious that they do need help.

Two participants commented on their observation that more women than men seemed to be cared for by family in the home. This was not only for those with impaired decision making capacity but also those who needed care because of disability or old age. Discussion in the focus group gave several possible reasons which included women having a bigger role in the family, closer day to day connection to

family and isolation of men who displayed violent behaviour. As one participant said:

The type of behaviour of females is more able to be tolerated rather than the violence of some men who have shown this behaviour over time.

Decision Making for Indigenous Adults with impaired decision Making Capacity.

Impact of Government Policies

Responses to this question highlighted the impact of government policies which are still being felt today. Participants spoke of traditional practices where elders and significant others in the kinship system made such decisions. They referred to policies which involved the removal of people from their traditional lands, the removal of children from their families and a breakdown in the overall social organisation which affected decision making processes. As stated by one participant in a community where people from many different tribal groups were moved:

There are difficulties because there are no effective elder type roles/networks within family groups so traditionally you would expect to go to the elders within family groups or the elders within the community and they would be able to help support with those decisions.

Social and Health Factors

Participants also spoke of the social and health factors affect the decision making process such as over representation of Aboriginal and Torres Strait Islander people in prison, alcohol and substance abuse, suicides, and poor health especially the low life expectancy.

There's not that many old people here because they pass away early,

said one participant and referring to alcohol and drug abuse another said:

Some of our clients drink too much and take drugs so they can't help themselves let alone anyone else.

Dynamic Culture

There was also recognition that culture is dynamic with cultural practices changing over time which has some bearing on decision making. One participant reflects on this by saying:

People that are more educated in the western system tend to make their own decisions or these decisions are made by a small number of people within one family instead of a traditionally larger family group.

Decisions Dependent on Family Circumstances

Generally it was agreed that it very much depended on the family and the circumstances however there was some consensus that for Aboriginal people it was mainly a matriarchal decision making process while for Torres Strait Islanders it was more patriarchal.

A number of the participants were in the position of having someone in the family who was being cared for because of impaired decision making capacity and they spoke of their experiences. These varied from expectations that the oldest or youngest would take responsibility or that this fell on the one in the family who did not work or who was the least busy. One participant said:

In my case it is the youngest child in our family who is caring for our Mum and so I suppose because she is not married or in a relationship, she's got only one child and she's not working so she's the one that is the least busy.

Location also has a lot to do with decisions about who cares for people with impaired decision making capacity as people reported that the person living closest is often the one who takes on the responsibility.

Several participants spoke of decisions which resulted in shared care of the person with impaired decision making capacity.

We all help, we all chip in and take Mum, you know for the weekend or I will go up there (to the sister's place) and cook dinner and generally help out,

said one participant.

Conflict and Abuse

Several participants reported conflict within families regarding decision making. This was mainly to do with decisions about how the person's money was used and a lack of transparency around this issue. As one participant said:

We worked it out yeah but there is still - still have some conflict in my family like with mum's pension because we don't know where the pension goes. I don't think that my sister is the best person in the world (laughs) to budget and stuff like that.

Another person commented that:

There is a conflict when a carer is picked to look after the person then there were issues when a person is appointed as the carer but another family member holds the purse strings.

And from another participant:

There are certain individuals within the community with special needs that are targeted and are used as cash commodities they are an income source for the family and they are used and abused.

Understanding of the Roles of the Various Bodies who are involved with Assisting Those with Impaired Decision Making Capacity.

Suspicion

Generally there was suspicion of any authority which was seen to have the power of control over a person, their money or their property. Participants related this 'power' in contemporary society to that of past government policies which resulted in removal of people from their land and children from families and abuse of power. As discussed in one focus group:

People, especially them old ones - they too frightened you know to ask for help because they think that they can still be taken away and you know locked up.

Yeah and they don't have much money or things and they worry that that little bit of money will be stopped and how they going to live.

Confusion

There appeared to be some confusion about the roles of the various bodies involved with those with impaired decision making. Participants used the following terms, Adult Guardian, Health Guardian, Public Trustee, Public Advocate, Power of Attorney, the Tribunal and powers under the Mental Health Act as though they were interchangeable. One social worker commented on the confusion:

It's hard enough for professional people to understand what all them words mean - what each department does let alone just the average mob you know the workers and just people understanding that. Even if you look up on the computer you know the internet – it's hard to understand not that the average person would be doing that anyway.

From one community worker:

You know I always assumed if you come under the Public Trustee or the Health Guardian then you would do a baseline around their health issues – what does this person need for their wellbeing and the same would be done on the financial side – what debts are outstanding what needs to happen to stop the debt collectors knocking on the door. Isn't that what they are there for?

One participant said:

People should be referred to the health guardian when there are issues and they can't look after themselves – like someone who is really into the grog and they get into such a state that they can't make decisions about themselves they need that power of attorney to take over.

Another participant stated:

A lot of our clients come under that Mental Health Act and they need that advocate guardianship to take over to look after their affairs and things like their care and money. If there is problems then maybe the Tribunal, is that the right name? steps in to sort out.

Experiences with Adult Guardian and Public Trustee and Other Personnel involved in the process.

There were a few positive comments and this seemed to be in relation to staff/officers who were more experienced and who had formed relationships with the client and family.

Yes we had really good support from that person looking after us when we had problems with Mum's stuff – it was really explained in a good way and the person took the time to get to know us.

If the person has a lot of experience in doing the job then they know what they are talking about but sometimes there's a high turnover and the next person don't have a clue.

Mostly comments were negative. As one participant said:

I wouldn't put anyone under the public trustee because you take away all their rights and they don't feel like anyone cares about them and with the

family its all about the money as well and if you put them under the public trustee then they are left with nothing.

From a social worker:

I remember a few years ago I rang up the Public Trustee about one person and the Public Trustee Officer said, 'I am just fed up' so I said, why what do you mean? he said this person (the client) just rings up every week and I said well doesn't that tell you something is wrong. They don't case manage properly so there are all these gaps in understanding the help needed for the clients.

Another participant gave a lengthy report on the 'saga' of a person under the care of the Public Trustee who needed to buy new underwear. This person, who lived on an island (or the carer) had to catch the ferry to the mainland, then a taxi to the shopping centre get three quotes from shops for the garments, then get the quotes to the public trustee. She then had to wait to get a cheque from the Public Trustee and finally try and cash the cheque which was a problem because there were no banks on the island.

A community member stated that:

One old man walked an hour each week to get \$50 from the Trustee.

Not only was it not enough for him to live on but he couldn't afford the bus ticket to get the money.

The Appropriateness of the Current Guardianship Legislative Regime for Indigenous Queenslanders:

Appropriate Information

Many participants acknowledged the there needs to be something in place to protect those with impaired decision making capacity however there were problems with lack of appropriate information about the legislation, policies and processes. As discussed in one focus group:

Sometimes you don't even know that them things are there – how do you find out what is there to help you – and there should be help before it gets to that stage – but sometimes its only when that poor person is in real trouble that someone notices.

The problem is with that Trustee business once you are under that then can you get out of it if you can look after yourself again?

There is too much to take in and the family needs time – they need time to think and talk to all the family mob about it.

Adequate and Appropriate Consultation

Inadequate and/or inappropriate consultation was identified as another issue with the following response from one participant.

Look there are so many people – like agencies - involved in the process of assessing and monitoring someone and often the right hand don't know what the left hand is doing and they don't really talk to each other. Like there are doctors, nurses, health workers, aged care, community assessment teams, and what do you call all them others, physios and others – then there's the legal side and all the Indigenous organisations that are involved. Then there is the client and family who are sometimes left out or just told what is going to happen – well that's not consultation!

Other factors which need to be considered:

Literacy and Numeracy:

Some participants said that literacy and numeracy was an issue for clients and family. If they couldn't read and write or understand financial statements then they didn't want to say that they did not understand. As two participants said:

A lot of them can't read and that is a barrier for them, everything is related to reading, they feel shame, they don't want to talk to people.

The need to make them things (information) better to understand – have a video of the information or something.

There is so much paper work and people have to sign off but they really don't know what they are signing.

Transparency:

Some participants were concerned about the lack of transparency of the process involved with making decisions about the future care of people with impaired decision making capacity. This concern included how decisions were made and whether the people making the decisions actually had access to all the information or understood the family's position. One discussion revealed that:

Sometimes family are confused because they (staff) come and talk about one thing and then they go away and then come back again and there is

nothing laid out that this is the whole process and this is how we are making the decisions.

Yeah – and if the family don't agree with something about the decisions they are too shame to talk up or they are too frightened in case it makes it bad for the person.

That's true eh but the other thing is that they don't really know what it means at the end of the day to not be in control of making your decisions until its all happened – then they are stuck with it.

There was general consensus on some of the other issues identified. Basically it was agreed that people employed in the services need to understand about history, kinship, cultural values and beliefs and contemporary issues for Indigenous people.

