Scottish Commission for People with Learning Disabilities

SCLD

Legislative, cultural and practice perspectives informing

Supported Decision Making in Scotland.

2025

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Contents

1. Executive Summary

Supported decision making (SDM) is a process which involves working with someone to assist them to make their own decisions. It includes many different models and practices and involves both informal support, such as friends and family, and formal support such as independent advocates or official supporters. The aim of SDM is to ensure that people feel heard and to respect and give effect to their wishes. Effective SDM includes good communication and providing people with information in suitable formats; ensuring people have sufficient time and a range of options; and avoiding undue influence.

In recent years, there have been significant developments in human rights law including the United Nations Convention on the Rights of Persons with Disabilities (CRPD). This has led to demands for guardianship and non-consensual care and treatment under mental health and capacity law to be reformed and replaced with SDM structures. However, concerns have been expressed that the CRPD's approach to 'legal capacity' could put people at risk of not receiving necessary support, care and treatment. And there remains a degree of tension between demands for greater decision-making autonomy, and the current legal framework and associated practice in Scotland.

At present, many people with learning disabilities in Scotland continue to have some decisions made for them based on their perceived 'best interests', and as such, the development of their decision-making skills, and their 'will and preferences' may be overlooked or ignored. People with learning disabilities have reported feeling more independent and empowered when they are enabled to have greater choice and control and support to make decisions. Limiting people's ability to make decisions, on the other hand, can lead to feelings of powerlessness and frustration and may reinforce stereotypes which undermine self-respect and dignity.

Whilst SDM takes many different forms including independent advocacy, non-instructed advocacy, advance statements, 'circles of support' and communication and decision-making tools such as 'Talking Mats', research has pointed to a lack of general understanding and some distrust about what SDM entails. There have been calls for more research on SDM, alongside increased education and training to embed SDM in professional

practice. An important consideration for the effective implementation of SDM is how to manage potentially harmful decision-making and risk averse practice may present a challenge to supporting and enabling people with learning disabilities to make informed calculations of risk.

Sweden and Australia provide some useful learning for the implementation of SDM in Scotland. Approaches to the development of decision-making skills of people with learning disabilities in the Swedish education system have highlighted the value of building confidence and increasing awareness of the different types of decisions that people face throughout their lives including relationship management, voting, and career choices.

Studies in Australia, suggest that the provision of training and support mechanisms for both formal and informal supporters, alongside the development of community networks, can be effective in enhancing decision-making autonomy for people with learning disabilities. Australia also offers learning for Scotland around the importance developing frameworks which support implementation of SDM and the role of good practice guidelines to facilitate consistency in practice.

In Scotland, there have been two national reviews, the Rome Review and the Scottish Mental Health Law Review (SMHLR) which both considered SDM and the exercise of 'legal capacity' in detail and made recommendations to the Scottish Government. The SMHLR recommended replacing capacity-based assessments with a more holistic approach of autonomous decision-making (ADM) test, supported by a human rights enablement approach and comprehensive SDM scheme. The Scottish Government has responded to the SMHLR and produced a Mental Health and Capacity Reform Programme Delivery Plan which includes several objectives and actions with regards to enhancing support for decision-making. This includes consideration of whether a national framework or approach is needed.

It will be important that any development of a national strategy or approach for SDM, recognises that SDM is critical not only for the exercise of legal capacity but also for enabling people with learning disabilities to realise the right to independent living in the community. This requires support for people with learning disabilities to exercise choice and control across a wide range of areas such as education, employment, housing, social security, family life and sexual relationships.

Ultimately, the effective implementation of SDM in Scotland may require changes not only to law and practice but also to how we view and value people with learning disabilities as a society. Delivering these changes for Scotland will require strong leadership as well as significant and sustained resourcing at a national and local level.

2. Introduction

We all seek advice and assistance from friends and family as well as experts to make decisions in everyday life. This can range from advice on relatively minor issues to complex considerations such as buying a house or health care, and these considerations are influenced by a myriad of different factors and circumstances.

People with learning disabilities can benefit from additional support with these decision-making processes. However, their autonomy is often severely restricted by laws and practices which assert that they are not capable of making decisions for themselves.

