Office of the Public Advocate Systems Advocacy

A journey towards autonomy? Supported decision-making in theory and practice

A review of literature

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Introduction

Overview

The Office of the Public Advocate is examining the provision of decision-making support to adults with impaired decision-making capacity who interact with the Queensland guardianship system. More specifically, the Office is undertaking research to identify the systemic barriers and enablers in relation to protecting and supporting the right of a person to make their own decisions.

A suite of four documents form the foundation of the research: the conceptual framework, a literature review (this document), a synopsis of the legislation underpinning Queensland's guardianship system, and a targeted overview of guardianship legislation in other Australian jurisdictions. Together, these documents will inform the subsequent phases of the research.

This literature review explores recent debate in relation to current guardianship systems, in particular the degree to which contemporary guardianship recognises and protects the autonomy and self-determination of people with disability. As supported decision-making is central to many of these discussions, the literature review also explores the current ways in which supported decisionmaking is conceptualised and put into practice in Australia and selected overseas jurisdictions.

The first part of this review briefly explores the origin of guardianship in common law jurisdictions, culminating in the modern day legislative regimes in countries such as Australia and Canada. This is the backdrop against which the current call for further reforms is occurring. Contemporary appraisals of guardianship and substitute decision-making in light of the coming into force of the Convention on the Rights of Persons with Disabilities and implementation of the National Disability Insurance Scheme are also discussed.

The second part of this review examines supported decision-making as a concept and how it has been implemented to date with a focus on legislative frameworks in Canada and Europe. Current commentary and critique is presented in relation to the concept of supported decision-making and whether Australia's guardianship laws should be further reformed to incorporate this new model.

The terms used in this document should be considered as broadly inclusive, as opposed to limiting, with respect to their applicability. For example, references to people with intellectual disability or cognitive impairment are intended to include those whose cognition is impaired as a result of a broad range of conditions including but not limited to dementia, intellectual disability, acquired brain injury, mental illness or substance misuse. Further, the reference to 'people with disability' is often used in literature as an all-inclusive term. It should be noted that throughout this document, terms are generally used in a manner that aligns to the source being referenced.

Background

While it is recognised that we all, to some extent, seek support or assistance from others to make decisions, people with intellectual disability or cognitive impairment may require more assistance to make and communicate decisions about a variety of matters in their lives. In contemporary times, the legal response to this issue has focussed on substitute decision-making, which most often takes the form of guardianship and administration.

The development of guardianship laws in English law since the thirteenth century has traditionally focused on property or financial management. In recent times, and with the legislative reforms in most western countries, guardianship has expanded to cover both financial and personal matters. While guardianship has a long history of paternalistic decision-making, recently there has been a greater focus on maximising the autonomy of those subject to guardianship. Guardianship orders are now more likely to be limited to certain matters (rather than plenary appointments), and guardianship laws impose obligations on the relevant substitute decision-maker to ascertain the wishes and preferences of the person subject to guardianship to varying extents.

Corresponding with the growth of the disability rights movement and the coming into force of the United Nations Convention on the Rights of Persons with Disabilities, the concept of guardianship has been called further into question. Alternative models to substitute decision-making have emerged internationally. Collectively, these models are described as supported decision-making.

The concept of supported decision-making is central to many of the current discussions regarding the reform of guardianship legislation in Australia and internationally. 1 It covers a wide spectrum of decision-making models from informal support involving natural support networks to formally appointed co-decision-makers and representatives. Commonly, these models are united by a move away from an absolutist concept of capacity that deems a person to either be competent to make decisions or not. Supported decision-making recognises that many people with intellectual disability or cognitive impairment can make their own decisions with support and assistance. This may involve support and assistance to find and process the information needed to make the decision, express their will and preferences, and/or communicate their decision. Without such assistance, the same people may be deemed to have impaired decision-making capacity, particularly when applying traditional tests of capacity.

A number of Canadian provinces have been at the forefront of advocating for and implementing supported decision-making models, building on earlier developments in Scandinavian countries. These models have grown out of the same movement that advocated for community living for people with intellectual disability and the civil rights of people with disability. In Australia, it also currently forms part of the suite of reforms associated with individual funding and person-centred planning.

Much has been written about the normative aspects of this concept, in particular the benefits of supported decision-making and its alignment with the principles underpinning the Convention on the Rights of Persons with Disabilities. However as a relatively new model, there is still little known about how supported decision-making processes work, and what works well in practice.³

Many commentators have therefore suggested a cautious approach and that further empirical research is undertaken about how supported decision-making does and should work. Concerns about expanding the reach of the current guardianship system and creating another system of substitute decision-making, or a de facto guardianship system have been expressed in relation to Australia formalising or legislating supported decision-making practices without proper consideration.

Guardianship

Origins of guardianship and parens patriae jurisdiction

In medieval England, the Lord of the Manor had responsibility for the property and person of people with disability. Around the thirteenth century, this role transferred to the crown, coinciding with the consolidation of power in the king, the enactment of the De Praerogativa Regis, which was seen as declaratory of the common law, and the development of the monarch as pater patriae, or 'father over his children'. The monarch had both custody of persons with disability and responsibility for maintaining the person, their household and dependents out of the income from their lands.

¹ For example, Victorian Law Reform Commission, Guardianship: Final Report 24, Report No 24 (2012).

² Robert M Gordon, 'The Emergence of Assisted (Supported) Decision-Making in the Canadian Law of Adult Guardianship and Substitute Decision-Making' (2000) 31(1) International Journal of Law and Psychiatry 61, 63.

³ Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, 'Supported Decision-Making: A Viable Alternative to Guardianship?' (2013) 117 Penn State Law Review 1111, 1112.

⁴N O'Neil and C Peisah, Capacity and the Law (Sydney Law Book Company, 2011); J Seymour, 'Parens Patriae and Wardship Powers: Their Nature and Origins' (1994) 14(2) Oxford Journal of Legal Studies 159, 167.

Gradually this responsibility moved from the monarch to the Courts of Equity (Chancery), who developed arrangements enabling the court to appoint a guardian with a focus on managing the person's property and personal interests. The jurisdiction was very broad and the powers plenary (all pervasive). Upon settlement, the jurisdiction was eventually given to the superior courts of colonies, which in Australia meant the state Supreme Courts.

While the 'wardship of children' had quite a separate origin arising out of feudal system of tenures,⁷ it became substantially and procedurally assimilated with the parens patriae jurisdiction and as it came to make up the bulk of the court's work in this jurisdiction it constituted "a solid guide to the exercise of the parens patriae power even in the case of adults". 8

Ultimately therefore the parens patriae jurisdiction not only included those with impaired decisionmaking capacity (due to mental illness or disability), but also included children and was exercised generally "for the benefit of such who were incapable of protecting themselves". 9 The courts developed principles, such as acting in a person's best interests, for exercising this broad jurisdiction, which in relation to infants it is acknowledged "was the embodiment of a benevolent urge to protect children's welfare", 10 and also eventually coincided with a more interventionist role of both the state and the courts throughout the nineteenth century in respect of the welfare of children. 11

While the early exercise of the jurisdiction in relation to those with impaired decision-making capacity was focused on protecting the property of the person, and maintaining his or her dependents, the jurisdiction gradually moved beyond property management and financial issues.

The twentieth century

When a medical model of disability predominated and many people with disability were institutionalised throughout the twentieth century, all decisions were made for them by the medical staff of institutions, with the exception of financial management which was often carried out by state agencies such as the public trustee. 12 As people with disability began to move out of institutions from the 1970s onwards, there were new demands, including the need to negotiate access to a complex system of social services. The "need was increasingly for brokers to negotiate access, advocates to demand services, and agents to provide legal approvals for decisions". 13 There was also a need for accessible mechanisms for legally binding decisions to be made for people with impaired decisionmaking capacity for issues such as accommodation, health care and finances, because in the absence of a legally appointed substitute decision-maker, decisions made by informal decision-makers could not be legally recognised.¹⁴

These changes coincided with a growing disability rights movement and the recognition of people with disability as citizens with rights. As a result, the later part of the twentieth century saw significant reforms with guardianship legislation being enacted in each state and territory throughout the 1980s and 1990s.

⁵ T Carney and D Tait, The Adult Guardianship Experiment: Tribunals and Popular Justice (Federation Press, 1997) 10; Shih-Ning Then, 'Evolution and Innovation in Guardianship Laws: Assisted Decision-Making' (2013) 35 Sydney Law Review 133, 136.

⁶T Carney and D Tait, above n 5, 16; Shih-Ning Then, above n 5, 139.

⁷ Re Eve [1986] 2 SCR 388, [34] (Forest J).

⁹ *Butler v Freeman* (1756) 27 ER 204; Amb 301, [302] (Lord Hardwicke LC) in J Seymour, above n 4, 168.

¹⁰ J Seymour, above n 4, 167.

¹¹ Ibid 159, 177.

¹² T Carney and D Tait, above n 5 15.

¹³ Ibid 18.

¹⁴ Shih-Ning Then, above n 5, 138.

While the parens patriae jurisdiction of the superior courts has been preserved in the state Supreme Courts, there is now legislation in each state and territory that makes it easier and more accessible to appoint a guardian for adults with impaired decision-making capacity. Prior to this legislation, the appointment of guardians was costly and time-consuming and therefore rarely accessed unless a person had substantial property to be managed. Further, appointing a substitute decision-maker meant completely depriving a person of the ability to make any decisions, as guardians were usually given plenary powers, that is the power to make all decisions for the person.¹⁵

In contrast, since recent legislative reforms (in countries such as Canada and Australia), a tribunal (or sometimes a lower court) is typically empowered to appoint a guardian or other substitute decisionmaker. As a result, the procedures are less formal and the jurisdiction more accessible. Plenary appointments are not made automatically, and there is a much greater emphasis on consulting with and seeking the views of the person subject to guardianship.

Principles of best interest and substituted judgement

Consistent with the common law jurisdiction, all guardians appointed under the relevant legislation in each jurisdiction have a responsibility to act in the best interests of the persons under their guardianship. Some, but not all jurisdictions, require guardians to attempt to determine what the person subject to guardianship would have done if they had the capacity to make the decision; this is known as the substituted judgement principle. Some jurisdictions also place an onus on the substitute decision-maker to ascertain, and sometimes put into effect, the will and preferences of the person subject to guardianship and/or involve them in making a decision.

The exact nature of how guardians exercise their functions in each jurisdiction differs according to the duties and responsibilities of guardians, and the principles that apply in respective legislation. Appendix One summarises the relevant provisions in some provinces of Canada that lend support to the maintenance of a person's decision-making autonomy and the use of informal supporting mechanisms to make decisions instead of substitute decision-making through guardianship.

In New South Wales, Western Australia and the Northern Territory, legislation provides an obligation for guardians and administrators to consult with and take into account the views of the person they are responsible for, however the paramount consideration is a responsibility to act in the best interests of the person, that is, in a protective capacity rather than in accordance with the person's wishes or expressed opinions. 16 In Victoria and Tasmania, guardians and administrators are obliged to give equal consideration to the best interests of the person, the wishes of the person and the least restrictive alternative; however subsequent provisions give additional weight to the requirement to act in a person's best interests. ¹⁷ In Queensland and the Australian Capital Territory, guardians are obliged to the greatest extent possible to act in a way that, in Queensland, encourages the person to make their own decisions and to take into account the views and wishes of those under guardianship, and in the Australian Capital Territory, to give effect to the person's wishes so far as they can be determined. 18 In South Australia, a substituted judgement obligation is applied so that the paramount consideration for a guardian must be what, in the opinion of the guardian, would be the wishes of a person if they were not 'mentally incapacitated'. 19

¹⁶ Guardianship Act 1987 (NSW); Guardianship and Administration Act 1990 (WA); Adult Guardianship Act 1988.

¹⁷ Guardianship and Administration Act 1986 (Vic); Guardianship and Administration Act 1995 (Tas).

¹⁸ Guardianship and Administration Act 2000 (Qld); Guardianship and Management of Property Act 1991 (ACT).

¹⁹ Guardianship and Administration Act 1993 (SA).