Cultural Awareness

You know those officers who work in those places (Government and other agencies) should have things like cultural awareness programs so they understand what has happened to our mob and how this has affected them.

They (authorities) just don't understand about our culture eh! You know about kinship and things and responsibilities and who looks after who and what works for our people is not the same as what works for white people.

That's why some of our clients are a little bit frightened you know a bit reluctant to go under them (the Public Trustee) as power of attorney because they are too hard on our people - we need someone who understands community. There's an example of one person - for her to move into the family home she had to come with her own TV and DVD player - then the Public Trustee said, 'no we just brought her a TV and DVD 12 months ago', but what they didn't understand was that that TV and DVD belonged to everyone in that other house even though she paid for it – so she couldn't just up and take it.

Community Engagement

Another issue was the perceived lack of engagement with groups, organisations and communities. Participants felt that there was a disconnect between the agencies and the people resulting in many of the issues previously identified.

Yes if there was more contact and engagement with our people then there would be more understanding. If we could work together then we could help them put into place strategies to improve services.

It is more difficult in towns but in like rural and remote communities, those agencies (Office of Adult Guardian and Public Trustee) should do some work with the key stakeholders in the communities so that they are aware of the roles and responsibilities and how agencies can work together. Good to involve the elders too and get their advice. Even in towns there are Indigenous bodies and elders who can be engaged.

Employment of Indigenous People

Discussion highlighted the need to train and employ Indigenous people to work in the Offices of the Adult Guardian and the Public Trustee. Establishment of positions for Indigenous people to work as liaison officers or community workers in this field was seen as important.

Yes they need someone like health workers but call them something else to be like a liaison person to work between the services and the community and the family – someone who knows our ways and also knows what goes on in the community.

What qualifications do these people need to have to work in these positions – see this is an area where Indigenous people wouldn't think to work so they should be encouraged to do that.

SUMMARY OF FINDINGS

- The result of Government policies continues to impact on the decision making process for some families and communities regarding individuals with impaired decision making capacity.
- History has made people suspicious and fearful of authorities who are seen to have the power to take control over others.
- There was a clear lack of understanding and some confusion around the role of authorities (Office of the Adult Guardian and the Public Trustee) and other agencies responsible for the care of people with impaired decision making capacity.
- Decision making for families of those with impaired decision making capacity varied depending on family expectations, who was available, who had the least responsibilities and the physical location of the person in relation to family members.
- People with impaired decision making capacity were vulnerable to exploitation of their rights, money and property and abuse of money was reported in several cases.

- Conflict within families regarding decision making and control over money was evident.
- Experiences with dealing with services for those with impaired decision making capacity were mostly reported as negative.
- A need for legislative bodies to care for the rights of those with impaired decision making capacity was seen as necessary but with improved processes such as access to appropriate information and adequate consultation.
- There was general consensus that there was a lack of understanding of Indigenous people's history, kinship responsibilities, cultural values and beliefs and ways of working.
- A need for better community engagement was identified along with the promotion of Indigenous people to work in agencies dealing with people with impaired decision making capacity and their families along with the introduction of new Indigenous liaison officer positions to work in this field.

RECOMMENDATIONS

Clarification of the Role of Agencies and Promotion of the Office of the Adult Guardian:

- That Indigenous people have input into the development of appropriate strategies, resources and material to inform people of their rights and available services to assist them.
- That strategies include the provision of a transparent process with potential outcomes and implications clearly evident.
- That relevant Indigenous and other organisations are approached to form partnerships with the Office of the Adult Guardian to form a more coordinated approach to addressing the needs of Indigenous people with impaired decision making capacity and their families.

Workforce and Professional Development:

- That all staff at all levels of those agencies dealing with Indigenous people with impaired decision making capacity undertake a suitable program which provides them with an understanding of history, kinship, cultural values and beliefs, governance and decision making and effective means of communication.
- That all agencies dealing with Indigenous people with impaired decision making capacity have in place a reconciliation statement, a strategy to provide effective services for Indigenous people, a community engagement strategy and an Indigenous employment strategy.

Monitoring and Review:

- That strategies have key performance indicators which are used to measure the effectiveness of the strategies over time.

Further Research:

- That further research be conducted regarding the needs of Indigenous people with impaired decision making capacity and their families in relation to legislative requirements.

Appendix C Focus Groups: Central Queensland University

INDIGENOUS QUEENSLANDERS AND IMPAIRED DECISION MAKING CAPACITY

Report for the Central Queensland Region

Vicki Pascoe and Kylie Radel
CQUniversity Australia

October 2010

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Executive Summary

This pilot study was commissioned by the Queensland Office of the Adult Guardian in response to an upcoming review of the legislation around guardianship. A previous literature review conducted by Griffith University indicated there was little specific research into the area of impaired decision making capacity and its implications for Indigenous Australians.

This report entitled “Indigenous Queenslanders and Impaired Decision Making Capacity” provides the findings from the pilot study for the Central Queensland region component of the larger collaborative partnership between Griffith University, CQUniversity Australia and James Cook University.

The findings of this report arose from a series of focus groups conducted with Indigenous and non-Indigenous health and human service professionals including a number of Indigenous Elders. The focus groups were conducted at various locations in Central Queensland between April and June, 2010. The findings demonstrate:

- There are three main issues underpinning the findings of this research. Firstly, significant differences remain between Indigenous and Western world views based on individual versus collective ownership. Secondly, there is confusion over the roles and services of the Adult Guardian. Thirdly, this confusion is further complicated by a lack of perceived difference between the Adult Guardian and the services of the Public Trustee. As a result of these three main issues, there is considerable incongruence between individualised Western legislation around property ownership and individual rights and Indigenous family decision-making patterns.
- It was apparent that Indigenous decision-making practices were adversely influenced by fear and suspicion of authority. Participant responses revealed evidence of continuing trauma which could be attributed to ongoing ramifications as a result of colonisation. Participants still referred back to “living under the Act”.
- Family and kinship roles and responsibilities and the associated decision-making practices and processes do not dovetail well with Western individualised legislation.
- Overwhelmingly the perceptions of the roles of the Adult Guardian were either unknown or misunderstood. Often the Adult Guardian roles were confused with the Public Trustee. Further, the lengthy appeals processes and lack of transparency within the processes were raised as significant barriers to accessing the services. Participants reported both positive and negative experiences of their dealings with the Adult Guardian.
- Communication about the roles and services of the Adult Guardian was considered particularly unhelpful. For example, printed brochures were considered unclear and were not provided in “Indigenous friendly” language. Further, the Office was not considered to be effectively communicating what they do with appropriate service providers.

- A number of other issues were discussed during the focus groups. Participants indicated a lack of general knowledge of wills, health directives and powers of attorney. There also appeared to be a number of legislations and services with overlapping responsibilities but ineffective information sharing. Further, there appeared to be unclear guidelines as to which legislation or service might apply in specific situations. Participants also noted that privacy and confidentiality laws impeded continuity of care and client follow-up between service providers. The location and diversity of Indigenous communities may impact on the provision of services due to lack of recognition of heightened costs of living for rural and remote communities.
- Participants recommended that all services need to be able to take on new unskilled staff from the community to provide locally-based employment and training opportunities for rural and remote areas. Local knowledge of community dynamics and family decision-making patterns was seen as imperative to service provision and making 'good' decisions.

Recommendations from this study include:

- Brokering services at a local, community level;
- Better communication and promotion of the Office of the Adult Guardian and their services;
- Participants expressed a desire to "*sit down and yarn face-to-face*" with representatives from the Office of the Adult Guardian to better understand what they do.
- Decision-making and appeals processes require greater clarity and transparency.
- This study specifically highlighted the need for further research into the area of decision-making in Indigenous contexts and the need for the legislative review.

Table of Contents

The Research Project.....	5
Research Questions.....	6
Participants and Participation	6
Overview of the Central Queensland Participants.....	7
Research Findings.....	7
Exploring Decision Making in Indigenous Families	9
Decisions Influenced by Ingrained Fear and Mistrust of Authority	10
Perceptions of Impaired Decision Making Capacity	10
Perceptions of the Adult Guardian and the Public Trustee.....	11
Positive and negative experiences of the Adult Guardian, the Public Trustee and Mental Health Services	11
Negative experiences	12
Positive experiences.....	14
Adult Guardian and Public Trustee Roles as Perceived by Participants	15
Appeals Processes and Transparency	17
Communication about the roles and services of the Office of the Adult Guardian	18
Other Related Issues.....	19
Recommendations	20
1. <i>Brokering services at a local, community level</i>	20
2. <i>Better communication and promotion of the Office of the Adult Guardian and its services</i> ..	20
3. <i>Appeals Processes and Transparency</i>	20
4. <i>Clarification of the “Acts”</i>	21
Conclusion.....	21
References	22

Table of Figures and Tables

Figure 1	Impacts from the historical legacy of colonisation for Indigenous Australians	8
Table 1	Comparisons between Indigenous and non-Indigenous Australian worldviews	8
Figure 2	Family and institutional relationships in the care process	13
Figure 3	Family and institutional relationships in the care process from an Indigenous perspective	14
Figure 4	Key agency criteria for services	15
Figure 5	Communication issues and responses	18

Indigenous Queenslanders and Impaired Decision Making Capacity

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THE RESEARCH PROJECT

In Queensland, the Guardianship and Administration Act 2000 provides a definition of impaired decision making capacity, and a framework for substitute decision making for adults with impaired decision making capacity. However, there are questions regarding how applicable this system is for Indigenous Queenslanders.

