Scottish Commission for People with Learning Disabilities

SCLD

Supported Decision-Making in Comparative Perspective:

Lessons for Scotland

2024

Glossary of key terms

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)	The UN convention on disability rights. Ratified by the UK in 2009.
Mental Capacity	A diagnostic evaluation of someone's ability to understand information.
Legal Capacity	Someone's ability to hold rights and make decisions before the law.
Will and preference	What a person's wants and/or would prefer.
Best interests' paradigm	Decisions made in someone's 'best interest' by third parties i.e. not necessarily what the person themselves wants.
Supported decision-making	An approach to decision-making which aims to support people to make their own decisions, centring their will and preference.
Substitutive decision-making	The removal of someone's legal capacity resulting in a third-party making decisions for them.
Guardianship	Part of Scotland's framework of substitute decision-making. A court order which allows a third party to make decisions on behalf of a person deemed unable to make their own decisions.
Adults with Incapacity (Scotland) Act 2000	The statute that legislates for adults deemed to lack capacity. Guardianship orders fall under its remit.

Contents

1. Introduction

This document follows on from the first in a series of resources. The first paper outlined Supported Decision-Making (SDM), its presence in international human rights law, and how it may eventually be implemented in Scotland given the recommendations of the Scottish Mental Health Law Review.[1]

This paper presents and analyses three international case studies of SDM implementation (the Republic of Ireland, Sweden and Canada). Each example has been chosen to demonstrate a unique approach to support, capacity and decision-making for people with learning disabilities. The purpose of this analysis is to provide a reference point for how the questions and issues posed by SDM could be addressed.[2]

Scotland's Mental Health and Capacity Law Reform programme, still being in its early stages, has the opportunity to learn from the successes and failures of these and other international attempts to implement SDM. In aiding this purpose, this paper concludes every chapter with key learning points from the case studies that can be used to further foster discussion and highlight key issues of focus.

2. The Republic of Ireland

In the last decade, the Republic of Ireland has undertaken significant reform of its legislation surrounding capacity and decision-making. The Assisted Decision-Making (Capacity) Act 2015 (referred to henceforth as the '2015 Act') repealed the outdated 'Lunacy' Act of 1871 and created a new system of decision-making in Ireland.[3] The 2015 Act introduced multiple key changes including: tiered support arrangements, a Decision Support Service (DSS), and a new functional test of capacity. It also importantly abolished the Irish Wards of Court (guardianship) system. The principles of the 2015 Act embedded the presumption of capacity, importance of a person's wishes and the need to use the least restrictive

1 SMHLR (2022)

2 See "Supported decision-making in Scotland: discussion paper" Chapter 5 for an outline of the questions.

3 Inclusion Ireland

method of support. The introduction of this new system was seen as a largely positive step forward for the rights of disabled people in Ireland, but the Act has had notable issues at the stage of implementation.

The Irish Act has five types of support arrangements (two being 'plan ahead' arrangements). This chapter will focus on the three immediate support arrangements most relevant to people with learning disabilities[4]:

Type of support arrangement	Description
1. Decision-Making Assistance Agreement	• Person will choose a person(s) to assist them with making decisions. • Agreement is made as to what decision will be involved. • Decision making power lies solely with the person themselves.
2. Co-decision Making Agreement	• Appoints a co-decision maker: someone to make the decision jointly with the person. • Co-decision maker cannot make decisions on their own – they must be made jointly. • Co-decision maker cannot refuse to make a decision that is in line with the person's will and preference – unless they believe it will hurt the person or a third party. • Co-decision maker cannot stop the person from seeing someone or consent to restrictions of liberty. • Decision making power lies with both co-decision maker and person.
3. Decision-Making Representation Order	• Only a court can make this order. • All other options must have been explored. • Generally, Representative is known to the person, but they can be unknown appointed through DSS. • Court can decide that a least restrictive form of support is more appropriate. • Decision making power lies solely with Representative.

4 Table created using information from: the Decision Support Service Ireland

The decision support arrangements outlined above can all be 'mixed and matched.' For instance, one person could feasibly have two Assistance Agreements and one Representation Order or any other combination of arrangements, so long as each arrangement concerns a completely different decision.