Critiques of guardianship and calls for further reform

Disability rights movement and deinstitutionalisation

It is recognised that the changing view from people with disability being seen as limited rightsbearers to people with the potential for full legal capacity has been a paradigm shift brought about by decades of activism by the disability community.²⁰

In the latter part of the twentieth century, coinciding with civil rights movements generally, there was a growing recognition and advocacy for the equal rights of people with disability as citizens. This movement was led by family members of people with disability and professionals as well as people with disability themselves. ²¹ There was a corresponding emphasis on the integration of people with disability into the community, underpinned by the principles of normalisation and social role valorisation, which in turn, had a profound effect on disability policy, programs and services.²²

The movement of people with intellectual disability from large-scale residential facilities to community-based living, known as deinstitutionalisation, also began in the 1960s and 1970s, 23 and is recognised as one of the most significant changes in human services to occur in the twentieth century.24

Principles and theories of normalisation

Scandinavian countries led the way in relation to the deinstitutionalisation of people with intellectual disability and were at the forefront of the 'normalisation' movement. Guardianship reforms in Australia and Canada reflected the developments in Scandinavian countries.²⁵

Normalisation emerged as a concept in Scandinavian countries in the 1960s²⁶ and was associated with assisting people with disability to lead as close to 'normal' lives as possible, including access to community living, education and employment. First conceived by Bank-Mikkelson, ²⁷ and later further developed by Nirje, ²⁸ normalisation was an expression of the ideological concept of inclusiveness. ²⁹

'Social role valorisation', developed by Wolfensberger, extended the concept of normalisation, by advocating that the highest goal of normalisation should be the creation, support and defence of valued social roles for those who have been, or are at risk of being, devalued, including those with disability.³⁰ The transition from institutions to community living for people with disability was consistent with both normalisation and social role valorisation.

²⁰ Kristin Booth Glen, 'Changing paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond' (2012) 44(1) Columbia Human Rights Law Review 93, 123.

IM R Feigan, the Victorian Office of the Public Advocate: A First History 1986-2007 (PHD thesis, School of Social Sciences, Latrobe University, 2011).

²² Lesley Chenoweth 'Closing the Doors: Insights and Reflections on Deinstitutionalisation' (2000) 17(2) Law in Context 77, 82. ²³ L Young, A Ashman and P Grevell, 'Closure of the Challinor Centre II: An Extended Report on 95 Individuals after 12 Months of

Community Living' (2001) 21(1) Journal of Intellectual and Developmental Disability 51, 52. ²⁴ Lesley Chenoweth above n 22, 80.

²⁵ Robert M Gordon, above n 2, 63.

²⁶ N E Bank-Mikkelsen, 'A Metropolitan Area in Denmark: Copenhagen in Implications' (1969) in R Kugel and W Wolfensberger (eds), Changing Patterns in Residential Services for the Mentally Retarded, Presidential Committee on Mental Retardation, Washington D.C., 227-

²⁸ B Nirie, 'The Normalisation Principle and its Human Management Implications' (1969) in R Kugel and W Wolfensberger (eds), Changing Patterns in Residential Services for the Mentally Retarded, Presidential Committee on Mental Retardation, Washington D.C., 227-254. ²⁹ J A Nottestadt, 'Deinstitutionalization and Mental Health Changes Among People with Mental Retardation' (Doctoral Thesis, Faculty of Medicine, Norwegian University of Science and Technology, 2004) 17.

³⁰ Wolfensberger, W. 2011, 'Social Role Valorisation: A Proposed New Term for the Principle of Normalization', Mental Retardation,

The concept of 'dignity of risk', which is used by advocates of supported decision-making, can be defined as "the placement of greater value on respecting the individual's right to decide, even when a person's choices may seem foolish to others, than on protecting the 'best interests' of the individual". ³¹ It can also be traced back to Wolfensberger's thesis of social role valorisation.

The recognition of the interdependency of human beings

It is often argued that supported decision-making simply recognises the way in which most adults function in their daily lives, drawing on the advice, opinions and skills of family, friends and colleagues as well as professionals and experts to inform individual decision-making when needed.³²

"In complex, postindustrial and postmodern societies there is a high level of dependency upon the skills, acumen, ability, and knowledge of others when a variety of decisions are to be made. Many individuals use accountants and investment brokers, some purchase the services of lawyers, others seek the counsel of members of the clergy. Most use the services of health care professionals, who will often assist with complex health care decision-making."33

Many people with disability similarly depend upon social networks of family members, friends and others to assist them to make decisions at different times and to varying degrees.³⁴ When the human condition is viewed as one of interdependency and vulnerability, this leads to a different understanding of independence and autonomy. 35 The concept of 'relational autonomy' recognises that while we value self-determination, the reality is that we are dependent on others to varying extents to achieve this independence.³⁶

Independence, particularly for people with disability, has often been defined in terms of self-care activities. It is generally equated with the ability to do things such as cooking, washing, dressing, toileting, making the bed, and writing and speaking without help or assistance.³⁷ People with disability, however, have redefined independence as the ability to obtain assistance when and how one requires it.³⁸

Many have argued that the notion of independent decision-making is also highly ethnocentric and reflective of a western idea of autonomy. 39 Cross-cultural researchers and theorists have described societies, particularly Asian, African and some European cultures where there is an interdependent approach to agency and decision-making and where it is the norm to make decisions collectively within the context of families and communities.⁴⁰

³¹ P A Hommel, 'The More Things Change: Principles and Practices of Reformed Guardianship' (1996) in M Smyer et al (eds), Older Adults Decision-Making and the Law (Springer Publishing, 1996) 182-201 in Robert M Gordon, above n 2, 63.

³² Terry Carney, 'Participation, Rights, Family-Decisionmaking and Service Access: A Role for Law?' (Legal Studies Research Paper No 12, Sydney University Law School, 2012) 18.

Robert M Gordon, above n 2, 65.

³⁴ Terry Carney, 'Participation and Service Access Rights for People with Intellectual Disability: A Role for Law?' (2013) 38(1) Journal of Intellectual and Developmental Disability, 59.

³⁵ Solveig Magnus Reindal, 'Independence, Dependence, Interdependence: Some Reflections on the Subject and Personal Autonomy' (1999) 14(3) Disability and Society 353.

C H Kennedy, 'Social Interaction Interventions for Youth with Severe Disabilities Should Emphasize Interdependence' (2001) 7(2) Mental Retardation and Developmental Disabilities Research Reviews 122 in J Watson, 'Supported Decision Making for People with Severe or Profound Intellectual Disability: We're All in This Together Aren't We?' (2011) Sixth Annual Roundtable on Intellectual Disability Policy, 42. Solveig Magnus Reindal, above n 35.

³⁸ P J Rock, 'Independence: What it Means to Six Disabled People Living in the Community' (1988) 3 Disability, Handicap and Society 27; Solveig Magnus Reindal, above n 35.

³⁹ H Markus and S Kitayama, 'Models of Agency: Sociocultural Diversity in the Construction of Action' (paper presented at the Nebraska Symposium on Motivation: Cross-Cultural Differences on the Self, Lincoln Nebraska, 2003) in J Watson, above n 36, 41. C H Kennedy, above n 36 in J Watson, above n 36, 42.

However, some have argued that care must be taken in relation to the concept of relational autonomy so that the wishes of the individual are not overridden by the needs of the community. There is therefore a delicate balance to be achieved between recognising and accepting the interdependency of people with disability or cognitive impairment in accessing support to make decisions, but being careful to ensure that the wishes and preferences of the individual are also recognised and given effect to.

Convention on the Rights of Persons with Disabilities

Supported decision-making has also been given impetus by the coming into force of the *Convention* on the Rights of Persons with Disabilities (the Convention) in 2008.⁴² The Convention has been a significant influence in the movement away from what is seen as paternalistic substitute decision-making towards supporting people with disability to exercise their rights, including their legal capacity.

A general principle of the Convention includes "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons". ⁴³ Article 12 imposes an obligation on State parties to recognise that people with disability enjoy legal capacity on an equal basis with others. This further includes the right to be recognised as a person before the law and the right to have one's decisions and choices legally validated and recognised. ⁴⁴ Read with article 5, an overarching principle of equality and non-discrimination, there is an obligation on State parties to ensure support is provided to people with disability to enable them to exercise their legal capacity, so as to avoid discrimination. Discrimination includes the failure to ensure the provision of reasonable accommodation. ⁴⁵

Commentators have differing opinions, however, on the interpretation of article 12. Some suggest that it requires the elimination of any determinations of incapacity and the abandonment of guardianship laws, and a subsequent move from substitute decision-making to supported decision-making for all people with disability. ⁴⁶ Many have argued that the concept of guardianship is inconsistent with article 12. ⁴⁷ There were complex negotiations that led to the adoption of the final text of article 12 that also addressed the issue of whether guardianship should be expressly permitted in some cases or not. ⁴⁸ Following adoption by the United Nations General Assembly, the debates have continued into interpretation and implementation.

Upon the ratification of the Convention, Australia made an Interpretative Declaration in relation to article 12 that stated:

"Australia declares its understanding that the CRPD allows for fully supported or substituted decision-making arrangements, which provides for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards". 49

 $^{^{}m 41}$ Jonathan Herring, *Medical Law and Ethics* (Oxford University Press, 2012) 203.

⁴² Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007 [2008] ATS 12 (entered into force 3 May 2008) ('Convention on the Rights of Persons with Disabilities').

⁴³ Ibid art 3.

⁴⁴ E Flynn and A Arstein-Kerlake, 'Legislation Personhood: Realising the Right to Support in Exercising Legal Capacity' (conference proceedings at the Australian Guardianship and Administration Council World Conference, Melbourne, 2012) 1.

⁴⁵ Convention on the Rights of Persons with Disabilities art 5.

⁴⁶ E Flynn and A Arstein-Kerlake, above n 44, 1; N O'Neil and C Peisah, above n 4, 2-3.

⁴⁷ Michael L Perlin, 'Striking for the Guardians and Protectors of the Mind: The Convention on the Rights of Persons with Mental Disabilities and the Future of Guardianship Law' (2013) 117 Penn State Law Review 1159, 1177.

⁴⁸ Amita Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future' (2007) 34 *Syracuse Journal of International Law and Commerce* 429, 449.

⁴⁹ Convention on the Rights of Persons with Disabilities: Declarations and Reservations (Australia), opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008).

Australia appeared before the Committee on the Rights of Persons with Disability in September 2013. In its concluding observations, the Committee noted that it is "concerned about the possibility of maintaining the regime of substitute decision-making, and that there is still no detailed and viable framework for supported decision-making". 50 The Committee recommended that Australia "take immediate steps to replace substitute decision-making with supported decision-making and provide a wide range of measures which respect the person's autonomy, will and preferences and is in full conformity with Article 12 of the Convention". 51 The Committee also recommended that Australia review its Interpretative Declaration relating to article 12 with a view to withdraw it.⁵²

Other commentators however have emphasised that the proper application of the principles in guardianship legislation in Australia allow for supported decision-making to be practiced,⁵³ and advocate for putting these principles into practice to ensure that maximum autonomy can be realised for people with disability.

Regardless of the lack of consensus with respect to the status of guardianship laws in relation to the Convention, there is a general acknowledgement, underpinned by the paradigm shift that the Convention heralds, that the focus must move from what a person with disability cannot do to the supports that should be provided to enable them to make decisions and exercise their legal capacity.

In exercising their legal capacity, article 12 emphasises the provision of safeguards that "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". 54 The focus is on the 'will and preferences' of a person as opposed to their 'best interests', the latter of which some commentators argue risks the continuation of a paternalistic approach.⁵⁵

Critiques of substitute decision-making

Aside from the debates in relation to the status of guardianship and the Convention, the impetus for supported decision-making has grown out of a general challenge to the appropriateness and acceptability of guardianship for people with intellectual disability or cognitive impairment. 56 In particular, even though guardianship is supposed to be an intervention of last resort, there are concerns that it is overused and misapplied. This is worrying because of the significant impact on a person's civil rights as a result of a determination of a lack of capacity and an appointment of a substitute decision-maker.⁵⁷

Concerns relate both to the excessive use of guardianship but also the excessive breadth of some guardianship orders. 58 Carney and Tait have highlighted that the accessibility and low cost of Australian guardianship systems have resulted in guardianship applications being sought in preference to other options that are less restrictive and do not infringe on people's rights.⁵⁹

⁵² Ibid.

