

**THE WINSTON CHURCHILL  
MEMORIAL TRUST OF AUSTRALIA**

‘To investigate if supported decision making will reduce elder financial abuse in Australia’

**Brian Roche**

Public Trustee of Western Australia

Churchill Fellow 2017

*“The moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; those who are in the shadows of life; the sick, the needy and the handicapped.”*

**Hubert Humphrey (1911-1978)**

United States Vice President

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## Program

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I travelled during August and September 2018.

People and places visited:

### London, United Kingdom

- Diana Rose - Professor of User Led Research, Kings College London
- Janet Ilett - Deputy Official Solicitor and Public Trustee
- Julie Taylor - Secretariat, Official Solicitor and Public Trustee
- Helen Clift - Senior Lawyer, Official Solicitor and Public Trustee
- David Taylor - Senior Lawyer, Official Solicitor and Public Trustee
- Katrina London – Lawyer, Official Solicitor and Public Trustee
- Alex Ruck Keene - Barrister
- Denzil Lush - Senior Judge (retired), Action on Elder Abuse England
- Alan Eccles - Public Guardian, Office of the Public Guardian, Birmingham
- Gary Fitzgerald - Chief Executive, Action on Elder Abuse England
- Carolyn Hilder - Senior Judge, Court of Protection

### Edinburgh, United Kingdom

- Jan Killeen - ex Director of Public Policy, Alzheimer Society of Scotland
- Fiona Brown - Deputy Public Guardian, Office of the Public Guardian
- Sandra McDonald - ex Public Guardian, Office of the Public Guardian
- Shaben Begum - Director, Scottish Independent Advocacy Alliance
- Cathy Asante - Legal Officer, Scottish Human Rights Commission
- Colin McKay - Chief Executive, Mental Welfare Commission for Scotland
- Jill Stavert - Professor, Edinburgh Napier University

- Peter Quigley - Policy Advisor, Scottish Government
- Sarah Saddiq - Policy Advisor, Scottish Government
- Adrian Ward - Solicitor, ex TC Young Solicitors

#### **Vancouver, British Columbia, Canada**

- Catherine Romanko - Public Guardian and Trustee
- Kimberly Azyan - Executive Director, Public Guardian and Trustee
- Sherry Baker - Executive Director, British Columbia Association of Community Response Networks
- Kathleen Cunningham - Executive Director, Canadian Centre for Elder Law

## Executive Summary

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There has been in recent years a consciousness raising in Australia and in overseas countries about the prevalence of elder abuse, and a slow realisation of the enormity and scale of this emerging societal problem. It has at times been an uncomfortable conversation. Elder abuse is insidious. For years it was virtually invisible but thankfully it is now becoming part of daily media, social and political discourse. Elder abuse is rightly recognised as a significant social issue. Progress is well underway to address this issue but it is still years behind the good work done in the areas of child protection, and domestic and family violence.

Australia is experiencing a rapid ageing of its population. Australians are now expected to live almost 10 years longer than they were 50 years ago, with Australia's life expectancy now fifth highest in the OECD<sup>1</sup>. The ageing of Australia's population as a result of sustained below - replacement levels of fertility, combined with increasing life expectancy, is expected to see the number of people aged 65 years and over projected to nearly double from 3.8 million people in 2017 to 6.7 million in 2042<sup>2</sup>. This rapid ageing is a looming demographic time bomb that will put massive pressure on Government and private sector services and impact crucial public policy choices around social security benefits, health and aged care costs.

Ageing along with the prevalence of dementia are major contributing factors of elder abuse. The ageing baby boomer generation is particularly vulnerable to elder financial abuse as they are the wealthiest generation in history. The baby boomers have enjoyed a near 50 year economic miracle characterised by a boom in property prices and growth in superannuation funds due to strong economic prosperity over the last few decades. For the younger generations, the dream of home ownership has become largely elusive.

Sadly this has led to resentment, bitterness and at times a sense of entitlement. Too often parents or grandparents are guilted or harassed into becoming the major financiers to their family. These financial arrangements are often referred to as family agreements. The majority of the family agreements are informal, with no documentation, are never repaid and often invisible to other family members. There is often a blurring of what constitutes generational generosity and elder financial abuse. It is no different for other developed countries.

Elder abuse doesn't just happen in aged care homes, it happens daily to older Australians living in our community. Anyone can be a victim of elder abuse but age, disability and reduced cognitive function make a person far more vulnerable. It is absolutely unacceptable. Elder abuse adversely impacts on healthy ageing. Unless preventative measures are put in place to address the problem it will continue to grow. Older people as a group are deserving of special consideration, support and protection from abuse. Considering that the proportion of ageing Australians is steadily increasing, substantial law reform is required to protect this growing demographic<sup>3</sup>.

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<sup>1</sup> Australian Government 2018, *More Choices for a Longer Life*, Budget 2018 fact sheet

<sup>2</sup> ABS Population Projections, Australia, 2017 (base) 2066 *Quality Declaration*

<sup>3</sup> Queensland Law Society, *Submission 159*

The frailties that come with ageing, especially if coupled with a cognitive impairment like mid to late stage dementia, make older people in our community far more vulnerable to abuse and financial exploitation. More than 80% of people aged 85 or over have some disability<sup>4</sup>.

There are also other important risk factors at play that make older people susceptible to elder abuse:

- social isolation, either due to having no family or a result of deliberate isolation by the perpetrator of the abuse, and loneliness;
- dependence of the victim, due to a lack of experience with managing their finances, or illness or injury;
- dependence on the perpetrator, due to living arrangements;
- the victim being single or widowed;
- mental illness;
- gender and societal attitudes such as ageism; and
- the victim having only one child, with no other close family members to report concerns to authorities.

There is a widespread misconception that older people live in aged care homes. About 95% of older Australians live in private homes where accommodation arrangements vary. Some individuals either live alone or with a spouse, some share with siblings or other relatives, some share with friends of their own generation, and some live with single or married offspring who themselves may have children or grandchildren<sup>5</sup>.

These living arrangements, particularly those involving relationships of dependency, place older persons in a very vulnerable position.

Sadly on an almost daily basis we read in the newspapers, social media, or watch on television horrifying stories of abuse of older Australians. Only recently a Melbourne man was jailed for five years for the neglect and financial abuse of his elderly frail mother who was entirely dependent on him and his de facto partner. The grandmother of five had been removed from her aged care home so the couple could claim Centrelink benefits. His mother died in horrible circumstances<sup>6</sup>.

The case highlighted that elder abuse is often proximity based, and carried out by people living under the same roof where a relationship of trust exists or at least a relationship of trust should be expected. It doesn't matter if the breach of trust is criminal or not, it can be deeply damaging to the victim.

While there is no universally accepted definition of elder abuse the most widely accepted definition comes from the World Health Organisation:

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<sup>4</sup> Australian Institute of Health and Welfare 2011, *Australia's Welfare 2011*

<sup>5</sup> Carney AO, Terry, *Prioritising Supported Decision-Making: Running on Empty or a Basis for Glacial-to-Steady Progress?* (October 24, 2017). *Laws*, Vol. 6, No. 4, pp. 1-14, 2017; Sydney Law School Research Paper No. 17/89

<sup>6</sup> 2018, 'Son jailed for neglecting ailing mother', *The West Australian*, p38

*“Elder abuse is a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person. Elder abuse can take various forms such as physical, psychological or emotional, sexual and financial abuse. It can also be the result of intentional or unintentional neglect”<sup>7</sup>*

I am aware that as part of the Elder Abuse Prevalence Scoping Study, to be conducted by the Australian Institute of Family Studies, there will be options for achieving a nationally applicable definition of elder abuse.

The majority of perpetrators of elder abuse are intra-familial - it stays hidden because it takes place primarily within a domestic setting and largely occurs within the family. A lot of the time the victims may not even be aware it is taking place. Many are adult children acting as carers for one of their parents or a spouse caring for a frail partner. In 2011 the Productivity Commission noted that of the group aged 65+ who were needing care, 24% of primary carers were adult sons or daughters<sup>8</sup>.

Elder abuse can take several forms - financial and economic abuse, psychological abuse, emotional abuse, physical abuse and neglect, social abuse and sexual abuse. Elder abuse is very complex, as the victim may be subjected to one or a number of these forms and even these categories do not always truly reflect those interrelated complexities.

Research continues to show financial abuse as the most common form of elder abuse suffered by older adults. The World Health Organisation defined elder financial abuse as ‘the illegal or improper exploitation or use of funds of the older person’. Financial abuse takes place where a trusted third party takes advantage of a vulnerable elderly person or uses undue influence to persuade an elderly person to act in way contrary to their interests. It involves exploitative actions such as theft, fraud, and forgery, as well charging older people inflated fees for cheaper goods. Severe forms of exploitation include the selling the property of older people without informed consent, stealing the pension money of older people, or forcing older people to change their Will<sup>9</sup>.

In England, taking advantage of an older person by stealing from them was described as the practice of having ‘Tuesday friends’ as that was the day pensions were paid.

Other examples of elder financial abuse include:

- misusing an Enduring Power of Attorney;
- using an older person’s PIN to make large cash withdrawals from the person’s bank account through an ATM, or to make purchases for themselves in supermarkets, liquor stores, etc;
- obtaining access to an older person’s internet online bank details and transferring funds from the account;
- becoming a signatory to the older person’s bank account and withdrawing money for themselves;

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<sup>7</sup> World Health Organization 2002, *Toronto Declaration on the Global Presentation of Elder Abuse*

<sup>8</sup> Productivity Commission 2002, *Caring for Older Australians*, Report No 53

<sup>9</sup> Ananias, J. & Strydom, H. ‘Factors contributing to elder abuse and neglect in the informal caregiving setting’, *Social work (Stellenbosch Online)* 2014, vol. 50 no. 2

- abusing functions as administrator under the relevant Act;
- forcing someone to make or change a Will;
- inappropriately encouraging an older person to transfer valuable assets such as real property or shares into another name.