As noted above, the 2015 Act also saw the creation of a 'Decision Support Service' (DSS), which is an arm of the Irish Mental Health Commission but has a separate role. The DSS oversees these support arrangements, the complaints process, and maintains a panel of possible Decision-Making Representatives (appointed by a court when a person does not have a known suitable person). The power and regulation of the Act is therefore centralised and managed by the DSS.

2.1 Analysis

The 2015 Act undoubtedly brings Ireland closer to compliance with the UNCRPD. However, there have been issues with the Act and its implementation.

The 'co-decision maker' role is one of the unique features of the 2015 Act. Some have criticised the clarity and purpose of this support arrangement[5], arguing that it functions too similarly to the Decision-Making Assistance Agreement to be useful. This is because a co-decision maker cannot refuse a decision by the person except when there is risk of "serious harm."[6] A 'joint' decision under this legislation is only valid if both parties agree, except that one party (the co-decision maker) is unable to disagree. The co-decision maker role, from this perspective, is simply there to prevent the worst from happening and contribute in the exact same way as a decision-making assistant. This reasoning is very similar to that given in the Scottish Mental Health Law Review for why a co-decision maker role was not included in their proposals for Scotland.

However, the existence of a co-decision maker role could give more legitimacy to the perspectives of the family and carers of people with learning disabilities, allowing them to be and feel more involved in the

5 B.D. Kelly (2016)

6 Decision Support Service Ireland

decision-making process from the start. The appeal of a co-decision-making agreement is that it fills a clear gap in the spectrum between a limited support option and a full support option (under a kind of substitute decision-making). According to the United Nation's Committee on the Rights of Persons with Disabilities, all support arrangements must work to reflect a person's 'will and preference' or the best interpretation of them. It could be argued then that this approach makes sense as a co-decision maker should not be able to deny the person's will and preference (unless absolutely necessary) and that the added involvement of loved ones is beneficial enough to maintain this type of arrangement.

Supported decision-making in Ireland, as discussed above, has centralised oversight through the Decision Support Service. It has only recently started operating in 2023, making it difficult to say how successful the service will be in the long term and what the implications of giving this power to a singular body will be. In particular, discussions of accountability and routes to remedy will be important as the DSS develops. There have already been significant and controversial cases of Decision-Making Representatives being appointed from the DSS instead of family members in Ireland due to perceived conflicts of interest and "despite [the family's] good intentions."

The final and perhaps most important learning point from Ireland is about how a supported decision-making regime should be implemented. Implementation in Ireland has been extremely slow, the Irish Government only set a date for the official abolishment of the wardship system in 2023. This means that many disabled people with the ability to make decisions are still subject to substitute decision making in Ireland almost ten years after seeing Supported Decision-Making realised in Irish law.

Additionally, there is general sense of the Irish health system being "unable to cope" with the changes[7], practitioners feel they have not received proper training in order to understand and implement the new system.[8] On top of this, public awareness of the legislation also seems lacking, with a majority of the public (67%) not having heard

7 Éidín Ní Shé, et al (2020)

8 ibid

of the 2015 Act.[9] The experience in Ireland should teach us a lot about implementation and what needs to be done in order to see a supported decision-making system become reality in Scotland. In briefing paper 1, it was asked (question 3): how do we make sure that a Scottish Supported Decision-Making model is implemented properly (through training, funding and capacity building)?

The reality is that SDM cannot be addressed as an independent policy area; it is inherently linked to social care, health, education, housing and more. Without proper funding, planning and capacity building in all these areas, those implementing an SDM model will be left unsupported and unable to provide the services necessary. Implementing SDM in Scotland will no doubt take time, but we should start the preparation, training and capacity building now in order to avoid people with learning disabilities having to wait a decade after a hypothetical 'Support Decision-Making (Scotland) Act' has passed to see their rights realised.

2.2 Key learning points

- Providing an inclusive spectrum of support options is necessary – finding a middle ground between limited support and substitute decision-making could provide more legitimacy to family and carers' views without requiring the disabled person lose their legal capacity. However, having too many similar options may make the system inaccessible and unclear.
- The Decision Support Service – the existence of a centralised body gives people a clear and accessible point of contact and information without burdening other services. However, there may be justified worries about concentrating all regulatory power in one place (outside of courts).
- Implementation, proper funding, and awareness raising will ultimately determine whether a Supported Decision-Making regime is successful. The Scottish Government should prioritise and plan for the changes in all relevant sectors. SDM is not a standalone policy area.