⁵⁰ Committee on the Rights of Persons with Disabilities, Concluding Observations on the Initial Report of Australia, 10th session, CRPD/C/AUS/CO/1 (2-13 September 2013).

⁵¹ Ibid.

⁵³ N O'Neil and C Peisah, above n 4, 3-4.

⁵⁴ Convention on the Rights of Persons with Disabilities art 12(4).

⁵⁵ Centre for Disability Law and Policy, National University of Ireland Galway, Submission on Legal Capacity to the Oireachtas Committee on Justice, Defence and Equality, Mental Capacity Legislation, August 2011.

Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, above n 3, 1117.

⁵⁷ Ibid.

⁵⁸ Ibid 1118.

⁵⁹ D Tait and T Carney 'Too Much Access: The Case for Intermediate Options for Guardianship' (1995) 30(4) Australian Journal of Social

A related concern is that the process of guardianship disempowers people in that those subject to guardianship may not be involved in the process of making decisions about their lives. It is therefore argued that guardianship may have an anti-therapeutic effect, undermining a person's physical and psychological wellbeing by reducing their sense of control over their lives.⁶⁰

Challenging absolutist concepts of capacity

Related to the discussion and debates about guardianship and substitute decision-making, is a questioning of deterministic approaches to capacity. Capacity has traditionally been viewed by the law as a deterministic and absolute concept. A person either has capacity or they don't, and if they do not have capacity then this disqualifies them from making any decisions or even engaging in a range of activities.⁶¹

Guardianship laws often operate on a threshold of capacity. 62 That is the appointment of a substitute decision-maker requires a determination that the person has impaired decision-making capacity, even if it is only for that matter for which the appointment is made. Such a determination can have a radical effect on the person's autonomy. They no longer hold the legal authority to make decisions that relate to the matters subject to the guardianship order. This association between lack of competence and autonomy is emphasised by medical ethicists Beauchamp and Childress who comment that although "'autonomy' and 'competence' differ in meaning (autonomy meaning self governance; competence meaning the ability to perform a task or range of tasks), the criteria of the autonomous person and of the competent person are strikingly similar". 63

In the past, it was assumed that if a person has a disability, then they lacked capacity to make any decisions for themselves; this view sometimes prevails even in current times. But with changes in medical practice, psychology and the growth of the disability rights movement, such views have been challenged.⁶⁴ The dominant approach to assessing capacity for guardianship purposes is now predominately a functional one. This new approach has also intersected with reforms in guardianship laws including limited guardianship orders and legislative directions to consider the preferences of the person subject to guardianship. 65

There is a growing emphasis on strength-based assessments for capacity, where capacity should be related less to the level of a person's cognitive capacity or functional ability, but more to the level of support available to a person or that could be built around the person to make the decision. Values in Action, a United Kingdom organisation states that:

"the starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built into the expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choice".66

⁶⁰ Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, above n 3, 1120.

⁶¹ For example entering into a binding contract, disposing of property by will or gift, voting, becoming a member of parliament, holding various public offices, having sexual relations with another person, marrying, authorising many forms of medical treatment, engaging in various occupations as discussed in Victorian Law Reform Commission, above n 1, 100.

⁶² Shih-Ning Then, above n 5, 144.

⁶³ Tom L Beauchamp and James F Childress, *Principles of Biomedical Ethics* (Oxford University Press, 6th ed, 2009) 111 in Victorian Law Reform Commission, above n 1, 99.

¹ Kristin Booth Glen, above n 20, 98.

⁶⁵ Ibid 93, 115.

⁶⁶ S Beamer and M Brookes, *Making Decisions: Best Practice and New Ideas for Supporting People with High Support Needs to Make* Decisions (Values into Action, London, 2001) in Jo Watson, Submission No 19 to the Victorian Law Reform Commission, Review of the Guardianship and Administration Act 1986, May 2010, 10.

Supported decision-making

The impetus for supported decision-making

Advocates for supported decision-making are supportive of the concept because of its potential to replace paternalistic substitute decision-making approaches, and its consistency with the principles of the Convention on the Rights of Persons with Disabilities.⁶⁷ The fact that supported decisionmaking has the potential to enable a person to retain their legal capacity also means that there is greater protection of a person's autonomy and capacity for self-determination.⁶⁸

Supported decision-making is consistent with the 'social model of disability', which underpins the Convention and recognises that disability is a social construct; the result of a society that places physical, social and attitudinal barriers in the way of people with disability.

The potential to develop and enhance the overall physical and psychological wellbeing of people with disability is also recognised through the process of supported decision-making, which in turn could have positive health outcomes and improve the person's quality of life.⁶⁹

At a symbolic level, Carney for example, discusses supported decision-making as "an opportunity to re-imagine the disabled legal subject". 70

These normative aspects of supported decision-making are well articulated in literature, and are arguably a driving factor behind the current momentum as an alternative to guardianship.

The concept of supported decision-making

As a concept, supported decision-making embraces a wide range of models in theory, practice and legislation that have different degrees of alignment with the normative aspects discussed above in terms of maximising autonomy, retaining legal capacity, and exercising self-determination.

In general, the concept of supported decision-making differs from substitute decision-making in that a substitute decision-maker makes a decision on behalf of a person, whereas a supported decision involves the participation of, and ultimately decision by, the person concerned. A handbook on the Convention produced by the United Nations describes supported decision-making in the following terms.

"With supported decision-making, the presumption is always in favour of the person with a disability who will be affected by the decision. The individual is the decisionmaker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preferences of the individual. Even when the person with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to the wishes of the individual. This distinguishes supported decision-making from substituted decisionmaking, such as advance directives and legal mentors/friends, where the guardian or tutor has court authorized power to make decisions on behalf of the individual without necessarily having to demonstrate that those decisions are in the individual's best interests or according to his/her wishes".72

⁶⁷ Terry Carney, above n 34, 59.

⁶⁸ Ibid; Office of the Public Advocate (South Australia), Annual Report 2012 (2013) 54.

⁶⁹ Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, above n 3, 1127.

⁷⁰ Terry Carney, above n 34, 62 in Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, above n 3, 1127.

⁷¹ Victorian Law Reform Commission, *Guardianship: Consultation Paper 10* (released March 2011) 117.

⁷² United Nations, Handbook for Parliamentarians – From Exclusion to Equality: Realising the Rights of Persons with Disabilities (United Nations Department of Economic and Social Affairs, Office of the United Nations High Commissioner for Human Rights and Inter-Parliamentary Union, 2007) 89-90.

In contrast to substitute decision-making, supported decision-making usually involves the person retaining their legal powers of decision-making, 73 although a third party may provide assistance or support to make or communicate the decision. Sometimes this arrangement is authorised by law, but it can also be an informal arrangement. Importantly, it means that a person retains their autonomy and agency to make decisions.

It also reflects efforts to provide better ways of recognising and meeting the needs of adults who have difficulty with certain areas of decision-making but who could make their own decisions "with a little friendly help". 74 In the absence of appropriate support, these adults could be inappropriately subjected to guardianship.

Models of supported decision-making

The recognition and development of supported decision-making models commonly see them portrayed as part of a linear stairway leading downwards from autonomous decision-making to substitute decision-making. But as Carney and Beaupert have recognised, it is the middle of the stairway, between autonomous and substitute decision-making that attracts the most attention from policy makers.⁷⁵

Supported decision-making models may be informal, formalised through agreements, or provided for by legislation. If reflected in legislation, they may sometimes involve the appointment of supporters or assistant decision-makers by a court.

Circles of support

While more reflective of collective or collaborative decision-making, 'circles of support' are often spoken about as one of the models of supported decision-making. "A circle of support is a group of people, typically family members and friends, who meet regularly with a person with a disability to help that person formulate and realize his or her hopes or desires."⁷⁶ This model is focused on invigorating a natural support network for people with disability. 77 Watson describes the role of the circle of support as being to "collectively represent the person's wishes and best interests, identify and weigh up the available range of choices, implement decisions and review the impact of decisions, both positive and negative, on the person and others". 78

Circles of support can vary in their formality, but the common factor is the collective and collaborative nature of decision-making by a group of people representing the wishes of the person with disability.

It is recognised that this can be particularly challenging for those people with moderate to severe intellectual disability who are highly reliant on others for communication. While many people with intellectual disability have strong connections with family, friends and the community, this is not the case for everyone. Some people may have "small, highly restricted social networks limited to interactions with other people with intellectual disability, family members and paid workers". 79 Despite these challenges, many advocate for the importance of obtaining and interpreting the preferences, issues and wants of people with severe or profound intellectual disabilities utilising open, transparent and collaborative approaches.⁸⁰

⁷³ Terry Carney, above n 34, 60.

⁷⁴ Robert M Gordon, above n 2, 71.

⁷⁵ Terry Carney and Fleur Beaupert, 'Public and Private Bricolage – Challenges Balancing Law, Services and Civil Society in Advancing CPRD Supported Decision-Making' (2013) 36(1) University of New South Wales Law Journal 175, 183.

Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, above n 3, 1123.

⁷⁷ Ibid.

⁷⁸ J Watson, above n 66, 16.

⁷⁹ J Watson, above n 36, 39.

⁸⁰ C Fyffe et al 'The Next Steps: Adults with a Disability and Family Carers' (paper presented at National Disability Services Conference, Melbourne: Carers Association Victoria, 2010); J Watson, above n 36.

For example, Scope (a non-government service provider based in Victoria) suggests that consideration should be given to the provision of additional resources to establish, strengthen and extend the natural supports that might be present in vulnerable decision-maker's lives, rather than substituting them with professional services.⁸¹

The stepped model

The Office of the Public Advocate in South Australia has incorporated the many decision-making options into what they describe as a 'stepped model'. Previously, decision-making was often conceived as being binary in nature, that is either fully autonomous or, if this was not possible, as requiring substitute decision-making by another person or entity.

The stepped model presents the range of decision-making options as a continuum (as seen in Figure 1), 82 progressing from more to less autonomous decision-making by the person depending on the degree of third party intervention in the arrangement. As Carney noted, the model provides for "a more granular range of choices in place of the more binary one of making or denying guardianship...".83

The stepped model references a variety of supported decision-making mechanisms, as well as options such as representation agreements and co-decision-making, while still acknowledging substitute decision-making arrangements. The components of the model are briefly described below:

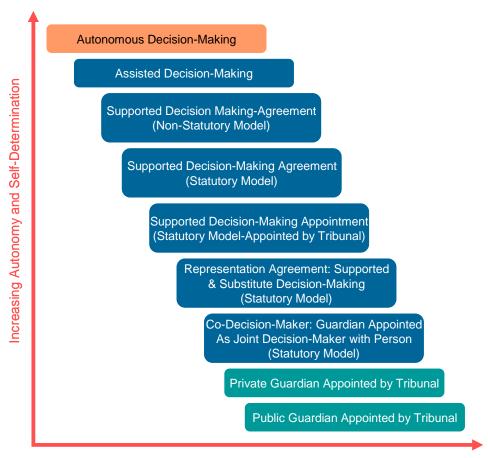
- Autonomous decision-making refers to situations where assistance or support is not necessarily required, although assistance, support and advice may be sought by a person.
- Assisted decision-making involves assistance with collecting information, explanation of alternatives or communication.
- A supported decision-making agreement may be entered into by a person where they want to document the involvement of another person in their decision-making arrangements. This may be informal or supported by legislation. Further along the continuum are arrangements whereby a tribunal or court may appoint a person to be a supporter.
- A representation agreement provides for an agreement between the individual and another person to support the person to make decisions or make decisions on their behalf. It may also be supported by legislation.
- A co-decision-maker may be appointed by a court or tribunal to make decisions with the person.
- Finally, substitute decision-making may involve the appointment of a private or public guardian.⁸⁴

⁸² J Brayley 'Supported Decision-Making – A Case for Change' (presentation at the Supported Decision Making Seminar, hosted by Queensland Advocacy Incorporated, Brisbane, 28 June 2013).

⁸¹ J Watson, above n 66, 16.