As the topic has risen in prominence in Australia in recent years, elder abuse has attracted extensive research by highly qualified academics and scholars. Concerns by Government have resulted in a number of State and Territory parliaments holding inquiries. The Commonwealth Government, responding to community calls demanding action, commissioned the Australian Law Reform Commission (ALRC) to conduct a major inquiry into elder abuse.

The terms of reference for the inquiry asked the ALRC to consider:

- existing Commonwealth laws and legal frameworks which protect elder persons from abuse by carers, supporters and representatives, including regulation of financial institutions, superannuation, social security, health and care arrangements; and
- the interaction and relationship of relevant Commonwealth laws with State and Territory laws.

In May 2017, the ALRC delivered its final report *Elder abuse - A National Legal Response*. The ALRC report made 43 recommendations aimed at safeguarding older Australians from abuse for consideration by the Commonwealth Government. The proposed reforms were wide ranging. The ALRC's capstone recommendation called for a National Plan to be developed to combat elder abuse.

The ALRC uses the concept of a National Plan in a broad sense to emphasise the need for a national approach to elder abuse and to provide a coordinating framework for State and Territory initiatives as well as those at the Commonwealth level.<sup>10</sup>

To their great credit there has been decisive action taken by the Commonwealth Government and all State Governments to progress this recommendation. In February 2018, the Council of Attorneys-General, comprising the Commonwealth and all State and Territory Attorneys-General, agreed to work together to develop a draft of the plan by the end of 2018. The plan will look to bring together in an integrated manner much of the work already undertaken at the Commonwealth level and by States and Territories addressing elder abuse.

The National Elder Abuse Plan would have five goals:

1. promote the autonomy and agency of older people;
2. address ageism and promote community understanding of elder abuse;
3. achieve national consistency;
4. safeguard at-risk older people and improve responses; and
5. building the evidence basis.

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<sup>10</sup> *Supporting Older People in Exercising and Protecting Their Rights* – Insights from the ALRC's Elder Abuse Inquiry. Keynote Address Aged Rights Advocacy Service, World Elder Abuse Awareness Day conference (2017) – *Elder Abuse: Challenges for Changemakers*, Emeritus Professor Rosalind F Croucher AM, President Australian Law Reform Commission (16 June 2017)

The Commonwealth Government also as part of its commitment to protect the rights of older Australians funded a national study to examine the prevalence and nature of elder abuse in our community and to provide evidence-based findings to inform the National Plan. This is in response to a recommendation of the ALRC report Elder Abuse—A National Legal Response.

#### Recommendation 3.5

There should be a national prevalence study of elder abuse to build the evidence base to inform policy responses.

This work is critical as there is currently no national evidence on the prevalence of elder abuse in Australia. International studies have shown it is likely that between 2% and 14% of older Australians experience elder abuse each year. The prevalence study will aim to identify the nature and scale of elder abuse, types of abuse, and who is committing the abuse. It is very important work as it is vital that future strategy, policy and program responses are formed from an appropriate evidence base. It will also be critical to the ability to measure the success or otherwise of the National Plan.

This work to strengthen the evidence base will be done in three stages and seek to build on existing research projects already commissioned by the Commonwealth Government through the Australian Institute of Family Studies (AIFS). AIFS is collaborating with the National Ageing Research Institute, the Social Research Centre, and the Social Policy Research Centre at the University of New South Wales to undertake this important research. Despite the difficulties and complexities involved, I hope genuine attempts are made as part of the prevalence study to include the cohort of persons with profound cognitive impairments.

In September 2018, the Western Australian Legislative Council Select Committee into Elder Abuse tabled in Parliament its excellent final report titled *'I Never Thought it Would Happen to Me: When Trust is Broken'*. The report correctly identified ageist attitudes were a cause and major driver of financial elder abuse. The mistaken belief that an older family member's personal assets and finances should be used for to benefit the children and their grandchildren.

The report identified amongst many things the phenomenon of early inheritance impatience, where abusers begin to feel entitled to an older person's finances before they have died. It can be opportunistic strangers who befriend an older person but it is mainly family members and caregivers. As parents live longer, children and grandchildren have to wait much longer to benefit from the proceeds of an estate. This impatience can see children pressuring family members to sell their home to access money or to sign legally binding documents such as loan contracts under duress. The abuser justifies the behaviour on the basis they would eventually get the money anyway from the Estate.

The report's various findings and its 35 recommendations will be an important resource to be considered by the Western Australian Government as it continues to develop and progress its policy responses to this emerging social issue. The Western Australian Government to its credit had already in June 2018 as part of World Elder Abuse Awareness Day convened a Western Australian-first Elder Abuse Awareness Summit.

The purpose of the Elder Abuse Awareness Summit was to invite key stakeholders to:

- share their views on elder abuse issues;
- consider strategies for tackling elder abuse; and
- discuss potential input to the National Plan on elder abuse.

The focus of my Fellowship was to investigate if a move to supported decision making would reduce elder financial abuse in Australia. It was not my intention to conduct a major literature review on elder abuse or supported decision making. The literature is too voluminous. My aim was to examine the progress being made towards supported decision making in the jurisdictions visited, make observations as to learnings for Australia (particularly in the context of my role as an administrator for people with a cognitive disability) and to see if there was evidence that supported decision making reduced elder financial abuse. I was also very keen to examine what safeguards were in place because I fear supported decision making may increase the possibility of abuse, undue influence and financial exploitation.

My dissemination plan in relation to my report involves the following:

- public availability of this report on the Winston Churchill Memorial Trust website;
- presentation of the report's findings and recommendations to Public Trustee staff;
- presentations at disability and legal conferences as opportunities arise;
- distribution of the report's findings and recommendations to the Australian Guardianship and Administration Council which comprises:
  - Public Advocates
  - Public and Adult Guardians
  - Boards and Tribunals, and
  - Public and State Trustees or their equivalent throughout Australia

## Western Australia

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In Australia guardianship operates under a substituted decision making system where a Court or Tribunal appoints a guardian or administrator in a limited or plenary capacity as a response to a situation where a person is deemed incapable of managing their own affairs. Another form of substituted decision making is advance planning tools such as enduring powers of attorney and enduring power of guardianship. Substituted decision making takes away a person's ability to decide for themselves and empowers another person (a proxy) to then make decisions for or on behalf of a person with a decision making disability - a case of 'stepping into their shoes'. Many people argue this type of decision making goes against the fundamental freedom and protection of all human rights.

The appointment of a substitute decision maker is often made by a Court or Tribunal in response to situations of alleged elder financial abuse of a person at risk. Western Australia, like the rest of Australian States and Territories in relation to guardianship and administration law, presently operates as a 'best interests' jurisdiction. In Western Australia the legislation governing the appointment of a guardian and administrator is the *Guardianship and Administration Act 1990 (GA Act)*.

In Western Australia, people with a decision making disability who have a guardianship or administration order made by the State Administrative Tribunal (the Tribunal) have a substituted decision maker appointed to act in their 'best interests'. The Tribunal has a wide ranging jurisdiction to deal with issues relating to elder abuse.

#### Requirements for a Guardianship Order under Section 43 of the GA Act

The person is:

- incapable of looking after their own health and safety;
- unable to make reasonable judgements in respect of matters relating to their person or
- in need of oversight, care or control in the interests of their own health and safety or for the protection of others; and
- in need of a guardian.

#### Requirements for an Administration Order under Section 64 of the GA Act:

The person is:

- unable by reason of a mental disability to make reasonable judgements in respect of matters relating to all or any part of their estate; and
- in need of an administrator of their estate.

Section 51 and Section 70 of the GA Act clearly state a guardian and administrator shall act according to their opinion of the *best interests* of the represented person. The GA Act, while providing guidance on what constitutes best interests, fundamentally leaves it to the guardian or administrator to use judgement and discretion.

In dealing with proceedings the Tribunal must observe an important set of principles set out in Part 2 of the GA Act.

- a) The primary concern of the Tribunal shall be the best interests of any represented person, or of a person in respect of whom an application is made.*
- b) Every person shall be presumed to be capable of –*
  - i) Looking after their own health and safety;*
  - ii) Making reasonable judgements in respect of matters relating to their person;*
  - iii) Managing their own affairs;*
  - iv) Making reasonable judgements in respect of matters relating to their estate;**Until the contrary is proved to the satisfaction of the Tribunal.*
- c) A guardianship or administration order shall not be made if the needs of the person in respect of whom an application for such an order is made could, in the opinion of the Tribunal, be met by other means less restrictive of the person's freedom of decision and action.*
- d) A plenary guardian shall not be appointed if the appointment of a limited guardian would be sufficient to meet the needs of the person.*
- e) An order appointing a limited guardian or administrator for a person shall be in terms that impose the least restrictions possible in the circumstances on the person's freedom of decision and action.*

*f) In considering any matter relating to a represented person or a person in respect of whom an application is made the Tribunal shall as far as possible, seek to ascertain the views and wishes of the person concerned as expressed, in whatever manner, at the time or as gathered from the persons previous actions.*

It is clear that the GA Act already starts from the position that the person is presumed to be capable and that an administration order not be made if there is a less restrictive alternative available. If the Tribunal finds the person has a family member or friend able to provide support, consult with the person and therefore enable them to make their own decisions, it will not make a formal appointment. The GA Act clearly supports the use of informal supported arrangements where available.

