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Supported and Substitute Decision Making under Mental Capacity Legislation: a review of the international evidence

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1.0 What is the issue?

1.1 In Northern Ireland there is not yet a comprehensive legal or policy framework to provide supported and/or substitute decision-making for people whose capacity to make decisions may be impaired.

1.2 There are people who, without support, would be assessed as incapable of making certain decisions but with the appropriate support are capable of making those decisions and so to not provide that support infringes their rights, undermines their autonomy and reinforces their exclusion from society.

1.3 Supported decision making should be considered as an important part of a continuum of decision making from autonomous decision making through to substitute decision making. Law and policy have tended to focus on either end of the spectrum and have approached capacity as if people are either globally capable or incapable, but most people require some level of support with decision making.

1.4 The Mental Capacity (Health, Welfare and Finance) Bill, which is hopefully to be considered within the term of this Assembly, offers an excellent opportunity to create this comprehensive legal and policy framework.

2.0 Definitions

2.1 *Mental capacity* – the ability to make your own decisions (Paradigm, 2008).

2.2 *Supported decision making* – “Supported decision-making is a framework within which a person with a disability can be assisted to make valid decisions. The key concepts are empowerment, choice and control” (Carter, 2009, p. 9). Carter (2009, p.8) also refers to the United Nations Handbook on the Convention on Rights of Persons with Disabilities, which states: “Supported decision-making can take many forms. Those assisting a person may communicate the individual’s intentions to others or help him/her understand the choices at hand. They may help others to realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity”. A further definition of supported decision making has been provided by the Victorian Law Reform Commission (2011, p.19), namely “An approach to decision making that involves providing a person with impaired capacity the support they need to make their own decision. It is often contrasted with substitute decision making, where a decision is made on behalf of a person who is unable to make that decision”.

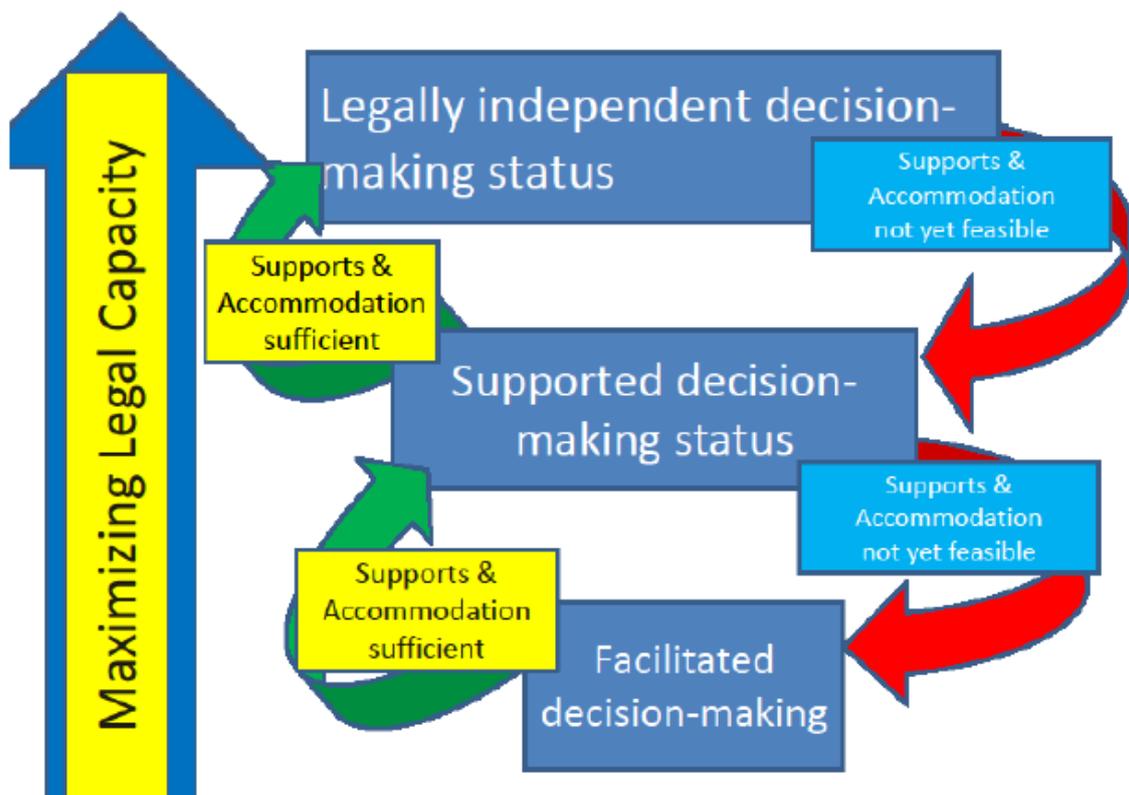
2.3 *Substitute decision making* – this refers to the legal frameworks in place to enable decisions to be made for people who lack the capacity to make them. It includes arrangements such as powers of attorney, court-appointed deputies,

guardianship, wards of court and compulsory intervention under mental health law. In some jurisdictions (for example Alberta and Saskatchewan in Canada) there are co-decision making arrangements which involve the courts appointing someone to assist the person make decisions, but under these arrangements the person's autonomy is not absolute and so may be regarded as a more limited form of substitute decision making.