Initial scoping work resulting in a literature review, has indicated that while there is a body of research in relation to disability, cognitive impairment and mental illness amongst Indigenous Australians, there appears to be little specific research into the area of decision making and any implications for impaired decision making among this population. It appears to be widely accepted that the incidence of acquired brain injury , alcohol and drug misuse, violence, injury and other factors is high within Indigenous communities and many Indigenous people experience vulnerability through disability, cognitive impairment or mental illness as a result of these factors. Yet relatively little appears to be known or understood about the situation of Indigenous people with impaired capacity. For example, there does not appear to be a great deal of clarity about how impaired decision making capacity is determined in the Indigenous context, about substitute decision making processes, about issues in relation to access to Guardianship and Administration services and the extent and nature of increased vulnerability.

Further, there is no indication in the literature that the fundamental question of the meaning of impaired decision making capacity for Indigenous people has been specifically or adequately addressed. This would indicate that there is a need for further research to address the issues of impaired decision making capacity and substitute decision making for Indigenous people, and their engagement with the Guardianship and Administration system.

This project is a pilot research project to commence this process. This pilot research sought to address these issues by conducting qualitative, focus groups with Indigenous and non-Indigenous service providers and health professionals.

Research Questions

To gain a better understanding of the above issues, the pilot research project addressed the following research questions:

1. What are the understood meanings of impaired capacity in Indigenous communities?
2. How are decisions made for Indigenous adults with impaired capacity according to Indigenous cultural expectations and practices?
3. Are the requirements of the current guardianship legislative regime appropriate for Indigenous Queenslanders?
4. Is the legislation appropriate and advantageous for Indigenous Queenslanders with impaired capacity?
5. Are there other factors which need to be considered in relation to substitute decision making practices for Indigenous Queenslanders with impaired capacity?

The research was designed to explore the cultural bonds of Indigenous Australians to better understand decision making practices to inform the legislation review. As such, the research is designed from a position of the six core values as identified by the National Statement including: reciprocity, respect, equality, responsibility, survival and protection, spirit and integrity. The communities involved in the research process guided the appropriate cultural research practices at a local level.

The researchers approached identified stakeholder organisation CEOs to explain the research and take their guidance as to how best to recruit participants. Recruitment endeavoured to protect the anonymity and minimise risk to participants. The researchers continued an ongoing consultation process regarding community and individual consent. This process was undertaken through the CEOs at their various locations. Letters of permission to access staff were sought from the organisations. Staff were reminded that their participation in the research was entirely voluntary and would not impact on their employment in any way. CEOs were asked to forward details of the research project to appropriate staff who were asked to contact the researchers directly if they wished to participate so that their anonymity was maintained.

The researchers acknowledge the diversity of Indigenous cultures and this is demonstrated by negotiating research protocols at each site guided by local community advice.

Participants and Participation

Participation involved attending a focus group for up to two hours which was audio-taped if permitted by participants. Participants were asked questions relating to their experiences and observations of: how decision making occurs within Indigenous communities; the Office of the Adult Guardian and the

Guardianship and Administrative Tribunal and associated legislation; and the meaning of impaired capacity from an Indigenous perspective.

Participants were principally Indigenous and non-Indigenous professionals from community agencies who are working with Indigenous people and communities – particularly, Indigenous people with impaired decision making capacity.

Overview of the Central Queensland Participants

- Rockhampton participants included an Indigenous psychologist, an Indigenous social worker, CEO of an Indigenous child safety organisation, an Indigenous project officer from the Department of Communities and an Indigenous Elder from Queensland Justice.
- Bundaberg participants included an Indigenous mental health nurse, an Indigenous Elder and director of an Indigenous health centre and an Indigenous community health worker.
- Mackay participants included a CEO and staff of an Indigenous health organisation including three Torres Strait Islanders.
- Woorabinda participants included a non-Indigenous director of nursing, Indigenous health workers, Indigenous enrolled nurses, a non-Indigenous nurse and two Indigenous Elders.
- Emerald participants included non-Indigenous psychologists, social workers and mental health workers, a non-Indigenous child safety officer and mental health nurse, and an Indigenous social worker. The Emerald focus group provided a significant contrast to other locations as all but one participant were non-Indigenous professionals.

RESEARCH FINDINGS

On analysis of the data, a number of themes were common across all focus groups as presented below. Significantly, all Indigenous participants demonstrated continuing trauma as a result of Indigenous people's historical relationships with government and authority in Australia (see figure 1 below):

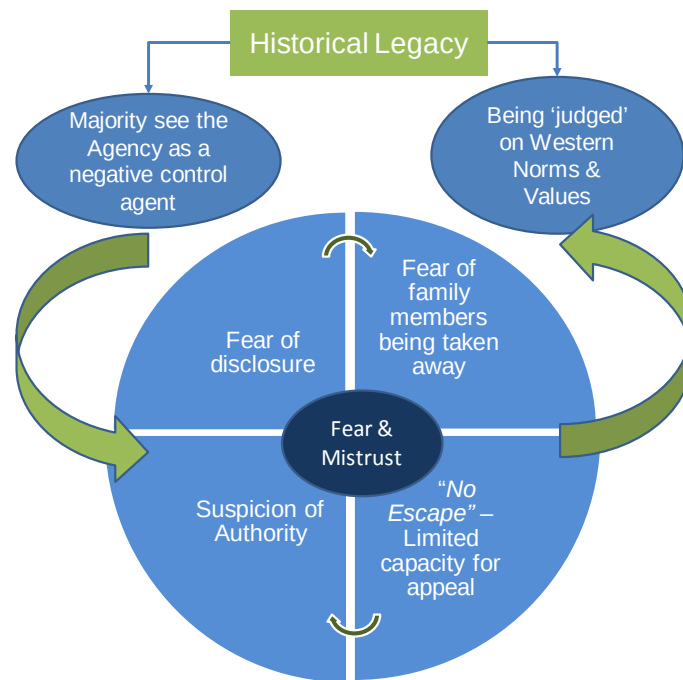


Figure 1 Impacts from the historical legacy of colonisation for Indigenous Australians
(Developed for this research by Pascoe and Radel, 2010)

The impact of the historical legacy of colonisation results in communities having a dominant Western framework for ‘doing business’ and responding Indigenous community cultures do not dovetail well with this framework as evidenced in Table 1 below. The table illustrates some of the incongruence between Indigenous and non-Indigenous Australian worldviews.

Table 1 Comparisons between Indigenous and non-Indigenous Australian worldviews

INDIGENOUS AUSTRALIAN SOCIETY	NON-INDIGENOUS SOCIETY
History is timeless	History is quantified and specified
Engage in holistic or ‘big picture’ thinking	Engage in observation and experimental thinking
Concept of time is circular, past continuous, without boundaries	Time is linear, referenced to points, future oriented
Spiritual views are not questioned	Spiritual views are debated and questioned
Being rather than doing is important- fit into the existing circumstances	Try to change existing circumstances
Immediate gratification important	Deferred gratification important
Indigenous society acceptable as it is	Society needs to change
Group oriented – everything is for all group members	Individual oriented – acquisitions are for you
Kinship important in family/extended family unit. A person can go from home to home	Kinship far less important
Spontaneous lifestyle – do what you want when you want to	Structured lifestyle – must plan and be stable if you want to succeed

Often uncritical due to respect	Critical – everyone is judged
Basically listeners – do not speak unless it is important	Basically verbalisers – think out loud, must speak
Use symbolic language	Literate – use books, and very verbal
Little eye contact – it is impolite to do so	Lots of eye contact – it is impolite not to do so
Indirect questioning – talk around the point	Direct questions – very to the point
Non-legislative – laws are morals and are to support the group, not to isolate anyone (reintegration)	Legislative – laws are written and offenders are isolated
Accepting of others following separation for wrongdoing	Not accepting of others following separation for wrongdoing
A non-market economy – money not important	Market oriented – money important and complex
Age is respected	Youth is respected
Giving is important	Saving is important

(Adapted from Sterling, 1986 cited in Hughes, More, & Williams, 2004)

The table reflects differences that may influence decision making in Australian Indigenous communities and families. As a result, communities are evolving in response to Western frameworks but are not fully acculturated. Communities are mediating different worldviews in relation to property ownership, wealth and possessions where Indigenous worldviews and traditions often assert common ownership. However, this common ownership is not comfortably mediated through individualised Western legislation.