⁸³ T Carney, 'Guardianship, 'Social' Citizenship, and Theorising Substitute Decision Making Law' in I Doren and A Soden '*Beyond Elder Law*: New Directions in Law and Ageing' (Springer, 2012), 17 in Office of the Public Advocate (South Australia), above n 68, 55. ⁸⁴ Office of the Public Advocate (South Australia), above n 68, 58.

Figure 1 The Stepped Model of Supported and Substituted Decision-Making



Increasing State Intervention

Source: Office of the Public Advocate (South Australia), Annual Report 2012 (2013) 58.

Legislative regimes

Legislative regimes for supported decision-making have been introduced in some provinces of Canada as well as various Scandinavian and European countries. This part of the literature review provides an overview of some of the international jurisdictions that have implemented supported decision-making legislation and the nature of those schemes. Appendix One provides a summary of the legislative models in some provinces of Canada.

Canada

Canada has been at the forefront of guardianship reform in terms of embedding alternatives to substitute decision-making in guardianship legislation. This process has sometimes been referred to as the 'third wave' of guardianship reform.85

The first wave of reform occurred in the 1970s and was associated with reviewing the laws dealing with 'committeeship' (court ordered guardianship and trusteeship) and focused on legislative models built around functional disability and partial guardianship as well as an avoidance of characterising adults as 'lunatics' or 'incapable'. 86 The second wave of reform was concentrated on adult protection, with many provinces introducing comprehensive adult protection schemes designed to deal with cases of abuse and neglect, particularly of the elderly.⁸⁷

⁸⁵ Robert M Gordon, above n 2, 61.

⁸⁶ Sarah Burningham, 'Developments in Canadian Adult Guardianship and Co-decision Making Law' (2009) 18 Dalhousie Journal of Legal Studies 119, 123; Robert M Gordon, above n 2.

⁸⁷ Sarah Burningham, above n 86, 138; Robert M Gordon, above n 2.

The third wave focused on new concepts of decision-making and liberal tests for capacity,⁸⁸ culminating in the recognition of assisted or supported decision-making in the guardianship legislation of many provinces of Canada such as Alberta, Saskatchewan, the Yukon and British Columbia. These legislative models are explored below.

Alberta

The Adult Guardianship and Trusteeship Act became law in 2009. While it retained and modernised a system of adult guardianship and trusteeship in Alberta, 89 it also introduced two new decisionmaking options: supported decision-making authorisations and co-decision-makers.

Supported decision-making authorisations

Supported decision-making authorisations are personal appointments where an adult forms an agreement with one to three other people, known as supporters, to assist them when making a lifestyle decision. 90 The adults who might utilise these supported decision-making authorisations are described as having the capacity to make their own decisions but "would like to have someone they trust help them in the decision-making process". 91 The supporter does not have the power to make legally enforceable decisions on behalf of the person, but a decision made or communicated with the assistance of a supporter is considered to be a decision of the person. 92

The legislative provisions authorise supporters to obtain personal information they need to assist the person to make a decision 93 and public authorities are authorised to disclose personal information about a supported adult to a supporter who is authorised to access it. 94 Supporters are also protected from liability if they act in good faith while exercising their authority or carrying out the duties of the supporter in accordance with the Act. 95

Co-decision-makers

In contrast to supported decision-making authorisations, co-decision-making orders are court appointments for joint decision-making, however they must be made with the consent of the adult. 96 They are described as appropriate where an adult's capacity to make decisions is significantly impaired but they can still make decisions with appropriate support. 97

Co-decision-making orders only apply to non-financial decisions and operate by requiring the appointed co-decision-maker and the person to work together and agree before proceeding with a decision. 98 The adult, however, has the final say and their view takes precedence. 99

Like supporters, co-decision-makers are protected from liability if they act in good faith while exercising the responsibilities of the role. 100 They are also entitled to all personal information from public bodies, except financial information, about the assisted adult relevant to carrying out the duties and responsibilities of the co-decision-maker. 101

⁸⁸ Robert M Gordon, above n, 62.

⁸⁹ Victorian Law Reform Commission, above n 71, 120.

⁹⁰ Adult Guardianship and Trusteeship Act, SA 2008, c A-4.2, s 4.

⁹¹ Alberta Human Services, Supported Decision-Making: Adult Guardianship and Trusteeship Act (5 September 2013) Government of Alberta <http://humanservices.alberta.ca/guardianship-trusteeship/opg-guardianship-supported-decision-making.html>.

⁹² Adult Guardianship and Trusteeship Act, SA 2008, c A-4.2, s 6.

⁹³ Ibid s 9.

⁹⁴ Ibid.

⁹⁵ Ibid s 10.

⁹⁶ Ibid s 13.

⁹⁷ Alberta Human Services, above n 91.

⁹⁸ Adult Guardianship and Trusteeship Act, SA 2008, c A-4.2, s 12; Victorian Law Reform Commission, above n 71, 121.

⁹⁹ Victorian Law Reform Commission, above n 71, 121.

 $^{^{\}rm 100}$ Adult Guardianship and Trusteeship Act, SA 2008, c A-4.2, s 23.

British Columbia

The Representation Agreement Act (RSBC 1996, c405) was enacted in 2000 as part of a package of reforms to the guardianship laws in British Columbia. 102 Guardianship in British Columbia, called 'Committeeship', is governed by the Patient's Property Act (RSBC 1996, c349) and can occur via a court order or a Certificate of Incapability, signed by the director of a provincial mental health facility, which includes most public hospitals. Committeeship requires a finding that the adult is 'mentally incompetent' and results in the appointment of a substitute decision-maker (either a private party such as a family member or the Public Guardian and Trustee). 103

Representation agreements

The stated purpose of the Representation Agreement Act (RSBC 1996, c405) is to provide a mechanism for adults to decide in advance how, when and by whom decisions about their health care, personal care or routine management of their financial affairs will be made if they become incapable of making decisions independently. It is also intended to avoid the court having to appoint a person to help the adult make decisions should they become 'incapable'. 104

A representation agreement is therefore somewhat similar to a power of attorney, ¹⁰⁵ except that there is a positive obligation on the representative to consult with the adult when helping the adult to make decisions or making decisions on behalf of the adult. 106

Furthermore, an adult may make a representation agreement even if they do not have capacity for certain matters. For example, an adult can make a standard representation agreement even if the adult is incapable of making a contract; managing his or her own health care, personal care or legal matters; or attending to the routine management of his or her own financial affairs. 107 A representation agreement with standard provisions enables authorisation for the representative to make decisions about the adult's personal care, routine management of financial affairs, health care and legal services. 108

An adult can only make a non-standard representation agreement if the adult is capable of understanding the nature and consequences of the agreement. 109

Representatives must consult with the adult when helping them to make decisions, and must comply with the wishes of the adult to the extent it is reasonable to do so. However, they can also make decisions on behalf of the adult. 110

A representative can access all information and records that relate to the incapability of the adult or an area of authority granted to the representative, ¹¹¹ and is protected from liability if they act honestly and in good faith and in accordance with the scope of their duties set out in the Act. 112

¹⁰² Nidus Personal Planning Resource Centre and Registry, A Study of Personal Planning in British Columbia: Representation Agreements with Standard Powers (2010) Nidus < http://www.nidus.ca/PDFs/Nidus_Research_RA7_InAction.pdf>; Nidus Personal Planning Resource Centre and Registry, Experiences of adults living with Fetal Alcohol Spectrum Disorder and their personal supporters in making and using a Representation Agreement (2009) Nidus http://www.nidus.ca/PDFs/Nidus_Research_RA_FASD_Project.pdf>.

¹⁰³ Nidus Personal Planning Resource Centre and Registry, A Study of Personal Planning in British Columbia, above n 102; Nidus Personal Planning Resource Centre and Registry, Experiences of adults living with Fetal Alcohol Spectrum Disorder, above n 102.

¹⁰⁴ Representation Agreement Act, RSBC 1996, c 405, s 2.

¹⁰⁵ Victorian Law Reform Commission, above n 71, 122.

 $^{^{\}rm 106}$ Representation Agreement Act, RSBC 1996, c 405, s 16.

¹⁰⁷ Ibid s 8.

¹⁰⁸ Ibid s 7.

¹⁰⁹ Ibid s 10.

¹¹⁰ Ibid s 16.

¹¹¹ Ibid s 18.

¹¹² Ibid s 23.

Where a representative is appointed to assist in making, or to make, decisions in relation to an adult's financial affairs, a monitor must also be appointed to ensure that a representative is acting in accordance with their duties. 113 Monitors may also be appointed for decision-making in relation to non-financial matters. 114

A qualitative study of representation agreements in British Columbia

A qualitative study of 989 representation agreements with standard powers was undertaken between 2006 and 2009. This study found that:

- People of all ages (from 19 to 99 years old) made representation agreements suggesting that the agreements were an important planning tool for the transition from youth to adulthood;
- Monitors were appointed in over half of the cases, which was interpreted to reflect that people valued that safeguard;
- 84% of representation agreements named more than one person, which was interpreted to reflect that people valued a 'team approach' to support; and
- Friends were chosen as representatives as often as relatives, which was interpreted to reflect that people's support networks extended beyond their immediate family. 115

Saskatchewan

The Adult Guardianship and Co-decision Making Act has been in force since 2001. It provides for both personal and property co-decision-makers. The Victorian Law Reform Commission noted that while co-decision-making appointments have been available for many years, only a handful have ever been made, which may be due to the cost involved in making an application to the Supreme Court. 116

Personal co-decision-maker

Personal co-decision-makers are appointed by the court and do not require the consent of the adult. 117 They are considered to be appropriate when an adult does not have full capacity to make decisions, but can still participate in the decision-making process. 118 While a personal co-decisionmaker may advise the adult and shares decision-making authority, the co-decision-maker must acquiesce in a decision made by an adult. A co-decision-maker cannot, for example, refuse to sign a contract to give effect to a decision if a reasonable person could have made the decision and no harm to the adult is likely to result from the decision. 119

The appointment of a personal co-decision-maker requires a capacity assessment. The court must be satisfied that the adult's capacity is impaired to the extent that the adult requires assistance in decision-making in order to make reasonable decisions with respect to some or all of the matters listed in the Act. 120

The personal co-decision-maker is protected from liability if acting in good faith and pursuant to the Act. 121

¹¹³ Ibid s 20.

¹¹⁵ Nidus Personal Planning Resource Centre and Registry, A Study of Personal Planning in British Columbia: Representation Agreements with Standard Powers (2010) Nidus < http://www.nidus.ca/PDFs/Nidus_Research_RA7_InAction.pdf>; Nidus Personal Planning Resource Centre and Registry, Experiences of adults living with Fetal Alcohol Spectrum Disorder and their personal supporters in making and using a Representation Agreement (2009) Nidus http://www.nidus.ca/PDFs/Nidus_Research_RA_FASD_Project.pdf.

¹¹⁶ Victorian Law Reform Commission, above n 71, 122.

¹¹⁷ Adult Guardianship and Co-decision Making Act, SS 2000, c A-5.3, s 14.

Law Foundation of Saskatchewan, Adult Guardianship in Saskatchewan: Application Manual (2002) Government of Saskatchewan http://www.publications.gov.sk.ca/details.cfm?p=9265.

Adult Guardianship and Co-decision Making Act, SS 2000, c A-5.3, s 17.

¹²⁰ Ibid s 14.

¹²¹ Ibid s 70.

Property co-decision-maker

Property co-decision-makers are similar to personal co-decision-makers except that the co-decisionmaker advises the adult in respect of matters relating to his or her estate. Decisions are made jointly, however a co-decision-maker must also acquiesce in a decision made by an adult. For example, the co-decision-maker must not refuse to sign a document to give effect to a decision if a reasonable person could have made the decision and no loss to the adult's estate is likely to result from the decision. 122 Further, any decision made, action taken, consent given or thing done by a property codecision-maker in good faith respecting any matter within her or her authority with the adult is deemed for all purposes to have been made as though the adult had capacity in respect of the matter.123

Like personal co-decision-makers, property co-decision-makers are protected from liability if they act in good faith and pursuant to the Act. 124

Yukon

The Decision Making, Support and Protection to Adults Act commenced in 2003. As well as containing a provision for the Supreme Court to appoint guardians, it also provides for supported decisionmaking agreements and representation agreements.