In practice the Tribunal's preference is to appoint family members or friends as guardians and administrators wherever possible. The Public Trustee is appointed administrator where the Tribunal has determined the person has a mental disability, is vulnerable to abuse and is unable to identify a family member who is willing, able and capable of being administrator. It is not enough merely for the person to be vulnerable (see *Public Trustee and KMH* [2008] WASAT 171). A physical disability is also not enough.

By contrast, a person does not need a mental disability to be placed under a guardianship order although practically everyone under such an order would have at least one. The GA Act states 'mental disability' includes an intellectual disability, a psychiatric condition, an acquired brain injury and dementia. Mental disability could include other conditions not specifically mentioned in the Act. What the Tribunal looks for is evidence of a link between the mental disability and the person's ability to make reasonable decisions concerning their affairs.

When the Tribunal makes a guardianship or administration order, it must set a date by which the order is reviewed, not exceeding five years from the date of the order. There is also the ability for a person under an order (or other people) to seek an earlier review. There are also times when, following such a review, the Tribunal revokes an administration order. That can happen for a number of reasons - the person recovers sufficiently from their mental disability; a family member who previously had a conflict of interest no longer has one; a family member who previously did not want to take on the role is now happy to do so; or, on further evidence, it is determined the person does not have a mental disability.

The sad reality is that the vast majority of the Public Trustee's appointments are the result of no family member willing or able to perform the duties, for persons with profound decision making disabilities. Many have mid to late stage dementia or acquired brain injuries. These profound cognitive impairments prevent them from being able to verbalise or communicate their will or preferences on important matters. A recent case in the Supreme Court of Appeal is noteworthy. In *The Public Trustee v Baker* [2014] WASCA 23 the Court when considering section 70(2) of the *Guardianship and Administration Act 1990*, said:

*'There will inevitably be many cases where the mental capacity of the represented person is such that consultation would be impossible. There will also inevitably be cases where the circumstances are such that the wishes of the represented person cannot be acted upon.'*

In November 2015, the former Department of the Attorney General finalised its review of the GA Act as a result of the requirement in section 14 of the Act to undertake regular statutory reviews of its operation and effectiveness. The report on the statutory review was tabled in the Western Australian Parliament on 2 December 2015. The statutory review made 86 recommendations, covering the operation of the GA Act. Many recommendations in the statutory review related directly to elder abuse and, as such, are designed to increase the safeguards to better protect the assets of older people.

Some examples relating to Enduring Powers of Attorney (EPA) include:

- increasing the penalty from \$1,000 to \$5,000 for failing to submit accounts or other relevant documents to the Public Trustee as required under section 80;
- increasing the penalty for a donee who fails to act properly under section 107 from \$2,000 to \$5,000;
- requiring that the donee of an EPA must date as well as sign the document; and
- requiring that the witness to an EPA under section 104(2)(a)(ii)(I) must not be a person who is appointed to be the donee or substitute donee of the EPA (other than a staff member of the Public Trustee or a trustee company that is the donee).

The State Government of Western Australia has committed to amending the GA Act to implement the majority of the recommendations of the statutory review. A Bill to amend the GA Act was approved by Cabinet in December 2017 and it is expected that the Amendment Bill will be introduced in the first half of 2019. The reforms to the GA Act are important in strengthening safeguards for older persons with decision making disabilities.

## Supported Decision Making

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There is a paradigm shift in many countries away from substituted decision making towards supported decision making related to adult guardianship. This has resulted from countries honouring the requirement of Article 12 of the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD was adopted by the United Nations General Assembly in 2006 and entered into force in 2008. The UNCRPD was the first legally binding and enforceable human rights treaty of the 21st century.

The UNCRPD saw supported decision making as an alternative to guardianship. The treaty was in response to many believing that guardianship was a blunt instrument failing to recognise that people with a disability should be treated equal before the law.

Interestingly, the UNCRPD did not provide a clear definition of supported decision making. For my purposes I consider the term supported decision making to mean an approach to decision making that involves ensuring that a person with a decision making disability be supported to enable them to exercise their right to make their own decisions. This also means ensuring that appropriate safeguards be provided, along with that support, to adequately protect the interests of the person with the decision making disability. The nature and level

of support that will be required will differ markedly, depending on the needs of the person being supported.

The UNCRPD stated that:

*This requires that “States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”, calling on states parties to abolish practices such as Guardianships and instead develop systems of supported decision making that can be incorporated into law.*

**Article 12 – Equal recognition before the law**

*States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.*

*States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.*

*States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.*

*States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.*

*Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.*

The UNCRPD was the result of strong lobbying by disability groups and organisations seeking to repeal substituted decision making systems, such as adult guardianship, and replace them with a ‘human rights’ approach of supported decision making. Their argument was a person should not lose their legal capacity simply because of a disability. It is an approach that treats people with disabilities with greater dignity and recognises that people with disabilities are persons equal before the law, with the right to make informed choices for themselves.

For disability advocates, a move to a supported decision making model became a human rights imperative. The core of supported decision making is that people with cognitive disability have access to assistance for decision making to enable participation in society on

an equal basis<sup>11</sup>. The focus is placed on the respecting the autonomy and independence of persons with disabilities, ensuring the will and preferences of the person with the disability drive decisions that impact on their lives. Presumption is always in the favour of the person with a disability who will be directly affected by a decision - that person is the decision maker.

Supported decision making has been an inherently informal process. Family and friends on a daily and weekly basis, without giving it much thought, support other friends and close family members to make small and big decisions. Some people need greater support than others. In essence, supported decision making systems are simply a legal framework formalising what many community-based and grass-roots organisations, predominately in the field of intellectual disabilities, already do. In this sense, supported decision making works very well on its own, outside the legal sphere. It happens on a daily, functional level. Where good relationships exist, the handling of funds and entering into arrangements is managed without much in the way of legal formality<sup>12</sup>.

Laws and policies associated with supported decision making are attempting to make that existing relationship more formal and binding. In supported decision making, the role of the supporter is to be able to explain the issues and enable the person with the decision making disability to exercise their legal capacity to the fullest extent possible and to interpret the will and preference of the person with the disability.

Australia signed the UNCRPD on 30 March 2007, ratified it on 17 July 2008 and assented to become a party to the Optional Protocol in August 2009. By ratifying the UNCRPD, Australia, under international law, is expected to comply with this treaty.

In ratifying the UNCRPD, Australia, like many other countries such as Canada, France, the Netherlands, and Norway, expressed reservations and declared it was their understanding that Article 12 allows for fully supported or substituted decision making arrangements as a last resort and subject to safeguards.

The Australian Law Reform Commission (ALRC) in its report 2014 report titled *Equality, Capacity and Disability in Commonwealth Laws* (Report 124) recommended that reform of Commonwealth, State and Territory governments' laws concerning individual decision making should be guided by four National Decision Making Principles:

1. The equal right to make decisions.
2. The provision of support in decision making to the level necessary to enable them to participate in decisions which affect their lives.
3. That decisions be directed by the individual's will, preferences and rights.
4. That the legal framework provides protection against abuse and undue influence.

The development of the four national decision making principles signalled a shift away from substituted decision making towards the more human rights approach of supported decision making as embodied in the UNCRPD.

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<sup>11</sup> Arstein-Kerslake, A, Watson, J, Browning, M, Martinis, J, & Blanck P 2017, 'Future Directions in Supported Decision Making', *Disability Studies Quarterly* vol 37, no. 1

<sup>12</sup> James, K, & Watts, L 2014, *Understanding the Lived Experiences of Supported Decision-making in Canada*, Law Commission of Ontario

The ALRC believed an individual should not be assumed to lack the ability to make decisions on the basis of having a disability. The central point of the inquiry was the equal recognition of people with disability as persons before the law and their ability to exercise legal capacity<sup>13</sup>. Persons with a disability who require support to make decisions should be provided with the necessary support to ensure they are placed at the centre in participating in decisions affecting their lives.

In its 2017 report titled *Elder Abuse - a National Legal Response*, the ALRC did not make any specific recommendations in relation to supported decision making. The ALRC did refer to its 2014 report *Equality, Capacity and Disability in Commonwealth Laws* which recommended a new model of decision making be introduced which included the introduction of supporters and representatives (last resort appointees carrying proxy decision making powers).

Supporters are the strongly preferred appointee. The supporter would assist a person with a decision making disability to make their decisions by gathering all the necessary information, providing advice to the person and then assisting to communicate that person's decisions. Representatives address circumstances in which a person may desire, or circumstances may require, another person to make decisions for them but must take into account the person's will and preferences. Representatives are only to be appointed as a last resort and in limited circumstances.

The ALRC recognised the inherent difficulties in protecting people from abuse and neglect in these situations and recommended the key safeguards outlined in Article 4 of the UNCRPD should be taken into account to protect persons under these circumstances.

Supported decision making places an emphasis on ensuring the will and preferences of the person drives decisions that they make and that others make on their behalf. Where, after all efforts have been made, it is not practicable to determine the will and preferences of a person, the UNCRPD argues the "best interpretation of will and preferences" must replace the "best interests" determinations. This seems semantic and a tacit acknowledgement of the need for substituted decision making. As Devi rightly says, however well-meaning or infused by UNCRPD thinking, that decision is ultimately just a better informed version of 'best interests' paternalism<sup>14</sup>.