3.0 Continuum of decision making

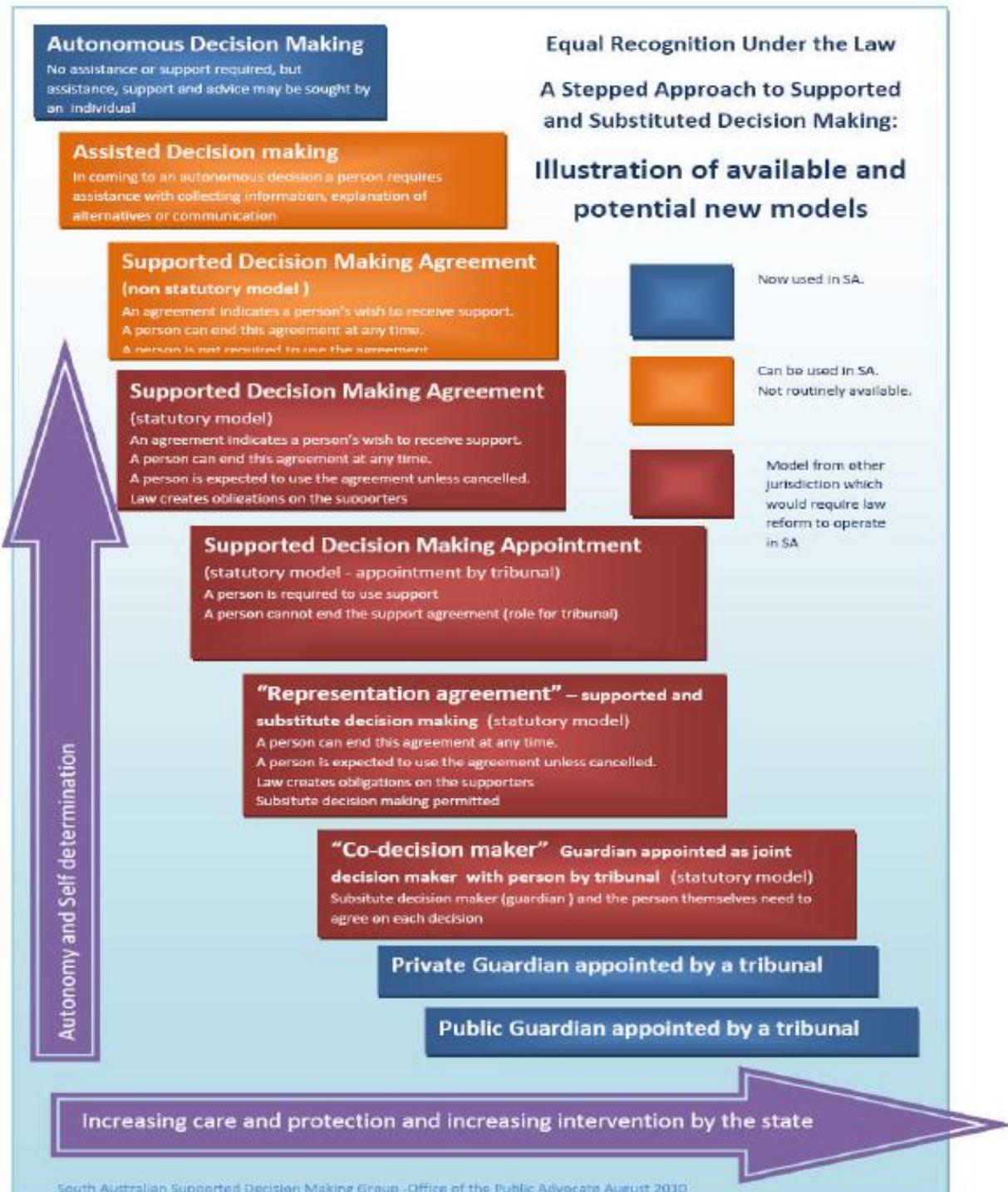
Two diagrams help to demonstrate the dynamic nature of decision making capacity and the range of levels and approaches involved. In Figure 1 Bach and Kerzner (2010) illustrate the possible relationships between decision making abilities, decision making supports and accommodations, and decision making status. This shows how people move between levels as abilities, supports and accommodations develop.