Supported decision-making agreements

A supported decision-making agreement is entered into voluntarily by an adult, ¹²⁵ however must be in the prescribed form. 126

The agreement authorises associate decision-makers to assist a person with making and communicating decisions. These agreements are for adults who can make their own decisions with some help. The associate assists the individual to make decisions. An adult must understand the nature and effect of the agreement to enter the agreement. 127

The purpose of the supported decision-making agreement is to:

- Enable trusted friends and relatives to help adults who do not need guardianship and are substantially able to manage their own affairs, but whose ability to make or communicate decisions with respect to some or all of those affairs is impaired; and
- Give legal status to persons providing support to adults to enable them to participate in discussions with others when the adult is making decisions or attempting to obtain information. 128

The role of the associate decision-maker under the agreement is to assist the adult to obtain and assess relevant information, to make and express a decision, to communicate the decision, and to endeavour to ensure that the adult's decision is implemented. 129 The agreement does not authorise the associate to make decisions on behalf of the adult. 130

¹²² Ibid s 42.

¹²³ Ibid s 49.

¹²⁴ Ibid s 70.

Decision Making, Support and Protection to Adults Act, SY 2003, c 21, schedule A, s 6.

¹²⁶ Ibid s 8.

¹²⁷ Ibid s 6.

¹²⁸ Ibid s 4.

¹³⁰ Yukon Health and Social Services, Adult Protection and Decision Making Act- Supported Decision Making Agreements (25 August 2010) Yukon Health and Social Services http://www.hss.gov.yk.ca/supported_agreements.php>.

An associate decision-maker has a right to assist the adult to obtain any information to which the adult is entitled in relation to a decision that the associate decision-maker is assisting the adult to make. 131 An associate decision-maker is protected from liability if he or she acts honestly, in good faith and in the best interests of the adult; and exercises the care, diligence, and skill of a reasonably prudent person. 132

Representation agreements

A representation agreement authorises a representative to make a limited range of daily living decisions regarding the adult's personal or financial affairs, as set out in the agreement. It is described as appropriate for adults who recognise that they experience difficulty when making some decisions. 133 However, an adult must understand the nature and effect of the agreement to enter into it. 134

A representation agreement is entered into voluntarily by the adult, ¹³⁵ and is not made by a court, but must be in a prescribed form. 136

Although representatives are authorised to make decisions, ¹³⁷ they must consult with the adult, comply with the adult's wishes if it is reasonable to do so, and encourage and assist the adult to make decisions or participate in decision-making. ¹³⁸ A decision made with the assistance of, or by, a representative shall be recognised at law as a decision of the adult. 139

A representative has the right to assist the adult to obtain any information related to the performance of the duties of the representative under the agreement, ¹⁴⁰ and is protected from liability if they act within the limits of their authority in the agreement. 141

Europe

Some unique models of alternatives to guardianship have also been developed in several European countries including Norway, Sweden, Denmark and the Netherlands. In these countries, there is a focus on alternative ways to provide support and assistance for decision-making for adults with disability, without removing their legal capacity. Unique to these approaches is the dependence (at least in Sweden) on an inclusive system of entitlement to support services for people with disability. This part will briefly discuss those models as well as developments in Ireland and the United Kingdom.

Sweden

In Sweden there are two forms of support: the *god man* (which translates to 'mentor' or 'good man'), which is the preferred and dominant model of support; and a trustee (forvaltare), which is an appointment of last resort, similar to a guardian. 142

 $^{^{\}rm 131}$ Decision Making, Support and Protection to Adults Act, SY 2003, c 21, schedule A, s 10.

 $^{^{133}}$ Yukon Health and Social Services, above n 130.

Decision Making, Support and Protection to Adults Act, SY 2003, c 21, schedule A, s 15.

¹³⁵ Ibid.

¹³⁶ Ibid s 17.

¹³⁷ Ibid s 15.

¹³⁸ Ibid s 23.

¹³⁹ Ibid s 25.

¹⁴⁰ Ibid s 24.

¹⁴² Kristin Booth Glen, above n 20, 140; Stanley S Herr, *Self Determination, Autonomy and Alternatives for Guardianship* http://ruralinstitute.umt.edu/transition/Handouts/Self-Determination.Herr.pdf>.

The god man (mentor) must act in consultation with, and with the consent of, the person and assists the person with personal, legal and financial decisions. The appointment of a god man does not involve a loss of legal capacity for the adult. 143 Procedures for appointment are relatively informal, and without cost to the person. While applications can be made to the district court, given most cases are based on consent, there is usually a review of the documents by the court, with no appearance or hearing necessary. 144 While most god men are close relatives or friends, every god man is paid a fee, the amount of the fee dependent on the complexity of the case. Professionals including lawyers, social workers and accountants can also be appointed. 145

The forvaltare is the intervention of last resort and, unlike the god man, results in the loss of legal capacity for the person. 146 It is mainly used in situations involving financial interests such as funds above a certain value. 147

In addition, Sweden has legislated for the right of every person with severe physical or mental disabilities to have an entitlement to support services. The Bill (Lag om stod och service till vissa funktionshindrade) came into effect in 1994 and gives people with functional disabilities the legal right to ten different kinds of support and services. ¹⁴⁸ For example, the law makes a personal assistant a mandated support service for people with disability covered by the scope of the legislation, which can be provided directly by the government or by a cash allowance to the person with disability who can employ their own personal assistant. 149

Each of Sweden's 270 municipalities has an office of public trusteeship administration that is charged with oversight of *qod men* and *forvaltares*. Mentorship is by far predominant over *forvaltares*. Mentorship has been in existence since 1976, where at the time some 30,000 Swedes were under guardianship. But by 1985, the availability of the mentor option reduced the number of people subject to guardianship to 17,000.¹⁵⁰

Advocates for the Swedish system argue that it provides for a range of least restrictive alternatives, from support services to mentorships, which do not result in the loss of legal decision-making capacity for the adult, ¹⁵¹ and suggest that it is a good model for other countries that are faced with similar challenges. These challenges include how to support people with disability to navigate the array of social services they need without disempowering or disenfranchising them; and how to provide assistance with medical, financial and other issues that were once taken care of by institutional staff who exerted a de facto guardianship. 152 Arguably, the entitlement to social support, including personal assistance also diminishes the need for guardianship.

Norway and Denmark

Since 1990, legislation in Norway and Denmark has made provision for two levels of intervention for adults who need assistance with decision-making: the 'assisting representative' (hjelpeverge); and the 'support person'. A support person assists the adult to manage their personal needs and with the expression of their interests, ¹⁵³ and their involvement does not result in the adult losing their legal capacity. If an assisting representative is appointed, the adult's legal capacity is removed only when necessary and the representative's decision will prevail only under carefully defined circumstances. 154

¹⁴³ Kees Blankman, 'Guardianship Models in the Netherlands and Western Europe' (1997) 20(1) International Journal of Law and Psychiatry 47, 55. Stanley S Herr, above n 142. 145 Ibid.

¹⁴⁶ Kristin Booth Glen, above n 20, 141. ¹⁴⁷ Kees Blankman, above n 143, 55.

¹⁴⁹ Stanley S Herr, above n 142.

¹⁵⁰ Ibid.

¹⁵¹ Kristin Booth Glen, above n 20, 142.

 $^{^{152}}$ Stanley S Herr, above n 142; Kristin Booth Glen, above n 20, 141.

¹⁵³ Kees Blankman, above n 143, 55.

¹⁵⁴ Robert M Gordon, above n 2, 63.

Ireland

The Assisted Decision-Making (Capacity) Bill 2013 was introduced into the Irish parliament in July 2013, and introduces six mechanisms for supporting decision-making for a person including: assisted decision-making; co-decision-making; decision-making representatives; enduring powers of attorney; decision-making orders by the High Court or the Circuit Court; and informal decision-makers.

The explanatory memorandum explains that the Bill "changes the existing laws on capacity, shifting from the current all or nothing status approach to a flexible functional one, whereby capacity is assessed on an issue- and time-specific basis". 155

Assisted decision-making

The Bill provides for a person who believes that their capacity is in question, or may shortly be in question, to appoint another person (such as a trusted friend or relative) to be a decision-making assistant. The appointment occurs by way of a decision-making assistance agreement. 156 While the decision-making authority stays with the appointer, the decision-making assistant helps the person to access and understand information and to make and express decisions. 157

Co-decision-makers

A person who considers that their capacity is, or shortly will be, in question may appoint a suitable person to make joint decisions with them. ¹⁵⁸ The co-decision-making agreement does not come into effect however until a court approves it. A court may approve a co-decision-making agreement for a person if satisfied that the person lacks capacity to make a decision or class of decisions on their own, but has decision-making capacity if assisted by a suitable person. ¹⁵⁹ While the co-decisionmaker and the person make joint decisions, the co-decision-maker must acquiesce in a decision made by the person and cannot, for example, refuse to sign a document required to implement the decision if a reasonable person could have made the decision and if no harm is likely to result to the person from the decision.¹⁶⁰

The role of the co-decision-maker is to explain relevant information and considerations relating to a decision, ascertain the will and preferences of the person, and assist the person to communicate their preferences in making a decision. 161

Decision-making representatives

A court may appoint a decision-making representative where the court is unable to make a codecision-making order or has made a declaration that a person lacks capacity even with the assistance of a co-decision-maker. 162

United Kingdom

The Mental Capacity Act 2005 (United Kingdom) came into effect in England and Wales in 2007. It provides a legal framework for the care, treatment or support of people who are unable to make decisions for themselves. The Act allows for personal care, health care and treatment to be provided to people who lack decision-making capacity by health care professionals as long as it is in their best interests and the care providers abide by the principles of the Act. 163

¹⁵⁵ Explanatory Memorandum, Assisted Decision-Making (Capacity) Bill 2013 (Ireland), 1.

¹⁵⁶ Assisted Decision-Making (Capacity) Bill 2013 (Ireland), cl 10.

¹⁵⁷ Ibid cl 11.

¹⁵⁸ Ibid cl 18.

¹⁵⁹ Ibid cl **17**.

¹⁶⁰ Ibid cl 19.

¹⁶¹ Ibid cl 21. ¹⁶² Ibid cl 23.

 $^{^{163}}$ Mental Capacity Act 2005 (UK) c 9, s 5.

The Act emphasises supporting people to make their own decisions and/or participating in decisions. This is provided for in the principles of the Act which include, for example, that "(3) a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success; and (4) a person is not to be treated as unable to make a decision merely because he makes an unwise decision". 164

The Act also provides for people to make a Lasting Power of Attorney. 165

The Court of Protection may appoint deputies who are family members or friends, to manage the affairs of a person who does not have capacity when they have not planned ahead by making a Lasting Power of Attorney. Deputies may be for property and affairs or health and welfare. There is no public guardian of last resort, but there is a list of professional panel deputies who may be appointed if there is no one else to act as a deputy in the person's life.

Consistent with section 42 of the Act, a Code of Practice has been established under the Act that provides guidance and information about how the Act works in practice. The Mental Capacity Act 2005 Code of Practice, which has statutory force, provides guidance to anyone working with, and/or caring for, an adult who may lack capacity to make certain decisions. For example, the Code provides guidance on how to implement the Act's five statutory principles, including how to assist a person to make a decision. 166

Trials of supported decision-making in Australia

Government trials of supported decision-making have been conducted in South Australia and the Australian Capital Territory. Trials are underway in New South Wales and Victoria.

While these trials have contributed to the knowledge and evidence base relating to supported decision-making, they have been based on small numbers of people with particular characteristics, conditions or backgrounds. There have not been any Australian trials involving a large number of participants or featuring participants with diverse characteristics, circumstances and levels of preparedness for increasing decision-making ability.

South Australia

South Australia was the first Australian State to embark on a supported decision-making trial. The South Australian Office of the Public Advocate conducted a trial of supported decision-making from late December 2010 to October 2012.