The following sections provide an outline of the findings of the pilot study highlighting: 1) decision making in Indigenous families; 2) impaired decision making capacity; 3) ingrained fear and mistrust of authority; 4) confusion about the Adult Guardian and Public Trustee and related positive and negative experiences; 5) key agency criteria for services; 6) communication issues and responses; and 7) the appeals process and other issues.

EXPLORING DECISION MAKING IN INDIGENOUS FAMILIES

Participants provided some general comments on making decisions in Indigenous families and communities:

- Decision making in Indigenous families and communities often involves extended processes, frequently incorporating extended family members as well as the immediate family.
- Specific family members may have allocated roles in decision making (which can also include specific gender roles and tasks).

- In cases where conflict exists, a decision can be escalated to community seniors or Elders¹ (or groups of seniors or Elders) if required.
- For Torres Strait Island communities, where such decisions are required it is largely the eldest son's responsibilities.
- Family decision making processes may be disrupted. For example, families may experience 'gaps' in the decision making processes due to losing family members through the 'Stolen Generations' experiences as demonstrated by the "Bringing Them Home" Report;

For individuals, their removal as children and the abuse they experienced at the hands of the authorities or their delegates have permanently scarred their lives. The harm continues in later generations, affecting their children and grandchildren (Human Rights and Equal Opportunity Commission, 1997, p. 4).

- Other participants also identified the potential for 'gaps' in family structures and therefore, decision making, as a result of issues such as substance abuse and suicide experienced in some communities.

Decisions Influenced by Ingrained Fear and Mistrust of Authority

- For most of the participants, there is a general fear of being 'under the Guardian'. This was considered akin to being "*under the Act*" – suspicion of authority controlling every aspect of people's lives. This fear was further transferred to all authority figures ("*the Bully Boys*") including doctors, trustees and police. Particularly for Indigenous peoples in Queensland, the historical situation centred on the Aboriginal Protection Act whereby, if someone asserted that a person was an Aborigine they could be placed "under the Act" for their protection "until the contrary was proven in court". "The court could also decide on sight whether a person was an Aborigine under the Act or not" (Broome, 1994, p. 163).
- Participants demonstrated particular mistrust of authorities in situations where family members could be at risk of removal from the family. One participant reported the situation of a parent caring for an intellectually impaired child/adult. The parent was "*afraid*" to apply for a carer's pension from Centrelink because they perceived they would need to provide information that would lead authorities to take the child/adult away. This fear could be associated with the past practice of removing Indigenous children from their families ('Stolen Generations') as previously discussed.

Perceptions of Impaired Decision Making Capacity

It was clear across all focus groups, that most participants did not understand the legal/legislated 'definition' of impaired capacity.

¹ The term "Elder" indicates a status given by the community based on particular knowledges rather than age.

- Several participants ‘translated’ the idea to mean “*Gone Womba*” or “*a little bit Womba*”, meaning that the person had some level of mental incapacity. Participants did not demonstrate that being “*Womba*” was in any way concerning. In fact, it was associated more with humour and a further reason for nurturing the person.
- Impaired capacity had no real meaning for most participants until it was ‘labelled’ by a doctor or assigned by another authority figure. In cases where the label was assigned, other family members then felt completely disenfranchised by the label and reported feeling “*cut off*” from that family member. Participants reported feeling powerless to ‘question’ authority and that their rights were eroded. As discussed previously, these feelings could reflect the historical legacy for Indigenous peoples as a result of their long-term relationships with governments and authority in Australia since colonisation.

PERCEPTIONS OF THE ADULT GUARDIAN AND THE PUBLIC TRUSTEE

Generally, participants were not clear on the roles of the Adult Guardian. However, participants were generally aware of the Public Trustee and felt that they were, in fact, one and the same as the ‘Guardian’ – they were essentially the same thing.

- Participants were generally unaware of the services provided by the Adult Guardian or the Public Trustee. The services that participants felt the Guardian provided were reasonably nebulous such that, one participant responded “*They do wills or something?*” Added to this confusion over the Guardian’s roles, another participant further highlighted the general lack of awareness of government processes and services. The participant asked the researchers if they (the researchers) could organise disabled access facilities in their home including a ramp and shower rail.
- The general confusion was also tied up with Mental Health service provision and the definition of impaired capacity. It was felt that there were “*too many Acts*”. One participant questioned, “*If impaired capacity is a disability then why does the Adult Guardian not come under the Mental Health Act or disability services?*”
- Participants who were health workers or mental health workers referred extensively to the Mental Health Act (processes and practices) as a template for best practice service provision.

Positive and negative experiences of the Adult Guardian, the Public Trustee and Mental Health Services

Of those participants who did know (or had previous contact with) the Office of the Adult Guardian, the Public Trustee and/or mental health services, participants generally reported negative experiences specifically of the Public Trustee.

Negative experiences

- Participants suggested that Guardians and Trustees need to establish “ground rules” in conjunction with family, to understand and set boundaries in relation to financial commitments. For example, one participant mentioned a case of a child being orphaned and as a result they received an insurance pay-out. The trustee was “only giving them \$50 at the beginning of the week and \$50 at the end”. The participant suggested that the Trustee was concerned with the rest of the family “ripping them off”. However, they also felt this allowance was insufficient for covering living expenses and reciprocity.
- Other participants reported that family members who were under the Guardian often became distressed at their inability to make decisions for themselves, thereby exacerbating their conditions. Once people with impaired decision-making capacity find themselves “under the Act”, they find they have lost all legal capacity to make their own decisions even if they feel they can make some decisions. As a result, they become very “apprehensive”.
- Further, other participants raised issues around the Guardianship processes whereby, there is “too much paperwork” involved and the processes are “too difficult”. For example, health workers noted that increasingly they are being approached to complete paperwork for clients where “people can’t understand the forms and therefore the health service is getting requests to fill them out on their behalf”.
- One participant commented that, in instances where,

“a mental health service is assigned as a case manager the case manager is then designated as the contact person for the disabled person. What happens when that case worker moves or goes on holiday? New staff coming through don’t know the process, they don’t know how they can advocate for clients or how they can appeal a decision. Mental health services don’t spend money on educating their staff in advocacy, so people don’t know.”

As another participant indicated:

“The continuity of care in the mental health service is appalling.”

- Participants also offered the following in terms of the care process as family members trying to maintain connection with their relative who was now ‘under the Guardian’:

Family networks of which the client is part, “is almost like twice removed from the actual home. Their involvement with the family is removed through the care process. Family have to always contact the case manager rather than just dealing with the family member who needs the help.”

“The thing that I’ve found, even within my own family network is ...you’ve got the family, then you’ve got the carers, then you’ve got the agency to which the carers belong [and] then you’ve got this mob here... the advocate officers.”

“The family have to go through this whole process, but the way we deal with [family issues] does not fit with the processes of the Guardian office. ...because we’ve got the carers and their agencies and we have to now be accountable to all these other people.”

“The decision makers are not responsible to the family first they are responsible to the legislation first and not always to the one Act but to multiple Acts which makes the decision making very murky... very, very murky...”

- The above relationships, responsibilities and connections are represented by the following diagram:

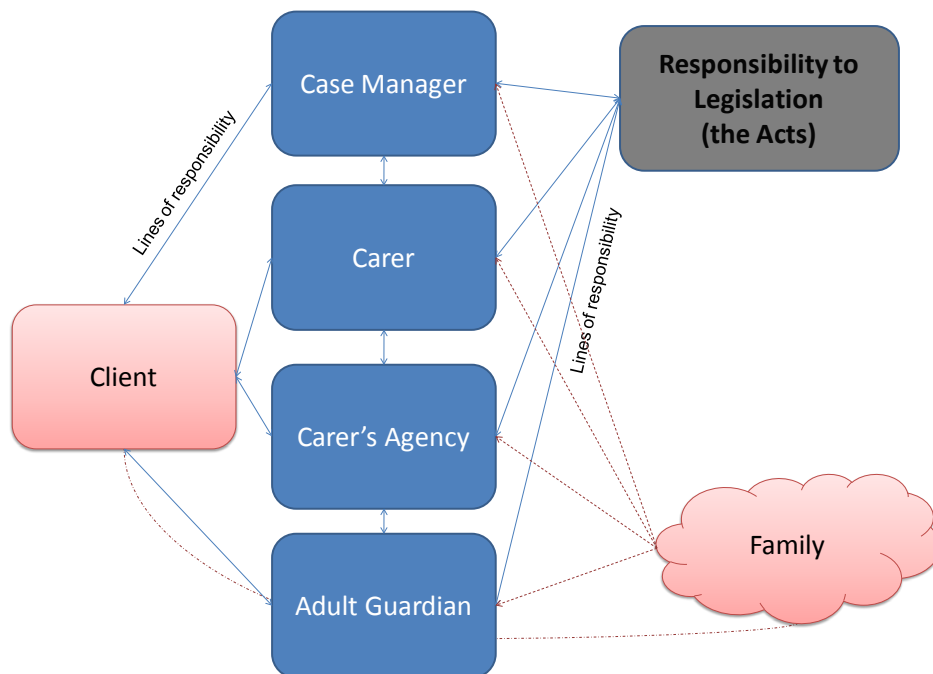


Figure 2 Family and institutional relationships in the care process
(Developed for this report by Pascoe and Radel, 2010)

Figure 2 summarises the participants’ discussions of their perceptions of the current structures and associated relationships that effectively complicate the communication and relationships between family, institutions and the person with impaired decision-making capacity. The result is to divide and disenfranchise the family.