Figure 1 Dynamic nature of decision making capacity (Bach and Kerzner, 2010)



In Figure 2, Chartres and Brayley (2010) provide more steps on the continuum. Figure 2 illustrates decision making in South Australia (SA) and possible developments there but it provides a useful summary of the spectrum.

Figure 2 Stepped approach to supported decision making in South Australia (Chartres and Brayley, 2010)



These figures are also brought together in a summary table below to allow comparison between the different models.

Table 1: Summary of continua of decision making

Basic model	Chartres and Brayley (2010)	Bach and Kerzner (2010)
Autonomous decision making	Autonomous decision making	Legally independent decision making
Supported decision making	Assisted decision making	Supported decision making
	Non-statutory Supported Decision Making agreement	
	Statutory Supported Decision Making Agreement	
	Supported Decision Making Appointment	
Substitute decision making	Representation Agreement Co-decision maker	Facilitated decision making
	Private and Public Guardians	

4.0 Need for a comprehensive legal and policy framework

4.1 There are a number of rights based, effectiveness and pragmatic arguments for providing this framework.

4.2 The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) requires States to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity” (Article 12(3)). There are people who, without support, would be assessed as incapable of making certain decisions but with the appropriate support are capable of making those decisions.

4.3 Article 12(3) is the key reference to supported decision making, but the whole of Article 12 represents a paradigm shift away from the focus of policy and law being only on substitute decision making for people who are assessed as lacking the capacity to make a decision. The article requires the development of a positive range of supports to enable people to fully exercise their rights and, wherever possible, prevent the need for substitute decision making (Quinn, 2010).

4.4 The central principle underlying supported decision making is autonomy, that “no person should have another person appointed to make a decision on their behalf, if they could make the decision themselves with assistance and support” (Chartres and Brayley, 2010, p. 1).

4.5 The effectiveness arguments focus more on the benefits that supported decision making provides for individuals, families and societies. Chartres and Brayley (2010) suggest that supported decision making has three broad benefits. First, it supports personal autonomy, authority and control that people have over their own lives. Second, it provides a clearer structure for individuals and families negotiating and making decisions and plans in the context of family, friends, informal carers and services. Third, they suggest that it provides a more comprehensive means of ensuring people’s legal and personal capacity to make decisions is promoted and respected. Chartres and Brayley (2010, p.32) go on to list the potential benefits for a person with disabilities as: “citizenship, personal empowerment; self determination; self esteem; respect for decisions; control over their lives; confidence in decision making; confidence in rights; development of decision making skills and capacity; increase in areas of decision making; and increase in support networks”.

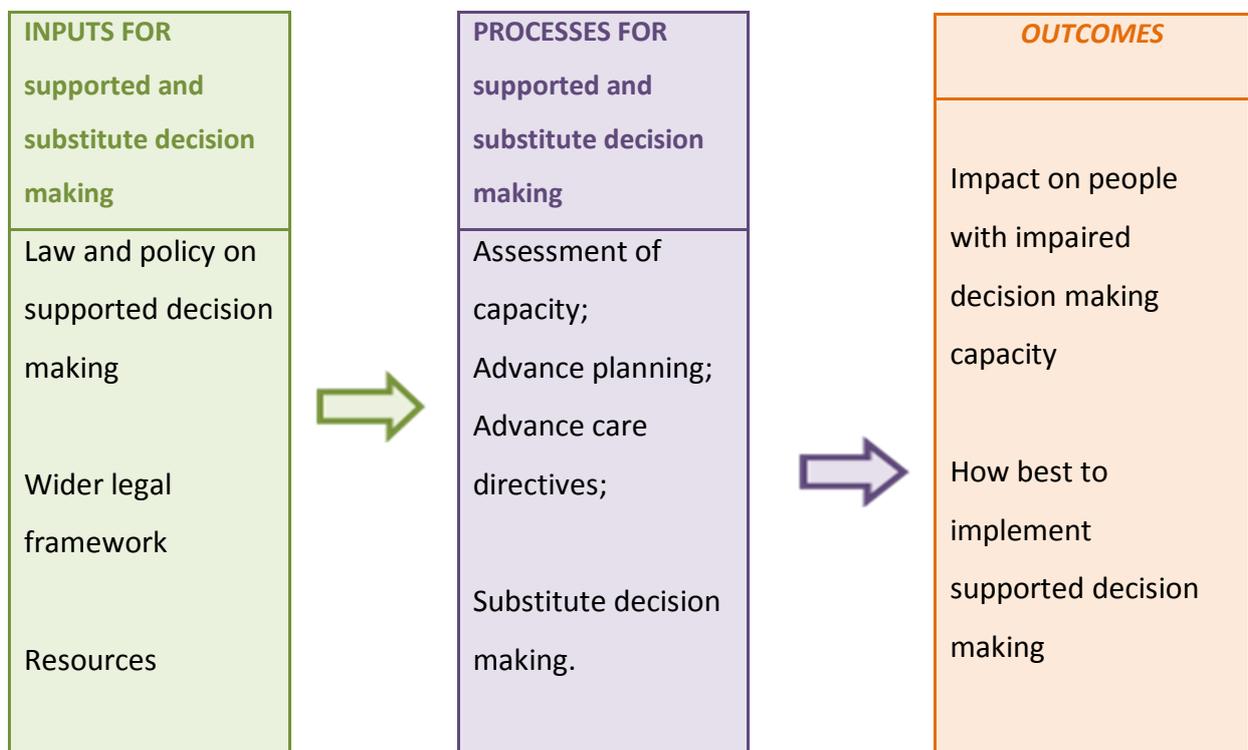
4.6 The process of developing and implementing supported decision making will also provide societal benefits. Some of the dangers of not respecting people’s rights to be fully included in society and not supporting people to make their own decisions have been demonstrated through the research on institutionalisation and the repeated inquiries into the abuse of people in care. The benefits to society of supported decision making include: contributing to a better and wider understanding of the

