

Scottish Commission for People
with Learning Disabilities



Supported decision-making in Scotland: discussion paper

2024

Glossary of key terms

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| 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. |

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1. Introduction

Decision making is an integral part of life. Many of us make decisions every day; about where we want to live, who we want to see or what we want to spend money on. People with learning disabilities are often prevented from making decisions about their own lives based on their deemed 'lack of capacity' and are therefore denied many of their human rights. In the last two decades, a new human rights-based approach to decision-making for people with learning disabilities has emerged and garnered international attention. This approach is called Supported Decision-Making (SDM) and aims to dismantle and replace existing practices of 'substitutive' decision-making (e.g. guardianship schemes) which allow others to make decisions on behalf of the disabled person themselves.

This discussion paper outlines the international legal context and importance of SDM, particularly in light of the Scottish Government's commitment to reform Scottish Mental Health and Capacity law and contributes to the seminal work done by other Disabled Persons Organisations in Scotland to forward SDM (particularly People First's framework¹). It concludes with some of the key questions that must be answered by the Scottish Government and other stakeholders in order to ensure an SDM model is properly implemented in Scotland.

¹ [People First \(2017\)](#)

2. Background

2.1 What is Supported Decision-Making?

Supported decision-making, put simply, is a human rights-based approach to decision-making for people assessed as having limited mental capacity, which centres a person's 'will and preference.' The supported decision-making paradigm emerged in the 1980s in Canada.² At this time, the purpose of supported decision-making was about "removing the barriers that prevented people with disability from exercising their right to make decisions by providing them with the support necessary."³ SDM has since developed largely as an alternative to the legal frameworks created across different jurisdictions for substitutive decision making. Substitutive decision-making happens when a third party makes a decision about a person "in their best interests" without considering that person's own will and preference.⁴ SDM approaches reject the use of substituting decisions and maintain that a person-centred approach should always be taken. From a human rights perspective, having a learning disability diagnosis or support needs should not warrant the removal of someone's human rights or the opportunity to make their own choices. These are the foundational principles of SDM, that someone's 'will and preference' should be central to any decision made about their life.

Supported Decision-Making

"A supported decision-making regime comprises various support options which give primacy to a person's will and preferences and respect human rights norms."

More specifically, in a human rights context SDM is inherently linked to a person's right to exercise their legal agency. The United Nations Convention on the Rights of Persons with Disabilities ('the Convention'), ratified by the UK in 2009, obligates that state parties respect, protect

² [Michelle Browning \(2021\)](#)

³ [Anna Arstein-Kerslake et al. \(2017\)](#).

⁴ [UNCRPD General Comment 1](#).

and fulfil the rights of disabled people on an equal basis with others. The Convention has been a key driver in the promotion and development of SDM internationally. Article 12(3) of the Convention, the Right to Equal Recognition Before the Law, forms the legal basis for SDM, as it requires state parties to “take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”⁵ The ‘support’ referred to as part of SDM can take a variety of forms and is defined very broadly; self-advocacy support, assistance with communication, accessible information formats and any other method of helping a disabled person to process information and make a decision.⁶

Although not mentioned explicitly in the Convention itself, an SDM model is, in the Committee on the Rights of Persons with Disabilities’ (‘the Committee’) view, essential to the fulfilment of Article 12 as well as many other rights detailed in the Convention.

As the Convention’s General Comment 1 states “without recognition of the person as a person before the law, the ability to assert, exercise and enforce those rights, and many other rights provided for in the Convention, is significantly compromised.”⁷ SDM is arguably the foundation of many human rights for people with learning disabilities. This underlies the importance of an SDM model as a mechanism for realising the rights of people with learning disabilities in Scotland and internationally. The purpose of SDM, and in fact the Convention itself, is not to make new rights but to reaffirm existing rights in the context of disability.⁸ SDM is therefore not a right in and of itself but a method of ensuring disabled people’s legal capacity and their right to access support is not unjustly denied. The UN Convention and the Committee make clear that lack of deemed mental capacity on its own should not warrant the removal of legal capacity in any case.

Legal capacity

Someone’s ability to make decisions and hold rights.

⁵ [UNCRPD, Article 12\(3\)](#)

⁶ [UNCRPD General Comment 1, para 17](#)

⁷ [UNCRPD General comment 1, paragraph 31](#)

⁸ [Piers Gooding \(2015\)](#)

2.2 Controversies and issues

Although those who advocate for a human rights-based approach to disability should always support some form of SDM, it is important to acknowledge that there are difficult questions that need to be addressed. Firstly, whether one model of support fits all people with disabilities. People with profound and multiple learning disabilities may need a 100% support model (akin to Guardianship) or a co-decision maker approach.⁹ The UN Committee suggests that when ‘will and preference’ cannot be legitimately determined that ‘the best-interpretation of someone’s will and preference’ should be used.¹⁰ However, this raises the question of how an ‘interpretation’ can faithfully be made for someone with a profound learning disability.