Alternatively, an Indigenous social worker participant discussed their perceptions of the role the Adult Guardian could take with regard to their specific rural community situation. The participant stated that there are an increasing number of service providers (as indicated on the left of Figure 3 below) who have funding to intervene. In addition, the service providers also have specific criteria and key

performance indicators to meet with regards to that funding. However, community and service providers cannot decide on a single course (or even a number of appropriate courses) of action. The participant explained that all of the service providers are essentially waiting on community members to make a decision about appropriate actions. The community members however, cannot agree and there is a great deal of political tension and manoeuvring involved. The tragedy is that the resulting inaction leads to sufferers of substance abuse continuing to rapidly deteriorate.

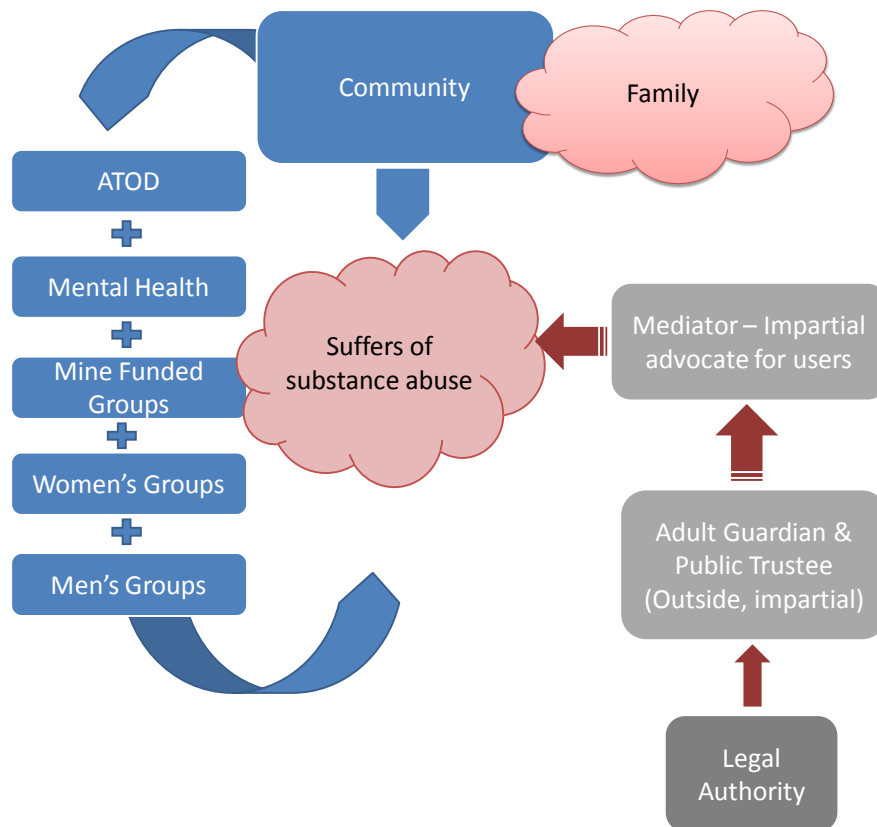


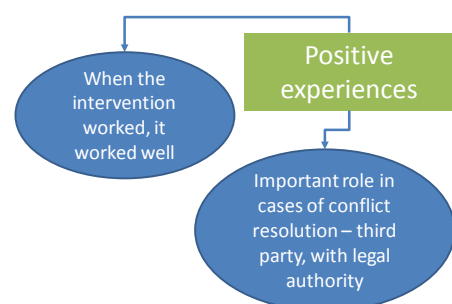
Figure 3 Family and institutional relationships in the care process from an Indigenous perspective
(Developed for this report by Pascoe and Radel, 2010)

In the participant's opinion, the role of the Guardian would be as impartial advocate on behalf of the sufferers. The Guardian is supported by legal authority which means they have 'real' power to ensure that the sufferers have appropriate care intervention. The Guardian's involvement minimises the potential for conflict within the situation as they have no political involvement in the community – their only concern is the welfare of the sufferers.

Positive experiences

Some positive experiences were also reported – particularly in cases of family conflict or where families were in situations of abuse.

- One participant spoke of their cousin with drug and



alcohol addictions who was physically abusing their parents to gain access to their disability pension to support substance abuse habits. When the Public Trustee was awarded control of the cousin's money, this diffused the conflict as the parents were no longer in that position of responsibility and vulnerability.

- Other participants reported that the independent control of a person's affairs eliminated the potential for family members and others to abuse the financial and physical situation. (For example, family members abusing the elderly.)
- Two participants from Woorabinda reported good service from the Public Trustee for managing family financial affairs. One participant's family member was in care in the hospital and the other was not living locally. However, it was also noted that the financial statements provided by the Trustee were "*difficult to read*" such that they did not clearly display information in a straightforward manner. Further, questions were raised around the application of the Trustee's administration fee. Questions were also asked about interest on monies held by the Trustee – how much does the government and the Trustee benefit from use of "*my money*"?

Adult Guardian and Public Trustee Roles as Perceived by Participants

Participants provided a number of instances where the Adult Guardian and Public Trustee could or should intervene and provide services for Indigenous individuals and communities as shown in Figure 4 below:

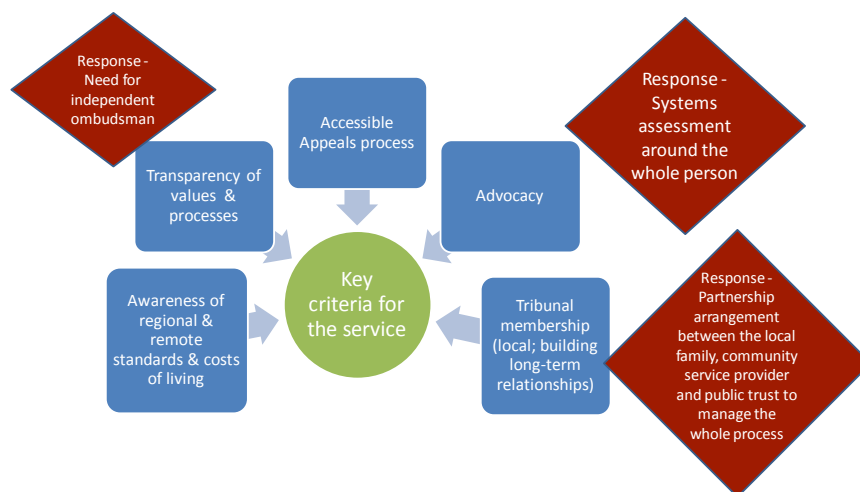


Figure 4 Key agency criteria for services
(Developed for this report by Pascoe and Radel, 2010)

- A Guardian should be the last resort.

- In instances where assistance is required, families and communities need the government to provide culturally appropriate tools (*“Indigenous friendly”*), resources and information to support the family to make an informed decision.
- Where Guardians are appointed they should:
 - consult extensively with family;
 - be on the ground / at grass roots level;
 - use a current Indigenous provider to be the broker of the advocacy service;
 - develop long-term trust relationships; and
 - acknowledge that decisions made within a family (extended) can take a great deal of discussion (up to years) and this should be understood as standard practice.
- Local people are essential to conduct assessments and case management of clients. For example, participants reported that when decisions were made, the decision makers were neither local nor did they appear to know anything about the local family situation. One participant discussed the *“hole in the fly screen”* where people came in to assess a person’s situation and made judgements without knowledge of the real circumstances regardless of whether the person was *“happy”* in that situation or not. The living environment was considered inappropriate and clinical, Western norms and values were applied to an Indigenous context.
- With regard to local assessment, it is also important to note the differences in the costs of living for rural and remote locations and this is often not understood or taken into account by urban-based decision makers.
- Specifically in relation to people on the tribunal, another participant mentioned that they felt that *“Nobody is actually trained in advocacy”* and that there is a fundamental need for decision makers to be local and an integral part of the process.
- In addition, it was stated that training could be beneficial for carers.
- The Office of the Adult Guardian should develop partnership arrangements between the local family, community service provider and Public Trustee to manage an integrated process.
- Considering the use of local Indigenous service providers, there should be an inclusive, multi-disciplinary, skilled team as the assessment panel and there should be a *“systems assessment around the whole person”*.