Supported decision-making (SDM) is a process which involves working with someone to assist them to make their own decisions. It is support that helps a person to form a view about what they want to happen and to make that happen. It includes support for the person to put those decisions into effect and can include support to challenge barriers that disable the person.[1]

SDM includes a multitude of different models and practices and involves both formal and informal support, such as friends and family or independent advocates or supporters. The exact form SDM takes varies depending on an individual's support needs, however building effective relationships between supporters and supported individuals is vital to the process.[2]

At present, forms of substitute decision-making, such as guardianship, are commonly used in Scotland where an individual is assessed as 'lacking capacity'.[3] However, in recent years there have been significant developments in human rights law leading to demands for guardianship and non-consensual care and treatment under mental health and capacity law to be reformed and replaced with SDM structures.[4]

1 Rome Review, Independent Review of Learning Disability and Autism in the Mental Health Act (2019)

2 Gillespie L and McCusker P, 'Supported decision making' (Insights 73, Iriss 2023)

3 Ibid p 4-5

4 Mental Welfare Commission for Scotland and Centre for Mental Health and Capacity Law (Edinburgh Napier University), Mental Health and Capacity Law: the Case for Reform (2017)

This report seeks to provide an overview of some relevant literature relating to legislative, cultural and practice challenges for SDM in Scotland alongside some learning from Australia and Sweden.

3. Legislative Context in Scotland

The Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003 are two key pieces of legislation which impact the decision-making autonomy of people with learning disabilities in Scotland. These laws permit substitute decision-making for people with learning disabilities based on an assessment of incapacity or significantly impaired decision-making ability (SIDMA).

The Adults With Incapacity (Scotland) Act 2000

At present, the Adults with Incapacity (Scotland) Act 2000 (2000 Act) provides several different mechanisms for substitute decision-making on the grounds of lack of capacity. These include intervention orders, guardianship orders and power of attorney. The 2000 Act defines incapacity as being incapable of acting, making decisions, communicating decisions, understanding decisions, or retaining memories of having made decisions in relation to any particular matter due to mental disorder or inability to communicate because of physical disability.[5]

The 2000 Act is governed by a set of principles:

- No one should intervene under the Act unless they are satisfied that the action will benefit the adult and that this benefit cannot reasonably be achieved without the intervention [6]
- The intervention must also be the least restrictive option available[7]
- Anyone determining whether to intervene, and what intervention to make, should take account of the past and present wishes and feelings of the adult [8]

5 Adults with Incapacity (Scotland) Act 2000 (asp 4) s 1(6)(a)-(e)

6 ibid, s 1(1)-(2).

7 ibid, s 1(3).

8 ibid, s 1(4)(a)-(c).

- The views of relatives and their primary carers should be factored in, as well as any guardian or attorney, or welfare attorney [9]

- The adult should be encouraged to exercise their own abilities regarding their property, financial affairs, and personal welfare, as well as develop new skills in these areas. [10]

A financial or welfare guardianship should be granted where someone is judged to be incapable of safeguarding their own interests [11] regarding their property, financial affairs or personal welfare and where no other means within the Act would protect these interests. A welfare guardian might be a relative, friend or a carer. The court can also appoint the chief social work officer of a local authority to be a person's welfare guardian. Local authorities also have a duty to make an application for welfare guardianship where it is needed and nobody else is doing so. [12]

Local authorities have a duty under the 2000 Act to supervise all welfare guardians, and to visit the guardian and the adult at regular intervals. They are required to consult with the Public Guardian and Mental Welfare Commission and investigate and receive any complaints. [13]

Mental Health (Care and Treatment) (Scotland) Act (2003)

The Mental Health (Care and Treatment) (Scotland) Act 2003 (2003 Act) applies to people who have a 'mental disorder'. This is defined under the Act and includes any mental illness, personality disorder or learning disability. The Act permits non-consensual care and treatment for people with a 'mental disorder' and other criteria including having Significantly Impaired Decision Making Ability and posing a significant risk to the safety or welfare of themselves or others. [14]

9 ibid, s 1(4)(a)-(c).

10 ibid, s 1(5).

11 ibid, s 58(1)(a)-(b).