9 Safeguarding Ireland

3. Sweden

Sweden abolished guardianship for adults in 1989.[10] From this date, no adult in Sweden could be legally declared 'incapable.' Guardianship was replaced with a system of two representative types the **god man** ("good man") and **förvaltare** ("administrator"). The god man is the least restrictive of the two (the administrator is a version of guardianship) but still has wide reaching authority.

Type of support arrangement	Description
1. Good Man	• Court appointed but requiring the consent of the person themselves. • Good man must receive consent each time from the person to act on their behalf (with exceptions). • Can act on almost all matters except marriage, confirming parenthood, and signing of a will. • Operates through a 'best interests' model. • Good man has no effect on a person's legal capacity, meaning they can still make decisions, enter contracts and give consent independently.
2. Administrator	• Operates more like traditional guardianship. • Appointed if a good man is deemed not suitable, as there a risk of the good man not being allowed to do their job or a person being at risk of harm or homelessness due to their vulnerability. • Court can appoint one without the person's consent. • Must consider a person's wishes but ultimately acts in their 'best interest'. • Decision-making lies solely with the Administrator as they can take action without the person's approval.

10 Montoya (2019)

Interestingly there is no definition of 'capacity' in Swedish law. Someone perceived as needing support to make decisions via a Good Man retains their legal capacity in full in terms of their rights. This means they are not prevented from making decisions on their own in any way. Even with an Administrator, a person can still make certain decisions on their own.

3.1 Analysis

Sweden is relatively unique in their approach to 'capacity' and supported decision-making. The clear benefit of the Swedish approach is the universal presumption of capacity as the system is based on perceived need not necessarily disability. A person's legal capacity is not restricted unless absolutely necessary, and the system of support allows for flexibility (a person can make some decisions with their Good Man and some without). Importantly, this flexibility does not require a person or their family to reapply for support each time in cases of fluctuating ability.

However, the primary failure of the Swedish approach is that it is not based in international human rights norms. In fact, there has been a notable lack of impact of the Convention on the Rights of Persons with Disabilities on Swedish law and politics.[11] The Good Man support system does comply with the CRPD in some ways, but in the consideration of will and preference, it fails on several accounts. The Good Man, for example, can be appointed and take action without a person's consent in cases where they are deemed to be "unable to consent."[12] Without a test of capacity it is not clear how the ability to consent is determined. Furthermore, very little guidance or accountability exists in Sweden for how a Good Man must act when a person is unable to consent to a decision. This means that there is effectively no consequences for a Good Man who chooses not to consider the person's will and preference.

In the first paper we asked (question 5) about the relationship between capacity, support and non-consensual treatment. It is important to remember when attempting to answer this question, that human rights approaches to disability should aim to move away from the medical model of disability. Mental capacity is a difficult concept to define and

11 Nilsson (2024)

12 Montoya (2019)

measure. People's ability to 'understand' can fluctuate greatly depending on external factors and the support available to them.[13] The Swedish approach ('godman'), although highly imperfect, shows us it is possible to create a supported decision-making system that is not overly reliant on capacity tests or medical assessments of disability. It is also demonstrates the importance of good and clear guidance. Much of the Swedish legal 'grey areas', mean that is there is a lack of accountability and clarity over how certain cases should be handled. The onus is often on individuals and families (who historically have been reluctant to go to court when discrimination occurs[14]) to seek out support and routes to remedy.

3.2 Key learning points

- The existence of substitute decision-making options does not necessarily require the removal of legal capacity.
- Robust systems of guidance and accountability are essential for decision-making supporters to properly fulfil their role.
- Supported Decision-Making regimes should be based in human rights norms. Obligations of duty-bearers should be clearly defined in accordance with the UNCRPD.

4. Canada (British Columbia)

Supported decision-making in Canada dates back to the 1970s. In Canada, legislation concerning capacity and decision-making support falls within provincial jurisdiction. The Representation Agreement Act (1996) was the first of its kind in the world, providing the legal basis for Supported Decision-Making in British Columbia. British Columbia (BC) and it's SDM approach has been recognised by the United Nations as "one of the leading jurisdictions in incorporating supported decision-making into law."[15]

13 Brown (2023)

14 European Union Agency for Fundamental Rights (2009)

15 Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol

The BC Representative Agreement Act provides a relatively simple, cheap and effective way for people with learning disabilities to formally recognise one or more people in their life as their Representative(s).[16] Agreements come with two different sets of powers; Section 7 and Section 9 powers. People with learning disabilities and their families will sign agreements under Section 7 (which is defined as for adults whose mental ability to 'understand' is in question).