Appeals Processes and Transparency

Participants reported a severe lack of right of appeal once an order or decision was made and there was no clear way to exit from being 'under the Trustee or Guardian' (again this is mostly in regard to the Trustee).

- Participants reported that people could be placed "under the Trustee" for either 2 years or 5 years and that it was very difficult to get an appeal before the end of that time with no scheduled review periods.
- Participants reported that the Guardianship appeals process was also extremely complicated. Particularly considering those under an order already had a disability that could limit an individual's capacity to make a successful appeal, participants felt they needed assistance to appeal. They also needed clear decision guidelines and people trained in 'advocacy' to work on their behalf.
- Participants reported there was "*no transparency in the process*".
- Participants felt that there was no way to know how decisions of the tribunal were being made. Also, decisions regarding ongoing care were not transparent. Many reported that Indigenous people with impaired capacity (either relatives or people under their care) were "*distressed*" by the appeals process and this stress further negatively impacted on their mental health. For example, one participant spoke of a relative who wanted a painting of a waterfall that was felt would calm and benefit their mental health. The process to access the funding was long and involved with a great deal of paperwork and the request was eventually declined as it was considered a "*non-essential item*".
- Participants compared the Adult Guardian/Trustee processes to those of Centrelink and the Mental Health Act. They indicated the Centrelink and Mental Health Act processes are more equitable and transparent. For example, one participant stated that, "*You can ask to see how and why a decision was made in Centrelink in your record*". The Mental Health Act appeals process was considered easier to access ("*it doesn't take nearly as long*") and far more transparent in that all the Mental Health Act documents have the appeals process clearly included on them.
- It was also noted that the decision-making and review processes "*should be standardised for every client*".
- With regard specifically to the tribunal, there needs to be greater transparency of the representation of people on the panel. For example, the panel should include an advocacy person and a human rights commissioner and clients need to know who these people are and their backgrounds. Again this was compared to the mental health process as an exemplar.

- A number of participants also raised the issue of needing an ombudsman or independent person to arbitrate in cases of dispute.

Communication about the roles and services of the Office of the Adult Guardian

Participants all reported greater need for clearer “*Indigenous friendly*” communication as shown in Figure 5:

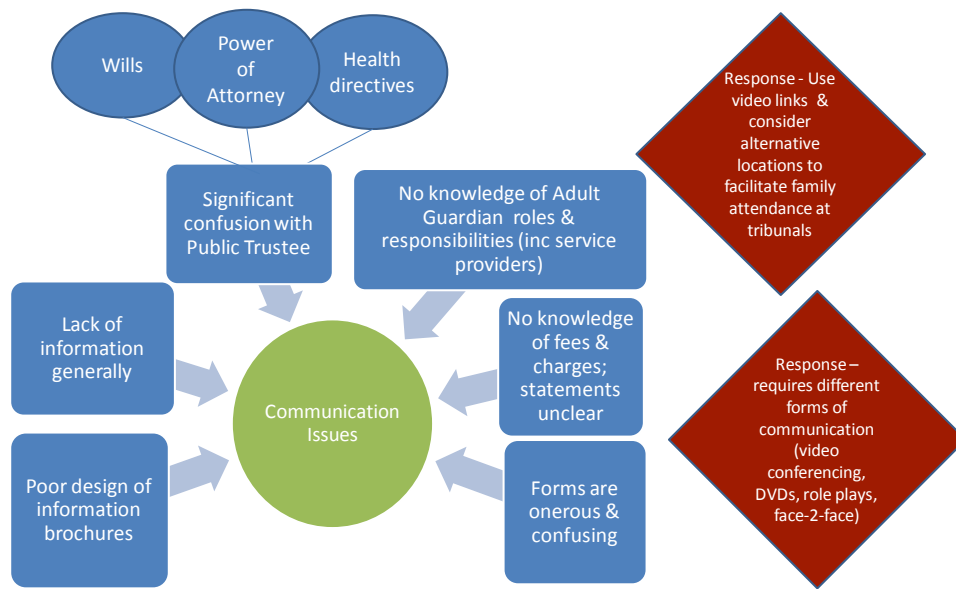


Figure 5 Communication issues and responses
(Developed for this report by Pascoe and Radel, 2010)

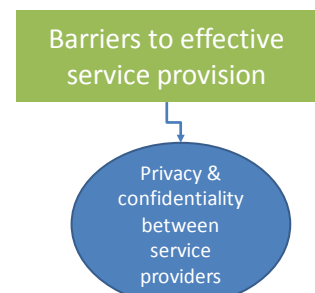
- Overwhelmingly, participants felt the brochure was unhelpful – “*it was too wordy and drab and didn’t really say who the Office were, how to contact them or what they can do for Indigenous people*”.
- Health professionals felt it would be particularly useful if the Office of the Adult Guardian could conduct information sessions with staff and with community members (both face-to-face and possibly utilising video conference facilities, particularly for remote locations).
- It was also suggested that ‘role play’ scenarios would be particularly beneficial to illustrate incidents where the Adult Guardian could assist.
- It is also extremely important that the person delivering the message is appropriate – they need to be “*genuine*”.
- Other participants recommended the use of video links to facilitate family attendance at tribunals.
- Communication brochures and materials should have no legal or government jargon.

OTHER RELATED ISSUES

- While it is perhaps not a specific domain of the Adult Guardian, almost all participants were unaware of the importance of a Will or the value of a Power of Attorney or a Health Directive. Further, as one participant asked:

“What if you (a service provider) are in a position of trust with an individual who has no other family left? Can you take over? Who decides? What are the boundaries around power of attorney?”

- A great deal more training and information needs to be provided for communities regarding the importance of these documents. Community members were not aware of the need for, or the process to prepare for, such circumstances prior to actually needing the Adult Guardian or Trustee services. Accessing the Guardian as *“the last resort”* becomes the ‘only option’ in instances where people are unprepared.
- All participants spoke of an issue with the privacy/confidentiality laws. Participants suggested that these laws actually impede the transfer of relevant information between service providers. For example, relevant client information is not transferred between: mental health institutions, child safety services, local Home and Community Care (HACC) and other service providers. Ideally, there should also be a seamless transition between child and adult services.
- As one participant noted, if the HACC referred a client to a mental health service then no information was passed back to the HACC service to enable case management when the client returned to the local area. Local service providers are then unable to follow up on outcomes and family needs. As one participant indicated, *“we have trouble referring people to mental health and then can’t continue in our care role because the privacy act says we can’t get any information about our clients”*. This links with the previous observations about the continuity of care in mental health service provision.
- Each service provider has an independent charter and due to the privacy laws they cannot communicate with other service providers to ensure continuity of care. As one participant noted, *“we don’t want to know all the details of the mental health issues but we don’t get even relevant information”*.
- Another participant told of a tragic event where as a direct result of the privacy/confidentiality issues, a young man committed suicide.
- These privacy conditions actually support and further reinforce one-way relinquishment. This therefore prohibits ongoing quality care, support and continuity to sense of community.



- Location and diversity of Indigenous communities can impact on the provision of services. Services are not necessarily locally based and service providers often do not travel to remote



communities. This means that clients located remotely must travel to attend tribunals or to access services and this is often not possible or very expensive and time consuming.

- All services need to be able to take on new staff with no skills to provide employment and training opportunities for rural and remote communities.

RECOMMENDATIONS

1. Brokering services at a local, community level

- 1.1. It is recommended that the Office of the Adult Guardian enter into brokerage arrangements or agreements with local Indigenous service providers. This would enable assessment to take place on a 'grass roots level' utilising local community knowledges and relationships.

2. Better communication and promotion of the Office of the Adult Guardian and its services

- 2.1. The Office of the Adult Guardian needs to review their information brochures. It is recommended to produce brochures and other promotional materials in clear language which is more readily accessible by Indigenous peoples.
- 2.2. Consider other forms of communication including a DVD demonstrating role plays of the roles and services of the Adult Guardian.
- 2.3. Consider also, video conferencing with local service providers (for example the Woorabinda and Emerald Hospitals).
- 2.4. Participants expressed a desire to "sit down and yarn face-to-face" with people from the Office to better understand what they do.

3. Appeals Processes and Transparency

- 3.1. It is recommended that the Office of the Adult Guardian and the Office of the Public Trustee collaborate whenever possible to streamline their processes and minimise bureaucracy particularly for the tribunal and appeals processes.
- 3.2. The membership and processes of the tribunal require greater transparency.

3.3. Particularly, individuals under the Adult Guardian require access to their information regarding the decision-making processes of the tribunal and all subsequent decision processes. Individuals need to know the information around why and how a decision was made and then clarity and transparency in the appeals process.