There may be occasions when a supporter may have to override a person's wishes. It is not always easy to balance respecting a person's wishes and safeguarding them from harm. In certain circumstances, the views of the person might lead to outcomes that are significantly detrimental to the person's health and welfare. In these circumstances, recognition of the representative's authority to make decisions contrary to the wishes of the person is essential<sup>15</sup>.

Fundamentally the model is about providing people with access to the necessary resources and supporters to assist them to make their own authentic decisions. It places a person's right

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<sup>13</sup> *Supporting Older People in Exercising and Protecting Their Rights – Insights From the ALRC's Disability and elder Abuse Inquiries*. Keynote Address ADA National Conference 'Human Rights & Social Justice: Shifting Client Control' Emeritus Professor Rosalind F Croucher AM, President Australian Law Reform Commission (23 March 2017)

<sup>14</sup> Devi, N 2013, 'Supported Decision-Making and Personal Autonomy for Persons with Intellectual Disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities', *The Journal of Law, Medicine & Ethics*, 41: pp.792-806

<sup>15</sup> Australian Law Reform Commission 'Equality, Capacity and Disability in Commonwealth Law' Australian Guardianship and Administrators Council Submission 91, *ALRC Report 124*

to dignity, independence and autonomy front and centre. To adopt this position in Australia, guardianship laws will need to be significantly changed to be brought in line with the UNCRPD. The challenge, in law reform terms, is to find an appropriate protective and safeguarding response without abandoning the emphasis on rights and particularly as expressed as the 'will and preferences' of the older person in the general context of increased cognitive impairment aligning with increasing age<sup>16</sup>.

Profound cognitive impairments such as dementia clearly provide serious challenges as to how best to ascertain and give effect to a person's will and preferences. General Comment 1 (para 21) states where after significant efforts have been made, it is not practicable to determine the will and preferences of an individual, the "best interpretation of will and preferences" must replace the "best interests" determinations. Even in these cases the expectation is that all efforts will be made to speak to family members and friends and look to past views and experiences of the person.

There is a need to be very mindful of undue influence and exploitation by supporters and the impact this may have on their decision making.

General Comment 1 (Para 22) states all people risk being subject to undue influence, yet this may be exacerbated for those who rely on the support of others to make decisions. Undue influence is characterised as occurring, where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation. Safeguards for the exercise of legal capacity must include protection against undue influence, however, the protection must respect the rights, will and preferences of the person including the rights to take risks and make mistakes.

Risk taking is an important part of decision making. Adults should be allowed to take risks and learn from them. People with no decision making disabilities make bad choices every day. It is a balance for supporters to allow for the freedom of the person to make mistakes but the need at times to override a person's decisions due to detrimental impacts on a person's health or financial well-being.

The move to supported decision making comes at a high cost. If a person has no family or no family members willing to take on the role of a supporter or representative, it takes time and effort to find and source alternative supporters. If alternative supporters can be found, it takes a long time to build up a trusted relationship. The trials of supported decision making that have taken place in Australia have confirmed it is resource intensive. Despite what some may wish, the evidence so far is that supported decision making simply cannot be delivered on the cheap, at low cost<sup>17</sup>.

Compliance with the UNCRPD is a work in progress both here in Australia and in the three jurisdictions visited on my Fellowship - England, Scotland and British Columbia. Law reform commissions in a number of Australian States have completed reviews of their guardianship

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<sup>16</sup> *Supporting Older People in Exercising and Protecting Their Rights* – Insights from the ALRC's Disability and Elder Abuse Inquiries. Keynote Address ADA National Conference 'Human Rights & social Justice: Shifting Client Control' Emeritus Professor Rosalind F Croucher AM, President Australian Law Reform Commission (23 March 2017)

<sup>17</sup> Carney AO, Terry, *Prioritising Supported Decision-Making: Running on Empty or a Basis for Glacial-to-Steady Progress?* (October 24, 2017). *Laws*, Vol. 6, No. 4, pp. 1-14, 2017; Sydney Law School Research Paper No. 17/89

laws and made recommendations to move away from ‘best interests’ and align their laws with the UNCRPD. Each jurisdiction is taking steps, cautiously, to get closer to compliance.

The slow progress across the world to supported decision making provides so far little tangible evidence as to whether supported decision making will indeed achieve the desired outcomes disability advocates are hoping for.

It is impossible to know whether supported decision making actually empowers persons with cognitive and intellectual disabilities. Furthermore, there is reason to be concerned that supported decision making might actually have the opposite effect, disempowering such individuals or making them more vulnerable to manipulation, coercion, or abuse<sup>18</sup>.

## Advance Planning

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The UNCRPD in General Comment Number 1 makes it clear that a legitimate form of supported decision making is advance planning. Planning in advance gives the person the opportunity to make clear their will and preferences which should be followed at a time when they are no longer in a position to communicate their express wishes to others.

There are three advance planning tools available in Western Australia under the GA Act. The tools are a less restrictive alternative to the appointment of a guardian or administrator.

### **1. Enduring Power of Attorney (EPA)**

Making an EPA while a person has legal capacity enables them to give someone (their attorney) the legal authority to make property and financial decisions on their behalf if they are unable to do so due to illness or loss of capacity.

### **2. Enduring Power of Guardianship (EPG)**

Making an EPG while a person has legal capacity enables them to appoint a person of their choice to make personal, lifestyle and treatment decisions on their behalf if they lose the ability to make these decisions due to illness or loss of capacity.

### **3. Advance Health Directive (AHD)**

Making an AHD enables a person to make decisions now about the treatment they would want, or not want, to receive if they became sick or injured and were incapable of communicating their wishes.

These advance planning tools are a positive form of substituted decision making because they are an act of self-determination made by a person at a time when they had full legal capacity, in contemplation of a future time when they may lack capacity. They allow a person to appoint another person to ‘stand in their shoes’ and make decisions on their behalf when they are no longer able to make such decisions.

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<sup>18</sup> Kohn, N & Blumenthal, J 2014 ‘A Critical Assessment of Supported Decision-Making for Persons Aging with Intellectual Disabilities’, *Disability and Health Journal*, Vol 7, no. 1, pp S40-43

Some people argue against these advance planning tools. Denzil Lush, a senior judge for over 20 years in the UK Court of Protection caused controversy when last September in a new foreword to his book *Cretney & Lush on Lasting and Enduring Powers of Attorney*<sup>19</sup> he attacked the power of attorney system stating that the “lack of transparency causes suspicions and concerns which tend to rise in a crescendo and eventually explode” .

Denzil Lush felt that there was far more scrutiny, better safeguards and greater protection offered by the default position of appointing a deputy (equivalent of a private administrator in Western Australia) by the UK Court of Protection. This, he argued, is because an appointed deputy is legally required to submit annual accounts to the Office of Public Guardian for examination. Deputies also have to provide a security bond, which can be claimed if there is a problem with money being spent inappropriately.

Interestingly, a similar surety bond scheme to that in the UK was tried here in Australia. In 2016, the NSW Trustee and Guardian introduced a bond scheme for private administrators but later abandoned the scheme after adverse media attention brought on by outrage from hundreds of spouses, parents and siblings who act as private administrators complained about the high fee structure and refused to comply.

Amid the controversy the NSW Civil and Administrative Tribunal (NCAT) determined that the NSW Trustee and Guardian did not actually have the power to require a private administrator to purchase a surety bond without either NCAT or the Supreme Court requiring the private administrator to do so. The NSW Trustee and Guardian choose not to appeal NCAT’s decision and issued refunds to all those affected.

While the introduction of the insurance bond scheme could have been better managed, its intentions were honourable. The scheme was attempting to protect vulnerable people, many elderly, from significant financial losses caused by the failures and unscrupulous behaviour of private administrators. In my view the main problem with the surety bond scheme is that, like here in Western Australia, except for the odd high profile case that reaches the media, the data shows the majority of this type financial abuse is carried out by people abusing an EPA rather than by private administrators.

The ALRC in its final report *Elder abuse - A National Legal Response* noted the considerable opposition to a mandatory surety bond scheme and did not recommend that the measure be adopted at this time.

While I share some of Denzil Lush’s concerns and acknowledge an EPA can be, and are often misused in Australia I believe these advance planning tools on the whole are extremely useful and practical documents that work well for many people in the community and are an effective safeguard against elder financial abuse.

In its 2018/19 Commonwealth Budget, the Federal Government announced a number of measures in response to recommendations in the ALRC’s 2017 Elder Abuse Report. As mentioned earlier the most important measure was to develop Australia’s first National Elder

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<sup>19</sup> Lush, D 2017, *Cretney and Lush on Lasting and Enduring Powers of Attorney*, 8<sup>th</sup> edn, Jordan Publishing Ltd, UK

Abuse Plan. There were a number of other key measures with a number impacting on advance planning tools. These measures included:

- A commitment to fund the establishment of a National Register of Enduring Powers of Attorney subject to the in-principle agreement of State and Territory governments to reform laws pertaining to enduring powers.
- Development of national Best Practice Guidelines for Legal Practitioners in relation to the preparation and execution of Wills,
- Examining the feasibility of developing generic enduring appointment forms that can be recognised in all State jurisdictions and the possible future development of nationally consistent legislation for enduring appointments.
- Funding provided to support the newly established peak body Elder Abuse Action Australia and for that body to conduct a scoping study for the creation of an Elder Abuse Knowledge Hub that would share expertise and promote best practice.