It involved setting up an agreement between a person with disability and a family member or friend who would act as a decision supporter. In all, 26 people whose capacity for decision-making was impaired as a result of a brain injury, intellectual disability, autism or a neurological disease formed agreements with supporters. Recruitment of participants was initially through referrals from disability service providers and the Office of the Public Advocate. A range of adult participants were engaged, from younger adults who were studying to older people living in residential aged care. Supporters included friends and a range of immediate family members. This trial considered healthcare, accommodation and lifestyle decisions. ¹⁶⁷ As a safeguard, a monitor role was established to provide oversight of the process and decisions made using it. 168

¹⁶⁴ Ibid s 1.

¹⁶⁶ Department for Consitutional Affairs (United Kingdom), Mental Capacity Act 2005 Code of Practice (2007) 29.

¹⁶⁷ Office of the Public Advocate (South Australia), above n 68, 56-62.

¹⁶⁸ Margaret Wallace, Evaluation of the Supported Decision-Making Project (November 2012) Office of the Public Advocate (South Australia) http://www.opa.sa.gov.au/resources/supported_decision_making, 43.

An evaluation of the trial was conducted by Margaret Wallace. It found that the project demonstrated specific benefits to most of the participants involved in the trials. These benefits were seen in their increased confidence in themselves and in their decision-making. There was also evidence of improvement in decision-making skills and growth in their support networks. Increased engagement with the community, either through expanding their options or through making decisions that changed their circumstances, was also reported. 169 Some participants did experience difficulty accessing the money required to give effect to their goals and decisions, with two participants reporting a mismatch between their goals and the decisions of administrators who controlled the funds. 170

The project infrastructure had two streams: Early Intervention (targeting young adults and people who had been recently diagnosed as having an acquired brain injury or neurological disease); and Alternatives to Guardianship (those adults who would be otherwise subject to guardianship). Limitations of the project were observed in the Alternatives to Guardianship stream. ¹⁷¹

The target of 20 participants in the Alternative to Guardianship stream was not met. The evaluation cited that organisational constraints and the difficulty of guardians taking on a number of supported decision-making clients (in addition to those under their guardianship) were contributing factors to the discrepancy in successes between the two streams. It was also thought that the greater likelihood for clients of public guardianship to be isolated and not have family or friends who could act as supporters also contributed to the discrepancy. 172

Carney commented that the pilot also excluded potentially more challenging participants such as those people with mental illness, dementia, or those experiencing abuse, neglect or conflict with family or friends. 173

In 2013, the South Australian Public Advocate made recommendations to reform state guardianship law to recognise supported decision-making agreements. Recommendations were also made in relation to how supported decision-making may be implemented at a broader community level using a 'population-based model'. 174

Legislative reform

The South Australian Public Advocate made a recommendation to the South Australian Attorney-General for two legislative changes in relation to supported decision-making. The first change was that the key principles in the Guardianship and Administration Act 1993 require supported decisionmaking. The second change would involve the inclusion of new sections in the Act that recognise supported decision-making arrangements. 175

In its most recent annual report, the Office of the Public Advocate highlighted that the inclusion of an additional principle requiring support should not be considered to be controversial or 'experimental law reform' due to the alignment of the principle with international human rights obligations. The need for more empirical research was acknowledged, however was not viewed as a barrier for this law reform. 176

¹⁶⁹ Ibid 4-5.

 $^{^{170}}$ Office of the Public Advocate (South Australia), above n 68, 63.

¹⁷¹ Margaret Wallace, above n 167, 43.

¹⁷³ Terry Carney and Fleur Beaupert, above n 75, 92.

Office of the Public Advocate (South Australia), above n 68, 15.

¹⁷⁵ Office of the Public Advocate (South Australia), *Annual Report 2013* (2013).

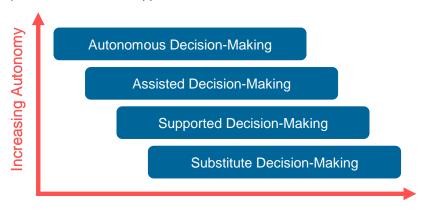
Population-based model of supported decision-making

Subsequent to their supported decision-making trial, the Office of the Public Advocate has adapted a 'population health model' to explore how supported decision-making might be used to uphold the rights of a larger and broader group of people than those involved in the trial. ¹⁷⁷ The model is being used to examine the possibility of implementing The Stepped Model via a series of primary, secondary and tertiary interventions. The application of the population-based model is proposed in the context of a simplified version of The Stepped Model (Figure 2). 178

The simplified model distinguishes assisted and supported decision-making. Assisted decision-making may be provided by a third party who is involved in a transaction with a person, for example, disability or mental health support workers, health workers, bank employees, retail employees or utilities employees.

Supported decision-making occurs when a person invites a third person to provide them with decision-making support and may include activities such as sourcing information, assistance in understanding the consequences of a decision, communicating decisions and other activies related to making and actioning a decision. 179

A simplified version of the Stepped Model Figure 2



Increasing State Intervention

Source: Office of the Public Advocate (South Australia), Annual Report 2013 (2013) 53.

The South Australian Public Advocate has argued that an effective decision-making regime must provide responses that are proportionate to need, and that the simplified version of The Stepped Model will ensure that the state provides appropriate support measures to protect people's rights, maximise people's autonomy, minimise the delivery and cost of disproportionate and intensive support responses by the state. The Public Advocate has suggested that there should be an expectation that assistance be provided wherever possible within the community. Assistance may take the form of longer discussions, second meetings, information available in plain English and communication assistance. 180

¹⁷⁸ Ibid.

180 Ibid.

¹⁷⁷ Ibid 52.

¹⁷⁹ Ibid 53.

The population-based model features three levels of intervention:

- Primary Universal Interventions such as awareness campaigns and stigma reduction targeted at the whole community;
- Secondary Interventions such as the provision of assistance and engaging a decision-making supporter targeted to specific sectors (e.g. disability, health, justice, education and training, finance); and
- Tertiary Interventions such as the facilitation of supported decision-making agreements targeted at specialist non-government providers and some individualised funding facilitators. 181

Australian Capital Territory (ACT)

The ACT Supported Decision-Making Research Project was conducted by ADACAS (and funded by Disability ACT) to examine supported decision-making in the lead up to the launch of the National Disability Insurance Scheme. It further explored the application of the supported decision-making model developed by the Julia Farr Foundation in partnership with the South Australian Office of the Public Advocate. 182

More specifically, the project inquired into how supported decision-making might be accessed by people with complex communication needs or those whose social isolation restricted their ability to identify natural decision-making supports. Participants either had a decision-making impairment, or their capacity to make decisions was either unrecognised or undervalued, which reflected a social model of disability. 183

Six people with varying degrees of decision-making capacity were recruited between November 2012 and January 2013 and participated in the program until its completion in June 2013. They utilised supported decision-making agreements with two parts. The first part provided a brief description of the agreement and who had made it and could generally be shown to third parties. The second part contained a lot of detail about the supporters and the types of decisions they provided support in relation to. The monitor was a key role, providing oversight of the supported decision-making agreement in practice. 184

A key finding from the trial was that, for each participant, their capacity for self-determination and autonomy was not limited by their ability to make a decision, but by the support they received to exercise their decision-making. Those who received support services experienced lower levels of selfdetermination as their lives can be governed by the decisions of other people, including family members and service providers. 185

This is consistent with research into the safety strategies used by people with intellectual disability, which found that people with intellectual disability who also required significant personal support experienced lower level of choice and control in their lives. It was also found that the surrounding circumstances of a person, not their capacity, had the most effect on implementing their personal strategies. The research showed that people implemented their strategies more successfully in more supportive environments. 186

¹⁸² ADACAS Advocacy, Spectrums of Support: A Report on a project Exploring Supported Decision Making for People with Disability in the ACT (September 2013), ACT Disability, Aged Care and Carer Advocacy Service http://www.adacas.org.au/decision-40 support/copy_of_SupportedDecisionMakingProjectFinalReport.pdf>. Ibid.

¹⁸¹ Ibid 54-55.

Fiona May, 'ADACAS ACT Initiatives' (presentation at the Supported Decision Making Forum, hosted by Queensland Advocacy Incorporated, Brisbane, 28 June 2013).

¹⁸⁵ ADACAS Advocacy, above n 182.

¹⁸⁶ Sally Robinson, 'Safe at home? Factors influencing the safety strategies used by people with intellectual disability', (2013) Scandinavian Journal of Disability Research DOI:10.1080/15017419.2013.781958.

While only based on a small sample, the ACT trial demonstrated that decision-making support, whether informal or formal, can create positive change for individuals, families, service providers and the community more broadly. It also confirmed the need for a spectrum of decision-making supports, from informal to formal, to meet the varied needs and capabilities of individuals. 187

New South Wales

The New South Wales Office of Ageing, Disability and Home Care, along with the Public Guardian and the NSW Trustee and Guardian have also commenced a supported decision-making pilot. The pilot will run for 12-18 months and will be subject to an independent evaluation. 188

It will involve 30 participants who receive direct or indirect funded support from the Office of Ageing, Disability and Home Care. Ten of these participants will be subject to an administration order made to the New South Wales Trustee and Guardian, with a sub-group also being subject to a guardianship order. 189 Participants will have a range of circumstances (age, supports, life stage etc). Supporters may be friends, family members, guardians, advocates or carers. 190

The initial set up of the pilot has found some issues with the availability of supporters for some people. However they have been careful not to exclude potential participants from the pilot if they do not have pre-existing trusted relationships, so that in some cases supporters will be volunteers who do not have to have a previous relationship with the person. The recruitment of pilot participants will be random and not just those who are ready and willing to make decisions with support. 191

The pilot will not require the use of formal supported decision-making agreements, but they will be available if people want to use them. The pilot aims to find new ways to support people with a disability to make decisions. That is, to learn how participants make decisions, what supporters do, how participants used the available tools and resources and whether they were useful, and whether education sessions increased the knowledge of individuals and service providers. The expected outcomes of the pilot include a draft supported decision-making framework, decision-making tools and resources and other educational material. 192

Victoria

The Office of the Public Advocate plans to commence a supported decision-making trial in early 2014. The trial will run for 12-18 months and will involve around 20 participants who have an intellectual disability, currently receive very little or no disability support, and are isolated within the community. The Office of the Public Advocate will collaborate with a disability advocacy agency to locate and recruit participants. 193

Trial participants will have the ability to utilise supported decision-making agreements and will be supported by 20 volunteers, who will be recruited to provide assistance to the trial participants. The trial will be independently evaluated. 194

¹⁸⁷ ADACAS Advocacy, above n 182.

¹⁸⁸ Melanie Oxenham, 'Supported Decision Making Pilot in NSW-A Joint Pilot' (presentation at the Supported Decision Making Forum, hosted by Queensland Advocacy Incorporated, Brisbane, 28 June 2013).

Ageing, Disability and Home Care, 'Supported Dcision Making Pilot - Participant Information' (Participant Fact Sheet, Department of Family and Community Services (NSW) February 2013).

¹⁹⁰ Melanie Oxenham, above n 188.

¹⁹¹ Ibid.

¹⁹² Ibid.

¹⁹³ Telephone discussion with Brenda Burgen, Supported Decision-Making Coordinator, Office of the Public Advocate, Victoria (14 October 2013). Final text was approved by the head of Agency.

Critique of supported decision-making

An emerging, but ill-defined concept

Commentators have recognised that supported decision-making remains an ill-defined concept, 195 and that it has "been interpreted as spanning everything from targeted legal powers and authorities through to facilitation of the normal interactions of daily family or social intercourse". 196 Supported decision-making as a concept has been used to describe a wide variety of models ranging from those where the individual with impaired decision-making capacity is the ultimate decision-maker to those where a person appointed by a court or tribunal makes the decision on the basis of what they believe to be the expressed will and preferences of the person. Some would argue that the latter example is not supported decision-making in its true sense. The preference is to reserve the term supported decision-making for those situations where the person being supported has voluntarily entered the arrangement and is the ultimate decision-maker, and to use terms such as co-decision-maker to describe these other versions of supported decision-making. 197

Shih-Ning Then has commented that literature on the topic has also confused quite distinct models of decision-making, for example it has not distinguished between supported decision-making and codecision-making models, which are conceptually (and legally) very distinct decision-making regimes.198

Related to these concerns is a lack of clarity about how supported decision-making forms part of the systemic mix of services, laws and civil society, ¹⁹⁹ and a corresponding acknowledgement that active participation by people with disability is dependent upon the success of supply side reforms (such as government and non-government responsiveness to consumer agency and choice) as well as demand side measures (such as informal supports, advocacy and other measures).²⁰⁰

Safeguards

One of the key concerns expressed about supported decision-making is that it may expose vulnerable people with impaired decision-making capacity to manipulation, coercion or abuse.²⁰¹

A number of mechanisms have been introduced in both formal and informal models of supported decision-making in response to the concerns about the vulnerability of people to be subject to exploitation, duress and abuse as part of supported decision-making arrangements. The South Australian trial of supported decision-making introduced the concept of the third party 'monitor' to observe the informal supportive relationship.