It is also essential not to underestimate the level of skill and resources that are required to support someone to make a decision without influencing or interfering with them. This is especially difficult in situations where someone appears to be making a decision that will negatively affect them or put them at risk. SDM firmly allows people with disabilities to make their own mistakes just like anyone else. However, this may be difficult for some practitioners or carers who feel it conflicts with their duty of care.

None of these issues dispute the value of SDM, they instead highlight the need for careful consideration of how an SDM model may be implemented. People with learning disabilities are a diverse group with a range of support needs and contexts. Any SDM system should then carefully consider the views of people with lived experience and their carers.

⁹ [Citizens Information Ireland \(2023\)](#)

¹⁰ [UNCRPD General comment 1, paragraph 21](#)

2.3 Considering the views of people with lived experience

Previous research exploring SDM and the views of people with learning disabilities specifically has highlighted that implicit “presumptions of (in)competence” can greatly impact someone’s confidence and ability to live an independent life.¹¹ When asked, people with learning disabilities have emphasised that although being given the opportunity to make decisions is positive, independence should not equal lack of support.¹² In SCLD’s own Universal Periodic Review focus groups in 2021, people with learning disabilities felt “that guardianship orders result in serious restrictions to their choice, autonomy and privacy.”¹³ It is because of these concerns that disabled people’s organisations in Scotland have long advocated for a SDM model.¹⁴ For people with learning disabilities, guardianship and particularly indefinite orders represent a serious risk to their human rights. Other studies have highlighted the general lack of public awareness of Mental Capacity legislation in Scotland and England, even people with guardianship have been found to have limited knowledge of their obligations and the options available to them, often citing “a lack of alternatives.”¹⁵ This demonstrates the need for more general awareness raising and further research.

¹¹ [Kate MacLeod \(2017\), p. 198; Dorothy Squatrito Millar \(2013\)](#)

¹² [P Webb et al. \(2020\)](#)

¹³ [The State of Our Rights \(2023\), p. 35](#)

¹⁴ [People First \(2017\)](#)

¹⁵ [Sam Wilson \(2017\)](#)

3. The current legal context in Scotland

Disability rights, being a relatively new area of international law, is expanding and developing quickly. Much of Scotland's current mental capacity legislation, at the time of its writing, was widely considered good practice and was welcomed by many disability rights organisations. It had person-centred principles and was largely based on the rights set out in the ECHR.¹⁶ However, even the ECHR (ratified into UK law by the Human Rights Act [1998]) is now considered outdated in respect to disability rights, as its only explicit mention of disabled people is considered offensive and stigmatising (“persons of unsound mind.”)¹⁷ Given the new legal context of the Disability Convention there has been wide-spread recognition of the need to review and reform current legal frameworks and systems.

3.1 Adults with Incapacity (2000) Act and Guardianship

Currently, Scottish mental health and capacity law does not reflect a supported decision-making model as it allows for substitute decision-making by third party decision makers. The Adults with Incapacity (Scotland) Act legislates for people deemed to lack or have limited capacity in Scotland and has raised a number of human rights concerns (particularly regarding Article 12, 14 and 19 of the Convention).¹⁸ A feature of the Act is that it allows for the issuing of a guardianship order. A guardianship order appoints a guardian who can make welfare and financial decisions for a person long-term. We know that the number of people subject to a guardianship order in Scotland has been steadily rising and that applications for orders are very unlikely to be denied. 17,849 Scots were living with a

Guardianship Order

A court order which allows a third party to make decisions on behalf of a person deemed unable to make their own decisions.

¹⁶ [Jill Stavert \(2018\), p. 6](#)

¹⁷ [ECHR, Art 5\(1\) sub-para \(e\)](#)

¹⁸ [UNCRPD, Art 12, Art 14, Art 19.](#)

welfare guardianship order in March 2023 – the highest ever recorded level.¹⁹ The most common diagnosis among these people was a learning disability (46%). Although Principles 2 and 4(a) of the AWI Act require that the least-restrictive option possible is taken and that any decision made must take into account a person’s wishes²⁰, we know that for many people with a learning disability, this is not the reality in practice.