12 ibid, s 65.

13 ibid, s 10(1)(a)-(e).

14 Mental Health (Care and Treatment) (Scotland) Act 2003

The 2003 Act gives everyone with a learning disability the right to access independent advocacy support and requires local authorities and health boards to provide this. It also includes additional forms of support that assist an individual's wishes and feelings to be known including advance statements.

In 2015, the 2003 Act was amended to include provisions intended to promote and reinforce the supportive role played by advance statements and independent advocacy. This included requiring local authorities, Health Boards, and the State Hospitals Board for Scotland to provide information to the Mental Welfare Commission about how they are meeting their duties under the Act to provide independent advocacy services. [15]

The 2003 Act also includes a requirement to allow the patient to participate as fully as possible in care and treatment decisions and to provide information and support to enable them to do so. However, whilst the principles that underpin the legislation seek to maximise the exercise of capacity, they are not subject to a hierarchy and therefore the individual's wishes and feelings are not afforded any primacy. [16]

15 Mental Welfare Commission for Scotland, The Right to Advocacy (2023)

16 Mental Welfare Commission for Scotland and Centre for Mental Health and Capacity Law (Edinburgh Napier University), Mental Health and Capacity Law: the Case for Reform (2017)

4. Human Rights and SDM

United Nations Convention on the Rights of Persons with Disabilities (CRPD)

The UK ratified the CRPD in 2009 and is obligated to fully realise all the rights and freedoms contained within the treaty. There are several key principles underpinning the CRPD that are fundamental to SDM. Firstly, respect for an individual's autonomy and their dignity in making their own decisions; secondly, enabling full participation and inclusion in society; thirdly, equality in opportunities and accessibility. [17]

Critically, Article 12 of the CRPD: Equal recognition before the law requires;

> States Parties shall take appropriate measures to provide access to persons with disabilities to the support they may require in exercising their legal capacity…
>
> States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law.

Therefore, the CRPD requires that people with disabilities enjoy legal capacity on an equal basis with others, and as such, states are obligated to assist and support them to exercise this.[18] States must also put in place effective safeguards to prevent abuse, give effect to the 'will and preferences' of the individual concerned and and ensure steps are taken

17 United Nations Convention on the Rights of Persons with Disabilities (adopted 12 December 2006, entered into force 3 May 2008) 3 UNTS 2515 (CRPD), preamble

18 ibid, art 12(2)-(3)

to prevent the occurrence of conflicts of interest and undue influence. [19] Furthermore, each safeguard must be tailored to the individuals concerned and only apply for the shortest period necessary. [20] It is also important to stress that the CRPD states that all people with disabilities must be recognised as equal before and under the law and, as such, are entitled to equal and effective legal protections and benefits. [21]

UN Committee on the Rights of Persons with Disabilities General Comment No.1

The UN Committee on the Rights of Persons with Disabilities General Comment No.1 develops the obligations of states in fulfilling the rights contained under Article 12. This has been viewed by many as a radical interpretation and as necessitating a 'paradigm shift' in approaches to mental health and capacity law. [22]

The Committee took the position that there are no circumstances under which it is permissible to derogate from the right to equality before the law. It commented that historically the legal capacity of people with disabilities has been restricted under substitute decision-making frameworks, such as guardianship and forced treatment laws under the guise of mental health law. [23] It stated that such these practices must be abolished if the legal capacity of people with disabilities is to be fully realized. [24]

The Committee noted a distinct difference between mental and legal capacity. Mental capacity relates to decision-making skills of individuals, which vary from person to person, and can differ in many different situations. [25] Legal capacity, on the other hand, is a universal attribute that an individual has by nature of being human. It refers to the ability to have rights and to exercise them. Under the CRPD, therefore, the Committee said perceived or actual

19 ibid, art 12(4)

20 ibid, art 12(4)

21 ibid, art 5(1)-(2)

22 Stavert, J 'Paradigm Shift or Paradigm Paralysis? National Mental Health and Capacity Law and Implementing the CRPD in Scotland' (2018)

23 ibid, para 7

24 ibid, para 7

25 ibid, para 13.