In various Canadian models of statutory supported decision-making, safeguards include periodic reviews of the arrangements by courts, the ability for courts to remove supporters where they have acted inappropriately, as well as the appointment of monitors in some situations, particularly those involving property co-decision-making.²⁰² However as Then argues, outside these mechanisms the onus is really on co-decision-makers and third parties to notify the court of any concerns or changes in capacity that affect the arrangements. 203

¹⁹⁵ Terry Carney and Fleur Beaupert, above n 75.

¹⁹⁷ Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, above n 3, 1120-1121.

¹⁹⁸ Shih-Ning Then, above n 5, 155.

¹⁹⁹ Terry Carney and Fleur Beaupert, above n 75.

Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, above n 3, 1114.

For example the requirement in British Columbia to appoint a monitor where a representation agreement is made for financial matters under the Representation Agreement Act, RSBC 1996, c 405, s 12.

Shih-Ning Then, above n 5, 161.

Some of the further safeguards suggested in Australia have included the registration of informal supported decision-making arrangements and a role for public guardians/advocates to investigate allegations of inappropriate behaviour by supporters.²⁰⁴

The discussion in relation to safeguards however opens up complex arguments about the 'dignity of risk' and the right of people with disabilities to take their own risks in decision-making and highlights tensions between autonomy and paternalism.

Many commentators agree that further research is necessary to realise proper safeguards for people with disability in these arrangements. ²⁰⁵ While the aim is empowerment, Kohn, Blumenthal and Campbell argue that without more evidence as to how it will work in practice "there is reason to be concerned that supported decision-making may allow largely unaccountable third parties to improperly influence the decisions of persons with disabilities, thereby disempowering persons with disabilities and undermining their rights". 206

Can supported decision-making live up to its potential?

Kohn, Blumenthal and Campbell, in their recent review of supported decision-making, express concern about whether, despite its appeal, supported decision-making can achieve its 'lofty goals', empowering individuals with disability to make their own decisions, ensuring these decisions are truly voluntary, and minimising the risk of coercion. 207

Similarly, Carney warns that there is potential for slippage between the aspirations of policy makers, "keen to expand personal autonomy of action and personalised decision-making, and the harsh realities of actual experience", which is illustrated by numerous jurisdictions that have implemented supported decision-making laws and programs. ²⁰⁸ However as Carney and others have commented, this slippage between goals and aspirations and the realities of putting models into action is not unique to supported decision-making, with issues also emerging with the operationalisation of 'best interests' decision-making in guardianship and the lack of recognition and understanding of enduring powers of attorney.²⁰⁹

Net-widening

A further key concern is that an unintended consequence of supported decision-making could be 'net widening', that is, supported decision-making orders may extend to a population broader than those who would have been subject to guardianship, and may inadvertently expand the reach of guardianship. ²¹⁰ The potential for supported decision-making to turn into informal substitute decision-making is also concerning to many commentators.

²⁰⁴ Barbara Carter, Supported Decision-Making: Background and Discussion Paper (November 2009) Office of the Public Advocate, Victoria http://www.publicadvocate.vic.gov.au/file/file/Research/Discussion/2009/0909 Supported Decision Making.pdf>, 22.

²⁰⁵Shih-Ning Then, above n 5, 133; Terry Carney and Fleur Beaupert, above n 75; Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell,

²⁰⁶ Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, above n 3, 1157.

lbid 1128.

²⁰⁸ Terry Carney and Fleur Beaupert, above n 75, 193.

²¹⁰ Ibid 175, 195; Terry Carney, 'Participation Rights, Family Decision-Making and Service Access: A Role for Law' (2011) Sixth Annual Roundtable on Intellectual Disability Policy.

O'Neil and Pesiah express a related concern that legislating for supported decision-making may also lead to the formal court or tribunal appointment of supporters where either informal support for the decision-maker is sufficient or in fact there is no need for a support person.²¹¹ This may occur because people with disability, whether or not they have lost the capacity to make their own decisions, may be under pressure by others to consent to supported decision-making.²¹² O'Neil and Pesiah state that "we need to argue for the practical individualised approaches to the assessment of the needs, goals and strengths of people with disabilities to facilitate their decision-making". ²¹³ They also advocate for careful, informed and individualised gatekeeping using current guardianship legislation. That is, ensuring that assessments of capacity are appropriate and task- and situationspecific, and incorporating a hierarchy of risk model, whereby decisions that incur a greater risk require a higher threshold for capacity, and thereby more rigid gatekeeping.²¹⁴

Carney has cautioned that supported decision-making reforms may be misunderstood by stakeholders as being little different from its predecessor, guardianship. He comments, "it has been previously questioned whether the brokerage role of a modern decisional assistant under the supported decision-making model is actually just the functional equivalent to that of a traditional guardian or administrator discharging their statutory duty to first act as an advocate (or the 'eyes ears and voice') for the person they represent". 215

However, Carney also argues that with the right educative and other measures, supported decisionmaking should ideally prevent informal substitute decision-making from occurring. He cites the lesson from the South Australian trial of supported decision-making where some participants sought informal decision-making support arrangements to prevent family and friends from taking over their life 216

Lack of empirical evidence

Much of the literature in relation to supported decision-making focuses on the normative aspects of the model, that is the alignment of supported decision-making as a concept with principles of autonomy and self-determination as well as the principles underpinning the Convention on the Rights of Persons with Disabilities. 217 Despite the existence of supported decision-making in practice, particularly in various Canadian jurisdictions for some time, there is little known about actual supported decision-making practices, how they work in practice, and what works well.²¹⁸

Perhaps a notable exception is the report produced by Michelle Browning, a Churchill Fellow, who undertook an investigation into new models of guardianship and the emerging concept of supported decision-making in the United Kingdom and Canada. ²¹⁹ Browning's investigation into the use of supported decision-making, in Canada in particular, found that there had not been a large uptake of new legislative agreements such as Representation Agreements in British Columbia and Yukon. Often this is because the people who would benefit from these agreements do not have close trusting relationships with a person who could perform this role.²²⁰ Given there was no register of supported decision-making authorisations in Alberta, it was difficult for Browning to determine the prevalence and success of this tool.²²¹

²¹¹ N O'Neil and C Peisah, above n 4, 5.

²¹² Ibid 12.

²¹³ Ibid 5.

²¹⁴ Ibid 12.

Terry Carney, 'Guardianship, "social" citizenship and theorising substitute decision-making law in I.Doron & A M Soden (eds), Beyond elder law: New directions in law and aging. (New York, NY Springer, 2012) in Terry Carney, above n 210, 59. ²¹⁶ Terry Carney, above n 210, 60.

Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, above n 3, 1112; Terry Carney and Fleur Beaupert, above n 75, 190.

Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, above n 3, 1112; Terry Carney and Fleur Beaupert, above n 75, 190.

²¹⁹ Michelle Browning, *To Investigate New Models of Guardianship and the Emerging Practice of Supported Decision Making* (2011) Winston Churchill Memorial Trust of Australia, Canberra http://www.churchilltrust.com.au/media/fellows/Browning_Michelle_2010.pdf,

^{29.} ²²⁰ Ibid.

²²¹ Ibid 23.

In 2013, Kohn, Blumenthal and Campbell concluded, following a review of the empirical literature in relation to supported decision-making in practice, that while supported decision-making presents an appealing alternative to guardianship and should therefore be given serious consideration by public policy makers, there is currently insufficient empirical evidence to know how and if it can remedy the problems posed by surrogate decision-making processes.²²²

However, Kohn et al also indicate that the dearth of empirical evidence about decision-making processes is not unique to supported decision-making and that there is also little evaluative empirical literature on guardianship. 223 They point to the need for further empirical evidence in two broad areas. First, evidence in relation to the utilisation of supported decision-making, including the demographic profile of those who participate (supporters and principles) and the commonality of such arrangements. Second, there needs to be further research on the outcomes of supported decision-making, including both process outcomes (how it works) and substantive outcomes (the actual outcomes for those who are supported). 224

Legislating for supported decision-making

Should we legislate?

There have been mixed reactions to the idea of formalising supported decision-making through legislation.

Scope, in their submission to the Victorian Law Reform Commission's review of guardianship laws, cautioned against the over-formalisation of supported decision-making through legislation, concerned that it could undermine existing natural networks of support.²²⁵

O'Neil and Peisah are also concerned that a legislated model of supported decision-making may force the formal appointment of support persons where either informal support is sufficient or there is, in fact, no need for a support person. They argue that:

"there is a substantial risk that the very existence of the regime will cause it to be used in circumstances in which the protections of those with decision-making disabilities that are currently in place are not seen as being needed. Consequently it is likely that a supported decision-making regime created by legislation will actually cut into and reduce the autonomy in decision-making that those with decision-making disabilities currently enjoy. As a result, people with disabilities may be forced to accept support they do not require when exercising their legal capacity to make decisions - an outcome diametrically opposed to the intent of Article 12(3)". 226

The Victorian Law Reform Commission, in its review of Guardianship laws in Victoria, recommended that new guardianship laws should enable the appointment of supporters to assist people with the process of gathering information, making important decisions about their lives and implementing those decisions, ²²⁷ and co-decision-makers to make joint decisions with people with impaired decision-making capacity.²²⁸

²²² Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, above n 3, 1114.

²²³ Ibid 1129.

²²⁴ Ibid.

²²⁵ J Watson, above n 66, 16.

²²⁶ N O'Neil and C Peisah, above n 4, 5-6.

²²⁷ Victorian Law Reform Commission, above n 1, 136.

While it would be possible for a person to appoint their own supporter/s, or for the Victorian Civil and Administrative Tribunal to appoint a supporter, the Victorian Law Reform Commission recommended that only the Victorian Civil and Administrative Tribunal be empowered to appoint a co-decision-maker. For the Victorian Law Reform Commission, formalising support relationships had the advantages of assisting other important people in the person's life to understand and recognise the significance of the support relationship, allowing the supporter to access information and be able to communicate decisions, and clarifying the supporter's role with third parties who interact with the person such as service providers, banks and others.²²⁹

Carney and Beaupert conceptualise supported decision-making as part of the suite of social or community services and civil society measures "aimed at advancing the rights of people with disability to participate in society as active citizens, with choice and control over the resources they need to maximise their participation in all aspects of social life, in accordance with the 'equality' of the CRPD". 230 While they recognise that legislative models have been introduced in some countries, most predominately in Canada, they argue that there is minimal available research on the practical implementation of supported decision-making in its different guises. They suggest that policy makers should be cautious and seek further empirical evidence about how supported decision-making should operate. "Supported decision-making, in its various social, quasi-legal and legal forms, warrants careful empirical research and pilot programs to guide legislative and social policy reform."231

Carney and Beaupart suggest that a number of critical issues need to be explored including what exactly is, or should be, meant by the term supported decision-making; the extent to which legal decision-making power resides with the supported person; whether statutory arrangements are necessary to incorporate protective measures or whether they will inherently change the nature of informal support arrangements that can be so empowering for people with disability; and finally whether formalising supported decision-making will lead to 'net widening', and at worst the creation of a de facto guardianship system.²³² They argue that the "realisation of the right to equality of participation on the part of people with cognitive and psychosocial disabilities is too fragile to be entrusted to experimental lawmaking or well-intentioned but ultimately mistaken application of normative principles."233

In response to Carney and Beaupart however, Brayley denies that more substantive law reform should be delayed while research is undertaken. Brayley, who has advocated for the inclusion of supported decision-making agreements in South Australia's Guardianship and Administration Act 1993, argues that new laws can be, and often are, evaluated after they are put into place. 234

²²⁹ Ibid 135.