3.4. Individuals also require more frequent, standardised review periods for the reassessment of their circumstances.

4. Clarification of the “Acts”

4.1. Individuals demonstrated there was a great deal of misinformation around the Office of the Adult Guardian and their services, particularly in regard to the application and limitations of the various “Acts” (the Mental Health Act, the Adult Guardian Act, Public Trustee Act, etc).

CONCLUSION

This pilot study has highlighted areas of need in Indigenous communities which require further research. As a result, this research has the potential to make a positive contribution towards understanding the uniqueness of substitute decision-making processes in Indigenous communities. This report provides a snapshot of experiences and concerns from Central Queensland Indigenous and non-Indigenous health professionals and community members.

This study constitutes a component of the larger collaborative research project in partnership with Griffith University and James Cook University.

REFERENCES

- Broome, R. (1994). *Aboriginal Australians – Black responses to white dominance 1788-1994* (2nd ed.). St Leonards, NSW: Allen and Unwin.
- Hughes, P., More, A. J., & Williams, M. (2004). *Aboriginal ways of learning*. Adelaide: Flinders Press.
- Human Rights and Equal Opportunity Commission. (1997). *Bringing them Home - Report of the National Inquiry into the Separation of Aboriginal and Torres Strait Islander Children from Their Families* April 1997 Canberra: Human Rights and Equal Opportunity Commission.

Indigenous Queenslanders and Impaired Decision-Making Capacity

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Introduction

A research partnership was initiated between the Office of the Public Advocate Queensland and Griffith University, to explore a range of research questions relating to Indigenous Queenslanders and impaired decision-making capacity (impaired capacity). Initial scoping work resulting in a literature review, has indicated that while there is a body of research in relation to disability, cognitive impairment and mental illness amongst Indigenous Australians, there appears to be little specific research about the area of impaired capacity and any implications for the Guardianship and Administration scheme amongst this population. This qualitative research sought to explore these issues by conducting interviews with key Indigenous and non-Indigenous stakeholders across Queensland,

Method

The research questions are:

1. What are the meanings of impaired capacity in Indigenous communities?
2. How has the issue of determining capacity for Indigenous people been addressed in Queensland, as well as within other jurisdictions in Australia?
3. How are decisions made for Indigenous adults with impaired capacity according to Indigenous cultural expectations and practices?
4. Are the requirements of the current guardianship legislative regime appropriate for Indigenous Queenslanders? Is the legislation appropriate and advantageous for Indigenous Queenslanders with impaired capacity?
5. Are there other factors which need to be considered in relation to substitute decision-making practices for Indigenous Queenslanders with impaired capacity?

Semi-structured interviews were conducted with key Indigenous and non-Indigenous stakeholders from the human service sector in Queensland. Snowball sampling was used to identify seven key informants, who had knowledge of, and experience in working with Indigenous Queenslanders with impaired capacity and their family and carers.

A schedule of questions was developed to guide the interviews:

- What happens when an Indigenous person has an intellectual disability or mental illness which may mean they have difficulty in making personal, health and/or financial decision? How are decisions made within Indigenous families?
- Does the term “impaired decision- making capacity” have much relevance for Indigenous persons?
- What sort of life areas and/or issues do Indigenous persons with impaired decision-making capacity require someone to help them with: managing their money? Decisions about medical or health issues? Accommodation? Decisions about personal issues?
- Do you know of any Indigenous persons who have had a guardian or administrator appointed? Has this worked well – why or why not?
- What do you know about the Office of the Adult Guardian in Queensland? Have you ever used their services?
- What do you know about the Public Trustee of Queensland? Have you ever used their services?
- How useful are any of the above agencies for Indigenous communities/persons/issues?
- Are there any other issues or factors which need to be considered for Indigenous Queenslanders, with relation to the issue of impaired decision-making capacity?

Emergent themes from the interviews are discussed in relation to the research questions.

Results

Seven informants from across Queensland took part in the interviews. Four interviewees identified as Indigenous, three interviewees were non-Indigenous. All participants work in the human services sector in Queensland, as either lawyers, advocates, practitioners, or researchers, and have knowledge and experience working with Indigenous Queenslanders and the Queensland Guardianship and Administration System.

What are the meanings of impaired capacity in Indigenous communities?

All informants were unanimous in their opinion that the term impaired capacity has no real relevance for Indigenous people. Indigenous people have experience and understanding of cognitive impairments and impaired functioning as a result of acquired brain injury, schizophrenia, substance misuse, dementia etc, as well as from psychosocial issues.

For elderly indigenous people, it's drug and alcohol abuse, for young people it is cannabis and mental health issues.

One issue some respondents noted is an increase in car accidents in some Queensland Indigenous communities that has resulted in acquired brain injury or Intellectual disability, as a result of an increase in car accidents, due to Indigenous Queenslanders receiving royalties from mining companies, resulting in an increase in the purchase of cars such as 4WDs.

For Indigenous Queenslanders, it was reported that there may be a cultural understanding of impaired functioning as that the person is *going back to spirit*, and preferred treatment may be through traditional means, such as the used of traditional healers, or through spending time in their country/homeland.

Someone who is not functioning well can recover without being removed, and in a culturally appropriate way.

One respondent stated that education and awareness raising of what impaired capacity is, and what decisions are covered under the Guardianship regime for people with impaired capacity, is needed in order to provide Indigenous Queenslanders with information about how the system may be utilised.

Answer the question for Indigenous people “Why do we need to know about this?”

How has the issue of determining capacity for Indigenous people been addressed in Queensland, as well as within other jurisdictions in Australia?

Respondents who had knowledge of capacity assessment and process, believed that the current assessment tools used and the process used to assess capacity are inadequate and flawed. Reasons for this view included that there is no baseline measurement of a person’s functioning before they lose capacity to compare to, that capacity assessments do not allow for personality differences and family differences, and the cultural bias in determining a Western concept according to a Western framework. An example given was the issue of ‘gratuitous concurrence’- when some Indigenous people are asked questions, the respondent wants to please and answer the ‘right’ way. Another example given was education and style of communication:

It’s this aspect of language and communication that underpins capacity assessments and measures of whether someone is functioning or not. Particularly if you are measuring using the instruments they currently use, and someone is less educated, and from a more remote area.

The professional who is assessing needs to be able to accurately assess capacity for Indigenous people, with training around factors such as non-verbal cues.

Problem with much of the research in psychology and law on assessing functioning is that it doesn’t look at the process; doesn’t look at understanding the interaction between all in the assessment process. Those being assessed, the assessor, the carer, plus an interpreter. And only the best of interpreters can properly interpret,

particularly in an assessment situation. So you are never going to really get what people are saying, you would need to record it and have it properly done but this would never happen in practice. So you are left with something that is flawed.

How are decisions made for Indigenous adults with impaired capacity according to Indigenous cultural expectations and practices?

It was reported that the traditional family protocol amongst Indigenous people is that the eldest in the family takes care of these matters, and they may use an Enduring Power of Attorney to do this. This is especially so for the Torres Strait Islander population. In some Queensland Indigenous communities and families, there can be cases of abuse, and Indigenous people breaking the traditional family protocol. Respondents indicated that most Indigenous people with an intellectual disability, acquired brain injury etc, are on disability pensions, and in cases of abuse, the family takes their money on payday, and leaves them with very little, perhaps a bit of food and a six pack. This has been seen to occur in cases of large compensation payouts from car accidents.

Are the requirements of the current guardianship legislative regime appropriate for Indigenous Queenslanders? Is the legislation appropriate and advantageous for Indigenous Queenslanders with impaired capacity?

Awareness, Understanding and trust

There is a low level of awareness and understanding of the Guardianship and Administration system amongst Indigenous Queenslanders, and a high level of confusion and mistrust about the roles and powers of the various agencies involved. This mistrust of government services is a result of the mistreatment Indigenous people have experienced through colonisation. Additionally, the recent global financial crisis has increased mistrust of Western services by Indigenous people. It was also reported that some non-Indigenous service providers know they will be blacklisted by the Indigenous community if they place people in the Guardianship and Administration system

With Guardianship, it wasn't so long up that if a white face showed up, it was to take our children away, although that's still happening. The history in this country is of institutionalization of Indigenous people in general. Even the name, the Adult "Guardian" is paternalistic, implies oppression, it's like the old days of the "mission Manager", or "The Protector".

Decision-making under Guardianship - is seen as only one option every given – to move away from family and country.

They don't know they can appeal decisions.

Informants suggested that consultation and education of Indigenous Queenslanders and their families around the functions of the different agencies is key to engaging Indigenous people in the system.

The guardianship and trusteeship may have good reasons behind it, but the communities need to know the theory behind it all and the ethics.

Agencies in the system

Most respondents' opinion from their experience was that Indigenous Queenslanders have had less contact with the Office of the Adult Guardian than they have with the Office of the Public Trustee. Some informants have found through practice that when the Office of the Adult Guardian intervenes to investigate a situation of abuse, the agency is useful, and sensitive in their approach. In appointing a Guardian however, the system was found to be time consuming and cumbersome.