These important projects are overseen by a steering group comprised of representatives from the Australian Guardianship and Administration Council and representatives from the Council of Attorney's General Working Group on Protecting the Rights of Older Australians. The Western Australian Government is represented on these working groups and is supportive of the work to be undertaken.

## Observations from Jurisdictions Visited

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### England, United Kingdom

The *Mental Capacity Act 2005* (MCA) was adopted by Parliament in 2005, came into force in October 2007 and applies to England and Wales. The MCA was designed for the protection and empowerment of adults who lack the capacity to make their own decisions, and applies to financial affairs, property, health and personal welfare.

Section 1 of the MCA sets out five fundamental principles:

**Principle 1: A presumption of capacity**

Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.

**Principle 2: Individuals being supported to make their own decisions**

A person must be given all practicable help before anyone treats them as not being able to make their own decisions.

**Principle 3: Unwise decisions**

Don't treat a person as lacking the capacity to make a decision just because they make an unwise decision.

**Principle 4: Best interests**

If you make a decision for someone who lacks mental capacity, it must be in their best interests.

**Principle 5: Less restrictive option**

Treatment and care provided to someone who lacks capacity should be the least restrictive of their basic rights and freedoms.

MCA states that whether a person has the mental capacity to make a decision is decision specific. This means that you have to look at the particular decision that is to be made and the person's particular circumstances.

The MCA sets out a two-stage test of capacity:

- **Stage 1** (Diagnostic test) - Does the person have an impairment of their mind or brain and, if so,
- **Stage 2** (Functional test) - Is the impairment sufficient to mean that the person is unable to make a particular decision when they need to.

The MCA established the Court of Protection to deal with all issues, including financial and serious health care matters, concerning people who lack the mental capacity to make their own decisions.

The Court of Protection can:

- determine whether or not someone lacks capacity to make decisions for themselves; and
- appoint a deputy (a substitute decision maker) with the power to make decisions for that person about their financial affairs, property and/or their health and personal welfare.

The Court of Protection can choose professional deputies from a panel (lawyers, doctors, and accountants) when no friend or relative is willing or able to act as a deputy for a person who lacks mental capacity and the person has not prepared a Lasting Power of Attorney. Deputies are permitted to charge fees for their services. All deputies, attorneys and professional deputies must abide by a Code of Practice that outlines their role and responsibilities under the MCA.

The Office of the Public Guardian (OPG) is charged with the statutory responsibility to supervise deputies appointed to manage a person's financial affairs. Deputies are required to submit accounts annually. As in Australia, there have been a number of high profile cases in England of financial elder abuse concerning the misuse of a vulnerable person's funds to avoid paying aged care fees.

I was told that the Court of Protection is increasingly witnessing private commercial operators enter the marketplace wishing to act as deputies for persons with decision making disabilities. This is of real concern, especially in light of a recent notable case, *The Public Guardian v Matrix Deputies Ltd & London Borough of Enfield* (2017) EWCOP 14. In this case a large and well known firm Matrix Deputies Ltd who provided professional deputy services to 44 vulnerable clients was found to have charged excessive fees, had inappropriate records of client's funds, displayed conflicts of interest, took commissions in relation to the sale of property owned by

clients, and failed to comply with Court orders. The judge stripped Matrix of its powers to act as a deputy for clients and ordered the firm pay over £250,000 indemnity costs to Enfield Council.

The MCA also supports those who have capacity to plan for their future. It allows for people to put in place advance planning arrangements in the event they may lose decision making capacity in the future. The MCA introduced Lasting Powers of Attorney (for health, personal welfare, property and financial decisions) and advance decisions to refuse medical treatment. Section 9(2) of the MCA requires Lasting Powers of Attorney to be registered in England with the OPG. Amongst its various responsibilities, the OPG is responsible for managing a Lasting Power of Attorney register and for investigating any complaints of misuse. There is no active monitoring of Lasting Powers of Attorney. They are considered a private contract. Attorneys are not required to submit statements for examination to OPG annually. OPG only investigates if it receives a complaint. While I was there OPG was about to trial mediation services (outsourced to a panel of solicitors) as a way to possibly resolve family disputes to avoid court action.

The OPG encourages people in England to put in place a Lasting Power of Attorney as part of their advance plans. There are now 3.5 million Lasting Power of Attorney registered with the OPG and growing exponentially. The establishment of a similar national register in Australia for enduring instruments was a key recommendation of the ALRC report into elder abuse.

## **Current law reform**

The MCA Act is currently being amended. The Mental Capacity Amendment Bill is in response to a series of recommendations from the Law Commission's March 2017 Mental Capacity and Deprivation of Liberty report<sup>20</sup>.

From what I gathered from my time in England, it is a very different Bill than what was called for in the Law Commission's report. Disability groups and other advocates are very unhappy. They felt it was a lost opportunity. The MCA Amendment Bill was expected to reflect a move towards the UNCRPD principles but instead the MCA Amendment Bill narrowly focused on the proposal for a Liberty Protection Safeguards scheme to replace the existing scheme which authorised deprivation of liberty of people who lacked mental capacity.

There had been earlier attempts at legislative change to deal with issues emanating from a landmark case *HL v United Kingdom*<sup>21</sup> which identified the need to improve safeguards for people who lacked capacity to consent to treatment and were being deprived of their liberty for treatment. Two new schedules were previously added to the MCA which became known as the Deprivation of Liberty Safeguards.

Despite these changes, the Law Commission found the law still failed to deliver the necessary safeguards and identified delays to reviews and renewals of deprivations of liberty safeguard

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<sup>20</sup> Law Commission, 2017, *Mental Capacity and Deprivation of Liberty*, presented to Parliament pursuant to section 3(2) of the *Law Commissions Act 1965* Law Com no 372

<sup>21</sup> *HL v UK* 45508/99 [2004] ECHR 471

authorisations. The situation was further exacerbated by the 2014 Supreme Court decision known as 'Cheshire West'<sup>22</sup> which widened the definition of deprivation of liberty.

The Law Commission had made recommendations (40 and 42) which would have aligned the MCA much closer to the principles of the UNCRPD:

**Recommendation 40.**

Section 4(6) of the MCA should be amended to require that the individual making the best interests determination must ascertain, so far as is reasonably practicable:

- (1) the person's past and present wishes and feelings (and, in particular, whether there is any relevant written statement made by him or her when they had capacity);
- (2) the beliefs and values that would be likely to influence the person's decision if he or she had capacity; and
- (3) any other factors that the person would be likely to consider if he or she were able to do so; and in making the determination must give particular weight to any wishes or feelings ascertained.

**Recommendation 42.**

The Secretary of State and Welsh Ministers should be given the power, by regulations, to establish a supported decision making scheme to support persons making decisions about their personal welfare or property and affairs (or both).

These Law Commission recommendations did not end up in the MCA Amendment Bill. This was disappointing as work by the Essex Autonomy Project (EAP) who, in their September 2014 Achieving CRPD Compliance report<sup>23</sup> and in their June 2016 Three Jurisdictions report<sup>24</sup> had also identified that the MCA was non-compliant with the CRPD.

The EAP is a collaborative, interdisciplinary research and public policy initiative based at the University of Essex in the School of Philosophy and Art History. These EAP reports found that the MCA provides for best interests decision making, so was non-compliant with the UNCRPD but it was remedial. The EAP has been internationally recognised for its work and plays a key role in educating policy makers around the world about the legal and ethical challenges associated with UNCRPD compliance. The EAP work was contentious in that it concluded that compliance with the UNCRPD did not require the abolition of substituted decision making.

## Scotland, United Kingdom

In Scotland, the *Adults with Incapacity Act (Scotland) 2000* (AWI Act) is the primary legislation that aims to safeguard the financial, property, health and welfare of adults over the age of 16 who lack capacity to make decisions regarding their finances, property, health or welfare. The AWI Act covers incapacity caused by stroke, mental illness, dementia, learning disability and acquired brain injury.

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<sup>22</sup> Cheshire West and Chester Council v P [2014] UKSC 19, [2014] MHLO 16

<sup>23</sup> Martin, W. Michalowski, S. Jutten, T. Burch, M. 2014 *Achieving CRPD Compliance*, Essex Autonomy Project

<sup>24</sup> Martin, W. Michalowski, S. Stavert, J. Ward, A. Ruck Keene, A. Caughey, C. Hempsey, A. & McGregor, R. 2016, *Three Jurisdictions Report: Towards Compliance with CRPD Art. 12 in Capacity/Incapacity Legislation across the UK*. Essex Autonomy Project

Other related legislation relevant to adults with a decision making disability are the *Mental Health (Care and Treatment) (Scotland) Act 2003*, the *Adult Support and Protection (Scotland) Act 2007*, the *Social Care (SDS) (Scotland) Act 2013*, the *Carers (Scotland) Act 2018* and the *Social Security (Scotland) Bill*.

Interestingly, while the MCA in England provides for best-interests decision making on behalf of a person lacking in decision-making capacity, the AWI Act doesn't mention best interests.

At present guardianship hearings are held in the Sheriff Courts in Scotland at the court closest to where the adult lives.

The AWI has embedded principles into its act similar to the MCA in England.

**Principle 1 – benefit**

Any action or decisions taken must benefit the adult and only be taken when that benefit cannot reasonably be achieved without it.

**Principle 2 – least restrictive option**

Any action or decision taken should be the minimum necessary to achieve the purpose. It should be the option that restricts the person's freedom as little as possible.