²³⁰ Terry Carney and Fleur Beaupert, above n 75, 199.

[.] 175, 200.

²³² Ibid.

²³³Ibid 175, 201.

Office of the Public Advocate (South Australia), above n 175, 58-59.

Imperatives to legislate

Broadly, there seems to be two key imperatives to legislate, particularly in light of the models for supported decision-making introduced in some Canadian provinces and currently under consideration in Australia.

First, legislative recognition for supported decision-making arrangements provides authority for decision-making supporters to access information necessary to support the person with decisionmaking and/or to communicate the person's decision to a third party; and to protect them from liability. Third party (such as financial institutions, hospitals and accommodation services) recognition of the right for supporters to access information and communicate decisions is often identified as a barrier to putting supported decision-making into practice in an informal way. Statutory recognition of supported decision-making may also provide supporters or co-decision-makers with protection from civil or criminal liability if they act honestly and in good faith and in accordance with the respective legislation.

The second imperative for legislative recognition for supported decision-making is that it can provide important safeguards for the person seeking support. Mostly these are in the form of imposing positive duties on supporters and co-decision-makers or the inclusion of a monitoring role played by courts, tribunals, public guardians or specially appointed monitors.

A possible third imperative is the approach taken in some Scandanavian countries where legislation also provides for guaranteed access to social services and other types of assistance, recognising the interdependency of these systems and the importance of adequate support to keep people out of more restrictive forms of decision-making such as guardianship.

Gaps in the Literature

While there is significant discussion in the literature in relation to the philosophical (including rightsbased) imperatives for supported decision-making, and the various legislative models of supported decision-making (in particular in the Canadian and Scandanavian jurisdictions), there is little empirical evidence in relation to the effectiveness of supported decision-making in practice nor whether and how it achieves its objectives of maximising autonomy and self-determination.²³⁵

There is also little information on the extent of the 'uptake' of the various supported decision-making mechanisms in Canadian jurisdictions such as representation and co-decision-making agreements, or details of how they work in practice.

Along with the small scope of trials to date in Australia, it is currently difficult to accurately assess how supported decision-making can and should be incorporated into the current mix of legislation, policy and support services.

 $^{^{\}rm 235}$ Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, above n 3.

Conclusion

There is no doubt that there is growing momentum for further reform to guardianship in its current form (either in law or practice) to make way for and enable less restrictive ways of assisting people with impaired decision-making capacity to make decisions. In particular, in light of the Convention on the Rights of Persons with Disabilities, these new approaches should enable people to exercise their legal capacity to the greatest extent possible.

The recent introduction of the National Disability Insurance Scheme in Australia provides an imperative for further consideration of supported decision-making policies and practices. The National Disability Insurance Scheme, when fully implemented, aims to empower and enable participants by placing them at the centre of decision-making about their lives, and give them more choice and control over the supports they receive. 236 People who experience difficulty with making decisions, including those who have previously had limited opportunity to participate in decisionmaking, may require support.

While as a concept, supported decision-making fits well with the values underpinning the Convention, commentators have emphasised that there is still much to learn about how it works and how it should work, as well as how to ensure that we do not inadvertently create another substitute decision-making system.

Regardless of whether models of supported decision-making are introduced into guardianship legislation, many have advocated for putting further resources into building the natural support networks of people with disability along with appropriate monitoring and safeguards. Careful, informed and individualised gatekeeping to guardianship that involves approaches to assessment of capacity that include the needs, goals and strengths of the person can also assist. This approach, which involves operationalising many of the existing principles of guardianship legislation can help to ensure that people are not inappropriately subject to guardianship and put at risk of losing their right to be involved in decision-making in relation to their own lives.

Given the interconnections between the various systems of support that are accessed by people with disability, the degree to which any reforms in relation to decision-making support for people with disability achieve the goals of maximising autonomy and increasing self-determination is likely to be contingent on many factors, not least of which being increasing recognition and support for upholding the rights of people with disability not just in legislation and policy, but most importantly in practice.

²³⁶ DisabilityCare Australia, One Big Difference to Lots of Lives: An Introduction to DisabilityCare Australia (July 2013) National Disability Insurance Scheme, Commonwealth of Australia

<http://www.disabilitycareaustralia.gov.au/sites/default/files/documents/An%20Introduction%20to%20DisabilityCare%20Australia.PDF>.

Appendix One: Supported decision-making in Canadian legislation

Alberta, Canada - Adult Guardianship and Trusteeship Act SA 2008 CA-4.2

Description	Appointment	Capacity	Prescribed form/order	Public Guardian	Authorised to make decisions	Personal information	Protection from liability
Supported decision-making authorisation For adults who have capacity to make their own decisions but would like some help. They sign a form to authorise a person to be their 'supporter'. 237	Supporter/s are appointed by the adult.	The adult must understand the nature and effect of a supported decision-making authorisation.	Prescribed form.	Public Guardian or Public Trustee cannot be appointed as a supporter.	The supporter does not have the power to make legally enforceable decisions on behalf of the person, but a decision made or communicated with the assistance of a supporter is considered to be a decision of the person.	Supporters may be given authority to obtain personal information to assist the adult make a decision. Public authorities are given authority to disclose personal information about a supported adult to a supporter who is authorised to access it.	Supporters are protected from liability if they act in good faith while exercising the authority or carrying out the duties of the supporter in accordance with the Act.
Co-decision-making orders For adults whose capacity to make decisions is significantly impaired but they can still make decisions with support. The adult and their co-decision- maker jointly make decisions. ²³⁸	Co-decision- making orders are made by a court and must be consented to by the adult.	The court must be satisfied that the adult's capacity to make certain decisions is significantly impaired, but the adult would be able to make these decisions if provided with appropriate guidance and support.	An order.	Public Guardian or Public Trustee cannot be appointed as a co-decision- maker.	Co-decision-making orders only apply to non-financial decisions and require the appointed co-decision-maker and the adult to work together and agree before proceeding with a decision that is covered by the order. The Adult has the final say.	A co-decision-maker is entitled to access all personal information (except financial information) about the assisted adult from public bodies as is relevant to carrying out the duties and responsibilities of the codecision-maker.	Co-decision-makers are protected from liability if they act in good faith while exercising the authority or carrying out the duties of the supporter in accordance with the Act.

²³⁷ Alberta Human Services, above n 91.

²³⁸ Ihio

British Columbia - Representation Agreement Act, RSBC 1996, c405

Description	Appointment	Capacity	Prescribed form/order	Public Guardian	Authorised to make decisions	Personal information	Protection from liability
Representation agreements Enable decisions to be made in advance of becoming incapable about when, how and by whom decisions about health care, personal care or routine management of their financial affairs should be made. 239	Representation agreements are made by an adult.	An adult can make a standard representation agreement even if they are incapable of making a contract, managing their own health care, personal care or legal matters; or routinely managing their own financial affairs.	A representation agreement must be in writing, and signed and witnessed in accordance with the Act, but there is no prescribed form. 240	An adult can appoint the Public Guardian and Trustee as a representative.	Representatives must consult with the adult when helping them to make decisions, and must comply with the wishes of the adult to the extent it is reasonable to do so; but can also make decisions on behalf of the adult.	A representative can access all information and records that relate to the adult's incapacity or an area of authority granted to the representative.	A representative is protected from liability to the extent they act honestly and in good faith and within the scope of their duties under the Act.

²³⁹ Representation Agreement Act, RSBC 1996, c 405, s 2. ²⁴⁰ Alberta Human Services, above n 91, 13.

Saskatchewan - Adult Guardianship and Co-decision- making Act SS 2000

Description	Appointment	Capacity	Prescribed form/order	Public Guardian	Authorised to make decisions	Personal information	Protection from liability
Personal co-decision-makers For adults who do not have full capacity to make decisions, but can participate in the decision-making process. A co-decision-maker can be appointed to assist the adult and jointly make decisions with them. ²⁴¹	Personal co-decision-makers are appointed by the court and do not require the consent of the adult.	There must be a capacity assessment. The court must be satisfied that the adult's capacity is impaired to the extent that they require assistance in decision-making in order to make reasonable decisions with respect to some or all of the matters listed in the Act.	An order.	The Public Guardian or Trustee can be a personal co-decision-maker.	The co-decision-maker advises the adult, and shares the authority to make decisions with the adult. However, a co-decision-maker must acquiesce in a decision made by an adult and must sign a document to give effect to a decision if a reasonable person could have made the decision in question and no harm to the adult is likely to result from the decision. Any decision made, action taken, consent given or thing done by a personal co-decision-maker in good faith relating to any matter within the authority is taken to have been made by the adult (s 23).	No explicit provision, but may be implied by section 23.	No action lies or shall be instituted against any person who performs a duty, exercises a power or carries out a responsibility pursuant to the Act for any loss or damage suffered by any person by reason of anything in good faith in the exercise of the duty, power or responsibility.

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²⁴¹ Law Foundation of Saskatchewan, above n 118.

Description	Appointment	Capacity	Prescribed form/order	Public Guardian	Authorised to make decisions	Personal information	Protection from liability
Property co-decision-makers For adults who do not have full capacity to make decisions, but can participate in the decision-making process. A co-decision-maker can be appointed to assist the adult and jointly make decisions with them. 242	Property co- decision- makers are appointed by the court.	There must be a capacity assessment. The court must be satisfied that the adult's capacity is impaired to the extent that the adult requires assistance in decision-making in order to make reasonable decisions with respect to some or all of the matters relating to his or her estate.	An order.	The Public Guardian or Trustee can be a property co-decision-maker.	The co-decision-maker advises the adult and shares the authority to make decisions with them. However, a co-decision-maker must acquiesce in a decision made by an adult and must sign a document to give effect to a decision if a reasonable person could have made the decision and no loss to the adult's estate is likely to result from the decision. Any decision made, action taken, consent given or thing done by a personal co-decision-maker in good faith relating to any matter within the authority is taken to have been made by the adult (s 49).	No explicit provision, but may be implied by section 49.	No action lies or shall be instituted against any person who performs a duty, exercises a power or carries out a responsibility pursuant to the Act for any loss or damage suffered by any person by reason of anything in good faith in the exercise of the duty, power or responsibility.

²⁴² Ibid.

Yukon - Decision Making, Support and Protection to Adults Act SY 2003

Description	Appointment	Capacity	Prescribed form/order	Public Guardian	Authorised to make decisions	Personal information	Protection from liability
Supported decision-making agreements For adults who can make their own decisions with some help. The associate assists the adult to make decisions. The agreement does not authorise the associate to make decisions on behalf of the adult. 243	Agreements are made between the adult and the associate decision-maker.	The adult must understand the nature and effect of the agreement.	Prescribed form.	An employer or employee of the adult, or a person against whom a family violence order has been made, is excluded from being an associate decision-maker. The stated purpose of the agreement is to 'allow trusted friends and relatives to help adults who do not need guardianship to manage their own affairs'.	The associate decision- maker assists the adult to make and express a decision which includes assisting the adult to obtain relevant information, explaining relevant information and considerations, and communicating the decision. The associate decision- maker is not authorised to make decisions on behalf of the adult.	An associate decision-maker has the right to assist the adult to obtain any information to which the adult is entitled in relation to a decision the associate decision-maker is assisting the adult to make.	An associate decision- maker is protected from liability for injury, death or financial damage or loss to the adult if he/she acts in good faith and in the best interests of the adult, and exercises the care, diligence and skill of a reasonably prudent person.
Representation agreements For adults who recognise that they have trouble making some decisions. An agreement gives one or more 'representatives' the authority to make day-to-day financial and personal decisions for the adult. ²⁴⁴	Agreement between the adult and representative.	The adult must understand the nature and effect of the agreement to enter into it.	Prescribed form.	Employers or employees, a paid carer, or a person against whom a family violence order has been made cannot act as a representative.	Representatives are authorised to make decisions on the adult's behalf, however the representative must consult with the adult and comply with the adult's wishes if it is reasonable to do so.	A representative has a right to assist the adult to obtain any information related to the performance of the duties of the representatives under the agreement.	A representative is protected from liability if they act within the limits of their authority in the agreement.

 $^{^{\}rm 243}$ Yukon Health and Social Services, above n 130. $^{\rm 244}$ lbid.

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