For Guardianship however, it is a lot of paperwork, and it can take up to 12 months for the process to happen.

Responses were varied about the usefulness of the Office of the Public Trustee for Indigenous Queenslanders and their families. Some respondents thought that when the Office of the Public Trustee has been involved as an Administrator for someone, this was viewed both positively and negatively by Indigenous Queenslanders and their families. In certain situations it was reported that Indigenous Queenslanders have

found the Office of the Public Trustee useful – when an abusive or exploitative relationships exists within a family, the public trustee can be useful as it provides rules around amounts of money released and who can access it.

Indigenous people do not like the public trustee, because money is then not available.

With paydays, the Public Trustee getting involved is good.

Some indigenous families are happy for the public trustee to get involved, as it works well to safeguard against this type of activity (abuse).

One respondent gave this opinion:

In the old days, disabled people would be left behind as in a hunter and gather society they couldn't afford to carry them along. Indigenous families shun these type of people, and are happy for guardianship to take over as they would be free from making decisions.

Again, trust in government agencies by Indigenous Queenslanders and their families is a key issue.

The Public trustee is not liked in general by Indigenous people. They say it's like going back to Mission Manager's days. The perception is that the Public Trustee has free range to make decisions about Indigenous' people's money.

People feel there is not enough transparency and accountability to do with how their money is managed – particularly around the profit that the agency would make from investing the money they hold.

Both the health system and the criminal justice system were mentioned by interviewees as being inadequate when dealing with Indigenous Queenslanders with impaired capacity. Examples were given of inappropriate accommodation and support that resulted in negative outcomes for Indigenous Queenslanders with impaired capacity.

Cultural differences

In instances where the system is used to support and protect Indigenous Queenslanders with impaired capacity and their families in a cultural appropriate way, the system is reported to work well. However, as the system has been designed around a Western cultural framework, the system does not allow for different cultural practices.

All informants replied that the Guardianship and Administration system is very complex for white people, without introducing cultural differences. An example is the Indigenous cultural concept of 'shame', particularly about telling your business to someone else, particularly a non-Indigenous person.

There is a stigma for Indigenous people about having other people making their decision, particularly white people.

The process can be extremely damaging, they feel shame and humiliation.

Another cultural difference in the Guardianship and Administration system was mentioned by one of the informants:

The system reflects the values for mainstream Australia – that the material is valued far above the emotional and the spiritual. Western people may see saving as important, Indigenous people may prefer to have their money spent sometimes.

Another key cultural difference relevant for the system is that the framework is predicated on the individualistic nature of a culture, versus a cultural that is based on the collective. Indigenous cultural norms are based on group decision-making and the concept of reciprocity, whereas the Guardianship and Administration system designates an individual for particular types of decisions, and does not allow for collective responsibilities, such as people sharing the financial responsibility for one person's debt. This is complicated when purchasing things such as cars and boats, where there is often collective ownership in Indigenous families and communities.

This type of functional interdependence between family and community members is not catered to in the Guardianship and Administration system.

Western/white people need to ask themselves, why are our cultural values better?

A few respondents suggested that guidelines need to be developed that address the Indigenous traditional family protocol and the interaction of the Guardianship and Administration system, for both Indigenous and non-Indigenous, human service agencies and workers, as well as the Indigenous community in general, in order to discuss incompatibilities in the system between different cultures, and to provide examples of addressing these.

Education

Agencies within the Guardianship and Administration system need to substantially increase their education initiatives to Indigenous Queenslanders, particularly by developing and using culturally appropriate documents and other formats, such as workshops and DVDs.

Because of the demographic and geographic spread of Indigenous people around Queensland, education can't just be the Government putting out a leaflet

Education about guardianship and trusteeship should be part of chronic disease management in the health system, but isn't.

The biggest area of need for education to be directed at Indigenous Queenslanders, as reported by informants, was to do with Enduring Power of Attorney and Advanced Health Directives. Another key area was around a person's rights and responsibilities once they are part of the system.

EPA's are raised quite a lot. Needs to be more education about EPA's etc, especially for young people.

Increased education and engagement by key agencies in the Guardianship and Administration system about the system, such as the Office of the Adult Guardian and the Office of the Public Trustee, of Indigenous and non-Indigenous human service agencies and workers, particularly Indigenous health workers, Indigenous Health Councils, Indigenous doctors, Indigenous legal services, hospices, hospitals, respite services, the Queensland Health Homeless Outreach Team and the Elder Abuse Prevention Unit Queensland.

The Indigenous legal services are another area that could be utilised – they mostly see their services are providing for criminal matters

Are there other factors which need to be considered in relation to substitute decision-making practices for Indigenous Queenslanders with impaired capacity?

Some respondents suggested the need for specified positions, including the development of a career pathway, for the employment of Indigenous people within key agencies in the Guardianship and Administration system. This was seen as key to progressing the engagement of Indigenous Queenslanders and their families and carers with Guardianship and Administration agencies.

A related issue to substitute decision-making is the availability of places and suitability of the Western aged care system. The informants reported that Indigenous Queenslanders did not always agree with Guardianship and Administration agencies or human service providers that the available aged care facilities are a suitable option for Indigenous Queenslanders with impaired capacity.

If there was more aged care funding to support people in the home, Indigenous people wouldn't need to be sent away to a nursing home etc.

Discussion

It was clear from all respondents that the term impaired capacity had little meaning for Indigenous Queensland. However cognitive impairment and a lack of functioning,

usually as a result of dementia, acquired brain injury, mental illness, substance misuse, Indigenous Queenslanders understood as going back to spirit, and as requiring traditional treatments.

Informants who had knowledge of capacity assessment believed current tools are flawed and inadequate, for a variety of reasons, such as due to the underlying western cultural framework of most of the tools and the process of assessment itself. Decisions made within Indigenous families and communities for Indigenous people with impaired capacity are usually made according to the traditional family protocol, where the eldest in the family make decisions. However, there are instances where the traditional family protocol is ignored.

There is a low level of awareness and understanding of the Guardianship and Administration system amongst Indigenous Queenslanders, and a high level of mistrust and confusion about the roles and powers of the various agencies.

In instances where the Guardianship and Administration system is used to support and protect in culturally appropriate ways, it works well for Indigenous Queenslanders. However the system is also culturally biased, and does not allow for different cultural practices.

Other key issue raised by informants included the lack of Indigenous people employed within the Guardianship and Administration system as a contributing factor to Indigenous Queenslanders lack of knowledge and mistrust of the system.

Conclusion

This study has explored how decisions are made for Indigenous Queenslanders with impaired capacity, by their families and carers. The legal construct of impaired capacity was found to have little meaning for Indigenous Queenslanders. There was found to be a great deal of confusion and mistrust of the Guardianship and Administration system and its agencies. The findings from this research provide guidance for recommendations to increase awareness and understanding of the Guardianship and Administration system amongst Indigenous Queenslanders.

Recommendations

Recommendations are provided to improve access to and the relevance of the Guardianship and Administration system in Queensland, for Indigenous Queenslanders with impaired capacity and their families and carers:

1. Increased education and engagement by key agencies in the Guardianship and Administration system about the Guardianship and Administration system, such as the Office of the Adult Guardian and the Office of the Public Trustee, of Indigenous and non-Indigenous human service agencies and workers, particularly Indigenous health workers, Indigenous Health Councils, Indigenous doctors, Indigenous legal services, hospices, hospitals, respite services and the Elder Abuse Prevention Unit Queensland.
2. Increased education and engagement by key agencies in the Guardianship and Administration system about what impaired capacity is and the Guardianship and Administration system, such as the Office of the Adult Guardian and the Office of the Public Trustee, of Indigenous Queenslanders, particularly those with impaired capacity and their families and carers. This should be conducted in culturally appropriate ways, and directed at areas of need and misunderstanding, such as Enduring Power of Attorney and Advanced Health Directives.
3. Guidelines should be developed that explain the system, and that address the interaction of the traditional family protocol and other cultural differences, with the Guardianship and Administration system, targeted at both Indigenous and non-Indigenous human service agencies and workers, as well as the Indigenous community in general, in order to discuss incompatibilities and to provide examples of addressing these.
4. Training is needed for both Indigenous and non-Indigenous human service agencies and workers, as a key source of information dissemination and support to Indigenous Queenslanders.
5. A review of the key legislation by Indigenous human service experts and the Indigenous community, to identify cultural incompatibilities in the legislation and to explore options for reform.

6. Creation of specified positions and a career pathway for Indigenous people within key agencies in the Guardianship and Administration system.

7. Further research to identify current assessment practices used by health practitioners in Queensland, and to evaluate these for cultural relevance to Indigenous Queenslanders.

8. Training for all workers in the Guardianship and Administration system by Indigenous experts in the interaction of the system with Indigenous culture.