importance of respecting the rights of all citizens; a more inclusive approach to disability; and generally enabling better decisions to be made.

4.7 The last benefit to society overlaps with the pragmatic arguments for supported decision making. These are based on the procedural justice research in mental health services which suggests that, in an assessment process, if people are listened to, respected and feel that their views are being considered, even if they do not agree with the outcome of that process, they are less likely to feel coerced and dissatisfied (McKenna et al., 2000; Galon and Wineman, 2010). In general terms, it seems reasonable to assume that if a person has received the support necessary to make their own decision, such as the type of service to use, they may be more willing to fully engage and benefit from that service.

5.0 Review of the international evidence

5.1 A Rapid Evidence Assessment was completed using database and grey literature searches. The findings were mainly from North America, UK and Australasia and organised using the following logic model.



6.0 Findings and implications of the review

6.1 In England Chapter 3 of the Mental Capacity Act 2005 Code of Practice (Department for Constitutional Affairs, 2007) provides specific guidance on how people should be helped to make their own decisions. It suggests that the following points should be checked: Providing relevant information; Communicating in an appropriate way; Making the person feel at ease; Supporting the person.

6.2 In Scotland there is guidance under the Adults with Incapacity (Scotland) Act 2000 relevant to supported decision making. *Communication and Assessing Capacity: A guide for social work and health care staff* (Scottish Government, 2008) aims to ensure all practicable steps have been taken to help the person make the decision.

6.3 The review suggests that it appears very difficult to ensure that good practice in supported decision making is consistently provided across all settings if it is not clearly required. Even in jurisdictions where there is clear commitment in law and/or Code of Practice guidance, inconsistencies arise and so an important, but not sufficient, implication is that reference to supported decision making, along with the associated provision of advance care planning and independent advocacy, should be included in the proposed Mental Capacity (Health, Welfare and Finance) Bill and/or its associated Code of Practice/guidance. This may be provided by the inclusion in the law of the commitment that “all practicable steps” must be taken before substitute decision making is considered and further specified in guidance.

6.4 There is a theme through the included studies of the need for staff training due to concerns about levels of knowledge; inconsistent practice; and the lack of involvement of service users (Goldsmith et al., 2008; Froggatt et al., 2009; Ahmed et al., 2011). There was also clear evidence of how effective the provision of training and information was for both staff and service users in relation to decision making (Karp, 2009) and advance care planning (Foy et al., 2007). It was also found that

advance care planning is not useful for everyone (Papageorgiou et al., 2002) and that an individual's preferences and circumstances need to be considered when all forms of supported decision making are being provided (Ekdahl et al., 2010; Funk, 2004).

6.5 There is a wide range of strategies within supported decision making approaches. At the most basic level the provision of clear information and the simplification of decision-making tasks can provide support for decision making (Wong et al., 2000). Person-centred planning is also supported although there may be complexities in its implementation (Robertson et al., 2005; Dowling et al., 2007). Independent advocacy, representation and supportive networks can also be used to support people to make their own decisions and prevent the need for substitute decision making.

6.6 The full range of supported decision making is necessary as the need for supported decision making and the approaches that will be most effective will vary across people, time and decisions and so supported decision making, like capacity, should be viewed as decision specific.

6.7 The Mental Capacity (Health, Welfare and Finance) Bill has the potential to provide a world-leading non-discriminatory and unified framework for substitute decision making. The focus, in the development of the Bill, has been on the arrangements for substitute decision making but it also offers the opportunity, perhaps in a commitment in the Bill and guidance in the Code of Practice, to develop a world-leading framework for supported decision making.

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