**Principle 3 – take account of the wishes of the adult**

In deciding if an action or decision is to be made, and what that should be, account shall be taken of the present and past wishes and feelings of the adult as far as they can be ascertained. The adult should be offered appropriate assistance to communicate his or her views.

**Principle 4 – consultation with relevant others**

In deciding if an action or decision is to be made, and what that should be, account shall be taken of the views of the nearest relative and the primary carer of the adult, the adult's named person, any guardian or attorney with powers relating to the proposed intervention, and any person whom the Sheriff has directed should be consulted, in so far as it is reasonable and practicable to do so.

**Principle 5 – encouraging the adult**

Any guardian, attorney, or manager of an establishment exercising functions under this Act shall in so far as it is reasonable and practicable to do so, encourage the adult to exercise whatever skills he or she has concerning property, financial affairs or personal welfare as the case may be and to develop new such skills.

When I visited Scotland I became aware that the AWI Act is currently under review and active consideration is now underway for major changes to the legislation. The Scottish Government is proposing reforms to the AWI Act to modernise the guardianship application process (there are currently major delays in processing an increasing demand for applications for adult guardianship orders), in response to implications from the judgement in the 2014 Cheshire West case (deprivation of liberty issues) and a need to align the AWI with the principles of the CRPD.

The Scottish Government, after receiving a report from the Scottish Law Commission 'Adults with Incapacity' in 2016, consulted widely with interested stakeholders seeking their views on what changes to the AWI should be made.

There were a number of proposed changes but the main areas were:

- enhanced principles within the legislation to reflect the need for an adult to have support for the exercise of legal capacity;
- the use of powers of attorney and advance health directives;
- an extension of the range of professionals who can assess capacity;
- a move to a form of graded guardianship;
- consideration of a change of jurisdiction for AWI cases from the Sheriff Courts to a Mental Health Tribunal;
- creation of a short term /emergency placement order that can be used at short notice; and
- consideration of changes needed to implement the UNCRPD.

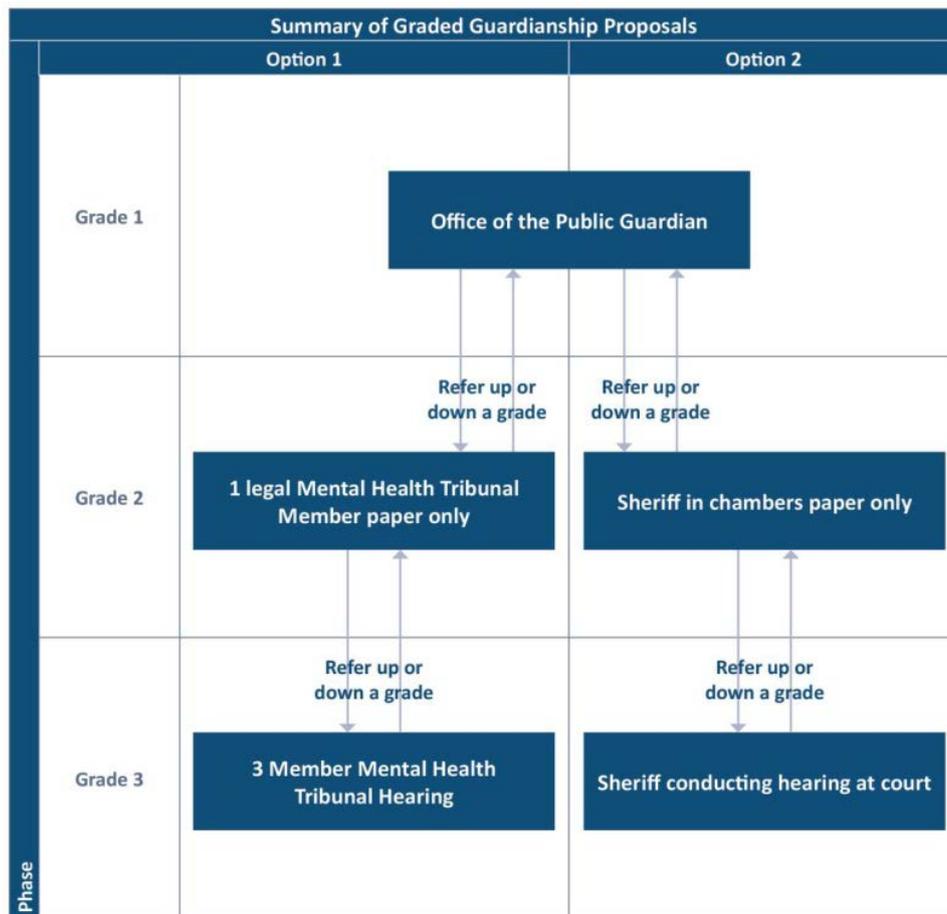
In speaking to the current Public Guardian and her predecessor while in Edinburgh I was informed that the proposal to introduce 'Graded Guardianship' covering financial and welfare matter was first proposed in 2011. The aim is to streamline the application process, alleviate court pressure, and reduce costs to Government by moving up the three grades, depending on the complexity of the matter.

The three proposed guardianship grades are:

**Level 1:** the simplest, application is to the Office of the Public Guardian who will have limited prescribed powers set by regulations for welfare matters and routine financial affairs (perhaps managing a state pension);

**Level 2:** an administrative application to the Sheriff in chambers, without a hearing, for more complex welfare and financial matters (perhaps sale of a house); and

**Level 3:** an application with a hearing at a Mental Health Tribunal due to disagreement between the parties including the adult, about the application.



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Not everyone was fully supportive of the proposal to introduce graded guardianship. The Law Society of Scotland did not oppose the general proposition of graded guardianship but had real concerns about granting guardianship by administrative means. It felt strongly that OPG did not have the requisite expertise and that an administrative process was non-compliant with the EU Convention that the appointment of a guardian was such a significant matter that it warranted a judicial process.

The AWI Act Scotland introduced compulsory registration for powers of attorney documents.

There are three types of Power of Attorney:

1. A Continuing Power of Attorney gives power to deal with financial and property matters for immediate use;
2. A Welfare Power of Attorney gives power to deal with health and welfare matters; and
3. Combined Power of Attorney gives power to deal with financial and welfare powers.

While not law to register the documents, for a document to be activated it must be registered with the Office of the Public Guardian (OPG). The OPG provides a simple online registration process. A solicitor or medical practitioner is required to assess the capacity of the person to ensure they fully understand what they are doing. If they are satisfied with this, they complete and sign a prescribed certificate that is required as part of registration.

<sup>25</sup> Scottish Government 2018, *Adults with Incapacity (Scotland) Act 2000, Proposals for Reform*

The OPG investigates if it receives a complaint of misuse. While there, the Public Guardian stated they were keenly watching and awaiting the results of the trial by the OPG in England looking at mediation services (outsourced to a panel of solicitors) as a way to possibly resolve family disputes to avoid court action. During my visit a leading barrister commented that the lack of mediation services was a major gap in Scotland.

I did not come across any campaigns specific to elder financial abuse per se while in Scotland. I was however very impressed by a campaign '*My Power of Attorney*' created to promote the benefits of powers of attorney. The campaign was a collaboration between the NHS Greater Glasgow, a number of local councils and local law firms wanting to "start the conversation" with loved ones about the benefits of power of attorney arrangements.

The campaign has run for four years with ads on TV, radio, newspapers, subway billboards and social media. The campaign had the support of the OPG who mentioned power of attorney applications had increased more than 50%.

One way of attempting to make the AWI Act more UNCRPD compliant was a proposal to appoint an 'official supporter'. Their role is not to make decisions on behalf of a person with a decision making disability but to support the person to better understand particular situations. It was yet to be determined how this informal supporter would be appointed. One way being examined was for a power of attorney to name the appointment of the informal supporter.

I have concerns about the potential for confusion with this official supporter role. I am not sure how it will be distinct from other existing roles such as attorney, guardian or independent advocate. The *Mental Health (Care and Treatment) (Scotland) Act 2003* Section 259 already gives any person with a learning disability or mental disorder the right to access independent advocacy. Independent advocates do not make decisions for someone. The advocate role is a safeguard for vulnerable persons, giving them a stronger voice by enabling them to express their own needs and make their own decisions.

The provision of independent advocacy services is not means tested. Although I did hear when in Scotland that given the growing demand for advocacy services it is being considered, as the lack of available advocates means too often advocates are brought in at crisis situations, rather than earlier on when they can be far more effective.

I also have concerns as to where informal supporters will come from. In my experience there are many vulnerable people who have no family member willing or able to support them - will informal supporters be individuals who volunteer, will they be organisations or will they be both, will they be able to charge fees for their services, will there be formal training or accreditation required and who will be responsible for monitoring them?

Even if all the proposed reforms make it into legislation, the Government still intends to allow for guardianship orders for those persons who, despite being given full support, are incapable of making their own decisions.

In parallel to pursuing these reforms the Scottish Government has commissioned work on a Supported Decision Making Strategy. This is because it was felt giving effect to the UNCRPD has wider implications across Government than simply reform of the AWI Act.

When in Scotland I came across an excellent Good Practice Guide on Supported Decision Making, available from the Mental Welfare Commission for Scotland. The guide was produced for the Commission by Jill Stavert, Professor of Law at Napier University. It is a very good practice guide, written for both facilitators and professionals, which outlined many case studies showing how supported decision making could work.

## **Review by United Nations of United Kingdom Compliance with the UNCRPD**

In 2009 the United Kingdom (UK) Government ratified the UNCRPD.

In 2010 the 28 Member States of the European Union (EU) ratified the UNCRPD.