Considering that the Scottish Government has previously committed to implementing a form of supported decision-making into Scots law, and that the reformation of the Adults with Incapacity (2000) Act and the Mental Health (2003) Act is of particularly high priority, we have an important opportunity in Scotland to ensure that SDM, the foundation of many human rights for people with learning disabilities, is concretely embedded in Scots capacity law and more generally our health and social care practices.²¹

¹⁹ [Mental Welfare Commission for Scotland \(2023\)](#)

²⁰ [Adults with Incapacity \(Scotland\) Act 2000](#)

²¹ [Scottish Government \(2023\)](#)

4. Mental Health Law Reform: the future of SDM in Scotland?

The Scottish Mental Health Law Review (SMHLR) was published in 2022²², following on from other similar reviews and consultations including the AWI Act consultation in 2018²³ and Rome Review (IRMHA) in 2020.²⁴ The SMHLR was a comprehensive review of all Mental Health and capacity law in Scotland. It set out key recommendations to the Scottish Government on how it believes the legislation should best be reformed with a ‘Human Rights Enablement Framework’ in mind. Since there is yet to be a concrete legislative programme from the Scottish Government covering Mental Health law reform and SDM, the SMHLR is one of the only blueprints we have to determine how an SDM model may eventually be implemented in Scotland. It should be noted here that given the length of this paper; it was not possible to address every point in the SMHLR. The Chapter will instead cover the two suggested changes most relevant to people with learning disabilities and the context of SDM.

4.1 Supported Decision-making framework.

The SMHLR adopts a definition of SDM which “includes support for the exercise of legal capacity.”²⁵ It importantly notes that, contrary to the UN committee’s view, they still believe that there is sometimes a need for non-consensual interventions, and these should be provided for in law. The report includes SDM as part of the Human Rights Enablement framework which should aim to “maximise a person’s ability to make an autonomous decision and ensure that priority or ‘special regard’ is given to a person’s will and preference.”²⁶ This would be supposedly achieved through the changes to the AWI Act and SIDMA capacity tests outlined below.

²² [Scottish Mental Health Law Review \(2022\)](#)

²³ [AWI Act consultation \(2018\)](#)

²⁴ [Rome Review \(IRMHA\) \(2020\)](#)

²⁵ [SMHLR \(2022\), p. 115](#)

²⁶ [Ibid, p. 792](#)

4.2 Graded Guardianship

As part of the AWI Act reformation, the SMHLR recommends a new system of ‘graded guardianship’ with three tiers of supporting agent:²⁷

1. Decision-Making Supporter
2. Person appointed under Power of Attorney
3. Decision-Making Representative

Tier 1 **DM Supporter(s)** would be appointed in cases where someone is able to make an autonomous decision. They would be required to support the individual; to communicate, process information, agree timeframes and establish their will and preference. The Supporter would have no formal legal powers and the decision would remain solely with the individual. However, the Supporter would likely be registered with the Office of Public Guardian to provide ‘legitimacy’ to the role.

The already existing model of **Power of Attorney** is not significantly changed under the recommendations. Some additions are suggested including: the certification process becoming an NHS service, more clarity as to when POA begins and ends and the development of an investigatory framework.

Tier 3, the **DM Representative**, is the proposal that effectively replaces guardianship. A DM representative(s) would be appointed with judicial oversight and may have health, welfare, property and/or financial powers. The representative must act within the framework of SDM and therefore would make decisions based on the will and preference of the disabled person (or the best interpretation of their will and preference). They would be supervised by the Public Guardian in respect of financial matters and by the Local Authority in welfare decisions. The DM representative may not therefore be significantly different from a Guardian under the current system but would be subject to the new SDM and human rights enablement framework.

²⁷ See full explanation: [SMHLR \(2022\), p. 721 -725](#)

4.3 Autonomous decision-making and non-consensual intervention

The proposals suggest that the current capacity and SIDMA tests be replaced with a ‘Autonomous Decision-Making (ADM) test’, “as it provides a more rights-based criterion for non-consensual intervention.”²⁸ The ADM test would only be used when non-consensual measures are being considered. The test “should include input from the person themselves, and with their consent, carers and family members [...] as well as anyone with relevant proxy decision making powers.”²⁹ The key difference between ADM test and SIDMA tests, the review argues, would be that it is not confined to a diagnosis of ‘mental disorder’ and that the ADM would not automatically allow non-consensual intervention.

4.4 Discussion

This proposed system is certainly more akin to the SDM framework the UN Committee intended. However, as SCLD has previously made clear,³⁰ the consideration of mental health and learning disability together is problematic (people with learning disability are included in the definition of ‘Mental Disorders’ and subject to the deprivation of liberty powers under the Mental Health Act) and risks erasing the specific issues that people with learning disabilities face.