Type of Representative agreement	Description
Representative with powers of Section 7 ('standard powers').	• Powers include: routine management of finances, minor and major health care, personal care and obtaining legal services. • Requires a monitor to be named if finances are included. Unless representative is a spouse or two people (or more) acting jointly. • For adults whose mental ability to 'understand' is in question.
Representative with powers of Section 9.	• Includes broader powers and more strict criteria for the creation of the agreement. • Powers include: authority to refuse types of health care, making arrangements for young children, consent to health care the person wanted when well but refuses when ill, and power to physically restrain and move the person even when they refuse. • For adults (19+) who are considered capable of understanding the nature of the S9 at the time of making it. • Consultation with a lawyer is required for this agreement.

Importantly having a Representative Agreement does not remove someone's own ability to act if they are capable (retaining their legal capacity) and having an agreement is not required to access any other goods, support or service.[17] Representatives (under S7 powers) are also

16 Stainton (2015)

17 Representative Agreement Act (3.1)

required, in line with UNCRPD, to act in accordance with a person's will preference when making substitute decisions (decisions on their behalf).

4.1 Analysis

The positive features of this legislation are its unique approach to assessing capacity and its strong basis in drawing support from a person's existing personal networks and community.

Someone's ability to enter an S7 Representative Agreement is determined by assessing "all relevant factors" including whether the person communicates a desire for help with a decision, whether they can express feelings of approval or disapproval and whether they have a relationship with their Representative that is built on trust.[18] Unlike other capacity or decision-making legislation internationally, the BC Act does not require a disabled person to understand a decision or its consequences to receive this type of support. The BC approach embraces a social model of capacity by expanding upon the nature of capability to include emotions, relationships, and non-traditional ways of communicating.

This innovative approach to Representative Agreements means that they can be based solely on someone's **trust** in their personal networks (their family, friends, carers and the wider community). Especially for people with profound learning disabilities, this provides a way of accessing decision-making support without having to give up their 'personhood' or rights as they do not need to demonstrate traditional 'legal competency'.

However, this legislation has been criticised for providing no access for people with learning disabilities to the powers covered by S9.[19] S9 does require the disabled person to be capable of understanding the authority they are giving to their Representative, meaning that many people with profound disabilities and their Representatives will be unable to access this section of powers for more critical decisions.

18 Representative Agreement Act (8)

19 Stainton (2015)

In our first discussion paper we asked (question 2) whether one model of supported decision-making can work for all people with learning disabilities? A clear strength of the British Columbian approach in relation to this is its flexibility and inclusive take on the assessment of capacity. Agreements are designed and adapted by the person and their supporters for their specific situation. Despite this though, some are still left feeling like they are unable to fully support their loved one with profound disabilities.

4.2 Key learning points

- Approaches to assessing capacity can be expanded to better reflect the social model of disability. The way a person communicates or their lack of ability to 'understand' should not result in a loss of personhood.
- There is merit in avoiding support systems which overly 'professionalise' decision-making and making use of existing support networks where possible.
- Debates around how (or even whether) capacity should be assessed should include people across the spectrum of learning disability (especially considering the needs of people with profound and multiple disabilities).
- Support arrangements should be as flexible as possible to accommodate a range of disabled people and circumstances.

5. Conclusion

Supported decision-making can take many different forms. The best method and implementation of a decision-making system will depend on a country's context, structures, and importantly the people using it. Nevertheless, there is clearly a lot to learn from those who have already created working Supported Decision-Making approaches and systems. The three cases studies discussed above give us a reference point when beginning to think about what we want a Scottish Supported Decision-Making system to look like. Particularly in the important areas of capacity assessments, types of support arrangements, and implementation.

This paper is the second part of a series of resources written by SCLD, aiming to engage wider stakeholders in discussions around Supported Decision-Making and Mental Health and Capacity Law Reform. It has attempted to address some of the key questions posed in SCLD's first discussion paper on Supported Decision-Making using case studies from the Republic of Ireland, Sweden and Canada.

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