The United Nations established a CRPD Committee based in Geneva which meets twice a year. The Committee is responsible for reviewing and commenting on the progress of state parties who are signatories to the UNCRPD. Article 35.2 requires States Parties to submit subsequent reports at least every four years and further whenever the Committee so requests.

The most recent review by the UNCRPD Committee of the UK began in March 2017.

In August 2017, the UNCRPD Committee published its latest report known as the 'Concluding Observations' after reviewing the UK's compliance with the UNCRPD. Reviews by the UNCRPD Committee take place about every four years. The UK Government had argued it had a proud history of being a world leader in furthering the rights of people with disabilities. The UNCRPD Committee acknowledged some progress has been made but found the UK failed to ensure the UNCRPD was reflected in laws and policies.

Their report was damning of the UK's inconsistent record on disability reform. The report made 80 recommendations for action by the UK Government and the devolved governments of Wales, Scotland and Northern Ireland.

*"The Committee expects the State Party to – without hesitation – develop and decide upon a concrete strategy ... to fully acknowledge and implement the Convention ... Hereby I send you home with your homework."*

**Stig Langvad**

Independent Expert Member and Rapporteur - UK UNCRPD Committee

In relation to the UK's compliance with Article 12 of the UNCRPD, it expressed deep concern over the prevalence of substituted decision making arrangements and the lack of recognition of the right to individualised supported decision making arrangements.

That UN Committee recommended the UK Government take immediate action to:

- **abolish ‘substituted decision-making’** where decisions are made for disabled people, by reforming mental capacity and mental health laws and policies; and
- **improve ‘supported decision making’** by developing ways of supporting disabled people to make their own decisions, for example, through research and sharing good practice.

The next progress report by the UK Government to the UNCRPD Committee is due in July 2023. The report will provide information on the progress of implementing the 80 recommendations.

## British Columbia, Canada

Canada was a pioneer in putting in place law reforms to enable supported decision making. British Columbia (BC) is internationally recognised for its leadership in enacting legislation in this field. The push for change came in the early 1990s through the concerted efforts by disability groups seeking equal legal rights and greater autonomy for people with disabilities. The first articulated principles of supported decision making were written by the Canadian Association for Community Living Taskforce in their report on Alternatives to Guardianship in August 1992<sup>26</sup>.

The changes owe their existence to the parents of children with disabilities and powerful advocacy by a coalition of community organisations who sought legal recognition for existing family helpers who daily provide crucial support to persons with disabilities. New legislation introduced in BC was an attempt to formalise these existing informal decision making arrangements. The aim was to achieve reform enabling self-determination. There is no question that BC’s disability advocates were pivotal in the campaign for the development of proxy-style representation agreements in the 1990s.

The disability community sought an empowering, normalising tool that would enable adults with challenges to make their own decisions to the greatest extent possible<sup>27</sup>.

After seven years of rancorous debate, legislation was proclaimed in February 2000. The intent was to modernise the laws applying to adult guardianship.

There are four inter-related pieces of legislation:

1. *Representation Agreement Act 1996 (RA Act);*
2. *Adult Guardianship Act 1996 (AG Act);*
3. *Public Guardian and Trustee Act 1996; and*
4. *Health Care (Consent) and Care Facility (Admission) Act 1996 (HCCF Act).*

<sup>26</sup> Arstein-Kerslake, A, Watson, J, Browning, M, Martinis, J, & Blanck P 2017, ‘Future Directions in Supported Decision Making’, *Disability Studies Quarterly* vol 37, no. 1

<sup>27</sup> Allan, M, & Watts, L, Canadian Centre for Elder Law, 2006, *A Comparative Analysis of Adult Guardianship Laws in BC, New Zealand and Ontario*, CCEL Report no. 4

Cunningham noted that since 2000, further amendments have been made, and more legislation, or parts of proposed legislation have been implemented<sup>28</sup>. They include:

- Financial decision making provisions under the non-standard provisions are found in a new *Power of Attorney Act* (POAA). The RA Act is limited to s.7 representation agreements and representation agreements with non-standard provisions dealing with personal and health care decisions.
- Safeguards in the RA Act have been modified, including that two adults, who meet the criteria of the RA Act, may be witnesses. A single witness is only required if the witness is a BC Lawyer or Notary Public. The rules governing when a monitor is required were amended.
- The HCCF Act was amended to recognise Advance Directives for health care; and
- Much of Part 2.1 of the AG Act dealing with statutory guardianship is in force. The statute provides for the assessment of an adult's ability to make financial decisions. After a thorough assessment process, with a focus on the functional assessment and the adult's need for assistance to manage his or her financial affairs, if there are no other options, including the possibility of appointing a family member or friend under a s.7 representation agreement, a certificate of incapability is issued and the Public Guardian and Trustee becomes the adult's guardian of financial affairs.
- All statutes expressly acknowledge the duty of the attorney, representative, temporary substitute decision maker, and guardian (Committee under the *Patients Property Act*) to foster the independence of the adult.

The RA Act was one of the first social experiments in the world to enable supported decision making so is the focus in this report. The RA Act was created to provide an alternative to adult guardianship. A key strength of representation agreements is they are not disability specific. The RA Act allows an adult to appoint a substitute or supported decision makers. The supported decision maker is called a representative.

The RA Act (amended September 2011) provides for two types of representation agreements:

- Representation Agreement Section 7 (RA7) deals with routine financial matters and legal affairs, and
- Representation Agreement Section 9 (RA9) deals with issues of health and personal care matters.

The RA Act, from speaking to key people in BC, is still highly contentious because a representation agreement does not require approval of a Court and challenged the accepted legal doctrines in relation to the mental capacity of a person to make decisions. The RA Act set out a lower threshold of capacity for a person to make representation agreements than the traditional accepted capacity requirements to create other advance planning tools such as enduring powers of attorney.

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<sup>28</sup> 5<sup>th</sup> World Congress on Adult Guardianship (October 23-26 2018) Seoul Korea, *New Developments in Supported Decision Making Systems, An update from Canada*, Kathleen Cunningham, Executive Director, British Columbia Law Institute and Canadian Centre for Elder Law

Section 8 of the RA Act sets out the test for incapacity for standard provisions:

- (1) An adult may make a representation agreement consisting of one or more of the standard provisions authorized by section 7 even though the adult is incapable of
  - (a) making a contract,
  - (b) managing his or her health care, personal care or legal matters, or
  - (c) the routine management of his or her financial affairs.
- (2) In deciding whether an adult is incapable of making a representation agreement consisting of one or more of the standard provisions authorized by section 7, or of changing or revoking any of those provisions, all relevant factors must be considered, for example:
  - (a) whether the adult communicates a desire to have a representative make, help make, or stop making decisions;
  - (b) whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;
  - (c) whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult;
  - (d) whether the adult has a relationship with the representative that is characterized by trust.

Lawyers in BC were concerned that the dilution of the capacity test would mean representation agreements were open to abuse and exploitation. To address these concerns the RA Act had a number of safeguards put in the legislation. The primary form of oversight is a 'monitor'. If finances are included in an agreement, the adult must in certain circumstances appoint and name a monitor. The monitor's role is to ensure the representative acts honestly and in good faith.

*Section 12(1) of the RA Act states:*

*"If the agreement gives authority over financial affairs and only appoints one person as representative, there must be a monitor unless the representative is the spouse, Public Guardian and Trustee or a corporate trustee."*

If the monitor believes the representative is not acting appropriately, the monitor may ask the representative to produce documents justifying their actions. If, after review, the monitor is not satisfied, the monitor must inform the Public Guardian and Trustee, who will investigate the issues. Although research suggests there appears a lack of clarity of the day-to-day role of a monitor they are considered a positive measure overall.

Another important safeguard is in the formal requirements of making the representation agreement. Certificates are required and must be signed by the representative, the witnesses, and monitor if applicable. These certificates outline duties and responsibilities of the parties. In 2010, the Nidus Personal Planning Resource Centre and Registry (Nidus) published findings from a study of 989 Representation Agreements. Nidus is a non-profit, charitable organisation based in BC.

Those I spoke to stated Nidus is a terrific organisation who played a significant role in the grass roots drive for reform of adult guardianship legislation. Their report provided valuable data on representation agreements such as, who were being chosen to be representatives often showing two supporters were named and on the use of monitors.

Interestingly the creation of an online register for representation agreements was envisaged in the drafting of the RA Act. The idea was abandoned by Government on the basis of the cost to administer the register and concern over liability obligations. It was like a lot of other things that went by the wayside in the name of political expediency. Compromise had to be made to move from an ideal position to a real one. Nidus stepped in to fill this gap.

In 2002 Nidus launched a voluntary online register for personal planning documents including representation agreements, enduring powers of attorney and advance directives. The registry has many benefits; the person on registration can grant access to third parties such as their representative, health authorities and financial institutions.

Reform in Canada towards supported decision making principles of greater autonomy and self-determination continues to evolve. Since the RA Act became law in BC, other provinces such as Alberta, Saskatchewan, and the Yukon have adopted their own forms of supported decision making.

In March 2017, the Law Commission of Ontario (LCO) released its report on *Legal Capacity, Decision-making and Guardianship*. The report noted that existing legal frameworks for adult guardianship were sound but made 58 recommendations to strengthen Ontario's laws and policies regarding powers of attorney, guardianship and health care consent.

The proposed reforms acknowledged the importance of increasing self-determination noting the potential benefits of supported decision making approaches for some people, but still felt there were situations that required substituted decision making arrangements.