This is clear in the approach which arguably uses an “on and off” view of capacity and decision-making. The options for support with decision-making suggested are still very binary and might not work for someone with fluctuating abilities. A person with a learning disability may need an option of support which is between a Supporter (minimal / no role in the decision itself) and a Representative (full control of the decision). The omission of a co-decision maker role from the proposals, as seen in Ireland³¹, is perhaps something still worth re-considering. As one model of decision-making may not work for everyone, especially considering

²⁸ [SMHLR, p. 250](#)

²⁹ [SMHLR, p. 251](#)

³⁰ [SCLD \(2023\)](#)

³¹ [Valerie E Murphy et al \(2020\)](#)

the wide range of people this legislation covers: disabled people, people with dementia, people in mental health crisis and people incapacitated temporarily via injury or other medical issues.

Additionally, the new Representative role is arguably just a rebranded Guardianship Order. It is therefore important to question why this model would be implemented differently from the current system. People may be asked to act in accordance with a person's will and preference but it will be difficult to enforce this on an individual basis, especially given the historical treatment of people with learning disabilities. The strength of the SDM framework and principles must be enacted in practice to avoid human rights violations.

Further clarity will also be needed in a variety of areas. For instance, the precise role of the Supporter is somewhat undefined. What is the exact extent of their involvement in a person's decision-making and how does this differ from independent advocacy? Additionally, it is unclear how an ADM test would work in practice. What would it specifically involve and how does it differ from other capacity tests? How does it relate to whether a non-consensual decision is made, if not automatically allowing it? The SDM and HRE framework look positive on paper, but the quality of implementation will be essential. Will there be a specific duty on public organisations to follow a national SDM framework or create their own? How will training and capacity building be provided?

Furthermore, will the whole system be accessible for people with learning disabilities and their loved ones? Accountability, monitoring processes and routes to remedy need to be clearly defined. The extra administrative burdens required under a new system like this will already be a worry for families and carers, as well as practitioners. Significant awareness building, training and resources will be required to ensure that nobody is left behind.

Overall, the proposals lack the detail necessary to know if it can really bridge the gap between theory and practice. Revising the legislative framework and principles surrounding decision-making and capacity in Scotland is absolutely essential but much more work is needed to be done in order to answer these questions, as well as more generally change social attitudes about our approaches to care and de-stigmatise the notion of people with learning disabilities making choices.

5. Questions

1. Can an SDM model ever work for people with learning disabilities under 'Mental Health' legislation?
2. Can one model work for everyone? i.e. We need a spectrum of support including maybe a 100% support or co-decision maker approach.
3. How can a new system be made properly accessible and understandable to everyone? Including the accountability and routes to remedy.
4. The SMHLR emphasises the importance of funding, guidance, training and capacity building.
 - a. What does 'SDM training' look like?
 - b. How do we ensure practitioners have the resources to embed SDM into their work?
 - c. What is the economic cost of SDM? How is it being funded?
5. How would an 'ADM' test work in practice?
 - a. How is this different from other capacity tests?
 - b. The SMHLR has suggested that a capacity test result would not automatically lead to non-consensual treatment - if so, what is the relationship of the test to whether agency is removed?
6. Indefinite guardianship was not discussed in the review. Is a new SDM system removing the option of long-term substitute decision-making?
7. How can we know that a reformed system would overcome current problems considering the principles of the AWI Act are somewhat in line with SDM already?
8. Do we need a national SDM framework, and should there be a formal duty on public organisations and/or care providers to follow this?
9. Are there ways current existing structures can be used to better implement SDM? Such as Scotland's strong independent advocacy organisations or a reformed Self-Directed Support system.

6. Conclusion

Although we are likely a while away from having a Scottish SDM framework and Mental Health and Capacity legislation in Scotland which properly reflects human rights norms, the work has definitely started. It is difficult to know how many of the SMHLR's recommendations will be adopted by the Scottish Government in reality, but the response so far indicates that the actual changes will be significantly weaker in the short term ("we will consider making smaller but significant amendments to the process of Guardianship to improve its efficiency"³²). Despite this, continued discussion surrounding SDM is essential as we reaffirm the rights of and advocate for people with learning disabilities.

This paper has attempted to highlight some of the contentions and questions surrounding SDM in the Scottish context, and in doing so allow those unfamiliar with SDM and the law reform programme in Scotland to engage with the topic and share their views.

³² [The Scottish Mental Health Law Review: our response, p. 20](#)



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