One of LCO's main recommendations in relation to supported decision making was to enable a person to enter into 'support authorisations' for day-to-day routine property and personal care decision making needs.

The LCO did not favour the representation agreement approach adopted in BC. Instead it preferred the Alberta approach of support authorisations as a more promising model for overall reform to decision making approaches. Again the threshold for capacity is lower than for other formal advance planning tools. To enter into these authorisations the person is only required to understand and appreciate the nature of the agreement. The LCO saw the availability of this decision making arrangement as an appealing, less restrictive alternative to formal adult guardianship.

The LCO stated that support authorisations are not an appropriate arrangement for persons with significant property assets or for persons with significant cognitive impairments to their decision making capabilities.

To safeguard against abuse and exploitation, the LCO felt with support authorisations there should be clear duties and responsibilities outlined for supporters. The LCO also held the view

the appointment of a monitor should be mandatory and not be, a family member or a person with any conflict of interest. The LCO called for ongoing pilots and evaluation of these new innovative models or approaches.

I was also interested in their recommendation to establish a dedicated panel for professional substituted decision makers. The LCO acknowledged the critical role the Public Guardian and Trustee play in the protection of persons with decision making disabilities where there are no family members able to act but noted growing workload pressures. In these circumstances it favoured the traditional approach of the appointments of substitute decision makers. This is an interesting development that would require a high degree of regulation and supervision.

Interestingly the much celebrated RA Act enabling supported decision making does not comply with the obligations of the UNCRPD because it preserves substituted decision making. Today the RA Act remains a contentious piece of legislation, criticised for its drafting and resisted by many in the legal profession, primarily due to its largely undefined capacity threshold.

For those reasons, together with the high cost, most people find the process of creating a representation agreement confusing, complex and require a lawyer to draft their agreement, which explain what seems to be a very low take-up of representation agreements. Another reason cited was the lack of Government-funded community education programs on the benefits of the RA Act.

## Conclusions

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Elder abuse is a very real social issue, it is inexcusable and unconscionable. In recent years there has been a clarion call for action. Elder abuse is deservedly receiving increased attention at Commonwealth, State, and international level. In Australia we have seen the establishment of a new national peak body Elder Abuse Action Australia, and a recent announcement by the Commonwealth Government for a Royal Commission into Aged Care Quality and Safety.

The Royal Commission comes after a series of reviews by the Commonwealth and State governments that revealed a string of disturbing revelations of abuse, and some 12 months on from shocking revelations of abuse at the Oakden Nursing Home in South Australia. I am confident the Royal Commission will build on the earlier work by the ALRC who in their report *Elder abuse - A National Legal Response* made 14 recommendations about improving aged care in residential and home settings.

My journey did reaffirm that in order to combat elder abuse there needs to be far more than a legal response. It requires a shift in culturally negative attitudes in Australia to respecting the elderly. I am at a loss to explain why ageing has somehow become a shameful experience. It is time for society to stop idolising and valuing youth or at least restore balance. Australia needs to be like Japan, China and Korea where ageing is rooted in the Confucian principle of filial piety - a traditional value that demands respect and care for parents. I appreciate filial piety may be beginning to wane in modern times but feel the culture of these countries has a lot to offer Australia.

Japan is a super ageing society. Its population is ageing at a rate unprecedented in the world. Well over 20 per cent of its population is 65 years or older. Japan recognised this emerging societal issue decades ago and has set about implementing a number of critical public policies to address the crisis. Japan's experience should provide lessons for Australia. In Japanese culture the elderly are highly respected and even celebrated. Culturally showing dignity is essential when addressing an elder in Japan. Japan even has a national paid holiday 'Respect for the Aged Day' to show appreciation to the elderly in their community.

Law reform is critical but so too is a need to drive cultural change to address other factors such as social isolation and ageism as part of important responses to combat elder abuse. Ageism interferes with happy and healthy ageing. Research, such as the work undertaken by the Benevolent Society in 2017 on the drivers of ageism<sup>29</sup>, demonstrates the highest priority areas to address ageist attitudes are in the workplace, health care, aged care and in families and local communities.

The UNCRPD started a revolution. There is an unstoppable momentum building for reform to guardianship laws in Australia and all around the world. Countries, such as Australia, who ratified the treaty are under a legal obligation to honour the requirement to implement supported decision making. Supported decision making arrangements are a less restrictive alternative to adult guardianship and trusteeship; are important in promoting the exercise of

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<sup>29</sup> The Benevolent Society, 2017, *The Drivers of Ageism Summary Report*

free will; would be a more human rights response to elder financial abuse; and should be available in Australia.

Social research shows the supported decision making approach works best in circumstances when a person with a decision making disability has a learning disability or intellectual disability. It appears far less certain for those persons with major mental health challenges, profound cognitive impairment or traumatic brain injuries. It is for that reason substituted decision making arrangements will remain a legitimate option until greater evidence is identified on how to best support and understand a person's will and preferences if they have these type of profound decision making disabilities.

I remain unconvinced that the intractable dogmatic position taken by the UNCRPD Committee, who seek to have all forms of substituted decision making abolished, has been useful or indeed helpful. It has no basis in a real world context. Sadly the fact remains that not every person is capable of making their own decisions or safeguarding their interests no matter how much support is provided.

I fear the hard-line position is counter intuitive. While research and small scale trials and pilot programs have taken place both here in Australia and overseas, including the pioneering work in Canada, much remains to be done. Work is well underway to work out the best way to incorporate supported decision making into guardianship laws in Australia. There is a danger of moving too quickly, attempting to pursue major policy and law reform without sound evidence lighting the way forward.

No Government anywhere in the world has infinite resources. Although not every person needs the same level of support, it is clear there is a substantial cost in providing all necessary resources and support to determine a person's will and preferences. I suspect major barriers such as the very high costs associated with the implementation of the supported decision making model and an inability to readily identify a trustworthy circle of supporters or representatives (and possible monitors), willing and able to support persons with decision making disabilities, explains the glacial progress. For example, in Sweden the greatest barrier to their much-hailed alternative to guardianship - the Legal Mentor Model (also known as the God Man model) - has been a lack of available mentors (family members, close friends, social workers, and lawyers) to meet the demand.

Even if supporters and monitors can be identified, a very real barrier may still be the significant investment both in time and resources needed in building the capacity of those supporters to accurately interpret the will and preferences of those they offer support. I also have concerns that unless underpinned by strong family bonds, the initial enthusiasm of volunteer supporters will wane in time and it will fall back to Government to intervene.

I was interested on my journey to see if, in the jurisdictions visited, particular attention had been paid to the experiences of indigenous communities and migrant population groups to determine how well the new supported decision making approach was working, any risks experienced, and if solutions had been developed to mitigate those risks. I am afraid the jury is still out. There has been some very good work done in raising awareness about the dangers of elder abuse, but the move to introduce and use more supported decision making in the

countries visited to those particular communities is in its early stages. There will need to be more research into this particular area.

The shift to supported decision making arrangements across the world remains in a state of flux. Apart from attempts in Victoria, the rest of Australia has been very slow to legislate, compared to other countries such as Canada and Sweden. Decision making is a central aspect of people's lives. Most people require some level of practical support with their decision making. For the moment, substituted decision making will need to remain and co-exist with the still ill-defined practice of supported decision making, both available on a continuum of decision making options, depending on the nature and extent of the person's decision making disability.

I did not witness evidence to suggest an expectation that supported decision making will lead directly to a reduction in elder financial abuse. Sadly there will always be people in society who commit despicable deeds and abuse a position of trust. There is also a need to exercise caution. What may begin as a trusted supported decision making relationship may easily slip back into substituted decision making through a gradual lapse to paternalistic and controlling behaviour and possibly forms of elder abuse.

There is a need to be careful that supported decision making is not merely symbolic and not a case of 'a rose by any other name would smell as sweet'.

## Recommendations

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- 1 Need for capacity building in the general community through greater education, by early intervention, and promoting positive family relationships as the most effective means to support a person with a decision making disability.
- 2 Need for funding to promote awareness in the community of the benefits of advance planning tools such as Enduring Powers of Attorney, Enduring Powers of Guardianship and Advance Health Directives.
- 3 Need for funding for more empirical research and, in particular, for larger scale, longer term pilot programs into how supported decision making can be applied to benefit persons with a decision making disability, including for those with profound cognitive disabilities.
  - i. That the pilot programs are rigorously evaluated for their effectiveness, in particular for persons with profound cognitive disabilities.
  - ii. That toolkits and best practice guides (that are culturally sensitive) on supported decision making be developed and made available to people with decision making disabilities, their families and professionals (health care workers, social service workers, aged care workers, community case workers, police and lawyers).
  - iii. That community based organisations are engaged to play a key role in educating professionals on supported decision making.
  - iv. That further research into how well a supported decision making approach may work, and if any additional risks would be experienced in CALD and Aboriginal and Torres Strait Islander communities.
- 4 Need for the National Plan on Elder Abuse to include a specific strategy on how to address ageism as a major contributing factor to elder financial abuse.
- 5 Further research to understand how to raise awareness and deal with elder abuse in CALD and Aboriginal and Torres Strait Islander communities.
- 6 That, as an alternative to formal Court proceedings, mediation services (culturally sensitive) be introduced - similar to that currently used in family law - and made available to families to resolve disputes involving elder abuse, including in CALD and Aboriginal and Torres Strait Islander People communities.
- 7 Need for training (possibly online) to be provided for those discharging duties under a Power of Attorney, similar to that provided for private administrators.

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