in mental capacity, cannot be used as justification for denying legal capacity.[26]

The Committee suggested that people with 'cognitive disabilities' are disproportionately affected by substitute decision-making regimes and the denial of legal capacity. It said that a person's disability or impairment should never be used as a basis for denying legal capacity under Article 12.[27] In turn, it stipulated that all domestic laws, practices, and policies limiting Article 12 rights should be abolished.[28]

The Committee noted that the type of decision-making support one requires will vary from person to person.[29] It suggest that any SDM framework should encompass the following:

- SDM must be available to everyone; based on the will and preference of individuals, not best interests
- Different forms of communication must not act as a barrier
- States should make support networks in communities available to those who are more isolated
- Financial costs should not be a barrier to the accessibility of support
- SDM should not be used as justification to limit other rights, such as voting or forming intimate relationships
- There should be a right to change or refuse support
- There must be effective safeguards in place

26 ibid, para 13.

27 ibid, para 9.

28 ibid, para 13-14

29 ibid, para 18.

- Capacity assessments should be replaced by assessment of support need.[30]

The Committee also highlighted that states are obligated to take steps towards the full realization of the rights under Article 12 in cooperation with people with disabilities and their organisations.[31] Additionally, the Committee commented that accessibility to information impacts the full realization of legal capacity, and it is up to states to ensure that all information regarding the exercising of legal capacity is accessible.[32]

Legitimate and proportionate restriction of rights

Whilst the Committee advocated for a universal approach to legal capacity, there has been concern that this could lead to a system which values the protection of autonomy over other human rights. Craigie has suggested this could leave potentially vulnerable individuals exposed to harm and lead to violations of other rights contained in the CRPD and other human rights treaties.[33]

There has also been concern expressed about systems of SDM which lack effective safeguards. There has been considerable discussion concerning the need for approaches to SDM to be balanced and Stavert has explored opportunities to work within substitute decision-making frameworks, provided that an individual's will, and preference are given proper respect in a way that least restricts their rights.[34]

Indeed, different opinions have been taken by UN bodies on legitimate and proportionate restriction of rights, in particular regarding coercion and deprivation of liberty. The UN Human Rights Committee for the International Covenant on Civil and Political Rights (ICCPR) has said with respect to Article 9 (Liberty and Security of Person):

30 ibid, para 29.

31 ibid, para 30.

32 ibid, para 37.

33 Craigie, J et al, Legal capacity, mental capacity and supported decision-making: Report from a panel event (2019), 167

34 Stavert, J, Supported Decision-Making and Paradigm Shifts: Word Play or Real Change? (2021)

> The existence of a disability shall not in itself justify a deprivation of liberty but rather any deprivation of liberty must be necessary and proportionate, for the purpose of protecting the individual in question from serious harm or preventing injury to others. It must be applied only as a measure of last resort and for the shortest appropriate period of time, and must be accompanied by adequate procedural and substantive safeguards established by law. [35]

The Case for Reform report highlights that the authorisation of such restrictions on rights, based on certain legal conditions and where appropriate safeguards exist, remains prevalent in many countries around the world including Scotland. [36]

35 Surveying the Geneva impasse: Coercive care and human rights (Gurbai, 2019)

36 Mental Welfare Commission for Scotland and Centre for Mental Health and Capacity Law (Edinburgh Napier University), Mental Health and Capacity Law: the Case for Reform (2017)

5. Decision-making capacity and SDM

In discussing SDM and decision-making capacity, it is important to recognise a distinction between legal and mental capacity.

Mental capacity relates to the decision-making skills of individuals, which vary from person to person, and can differ in different contexts.[37] As discussed, legal capacity is a universal attribute that an individual has by nature of being human.[38] It refers to the ability to hold rights and to exercise them.[39] Moreover, legal capacity is comprised of both legal standing and legal agency. In Scots law, it is not possible to challenge someone's legal standing (ability to hold rights and duties), but it is possible to limit someone's legal agency (use of these rights and duties) based on an assessment of mental capacity. [40]

The Case for Reform report pointed to some concerns at the way mental capacity is assessed. For example, it says that capacity assessments can often be made by professionals based on how an individual presents on a given day and with little or no knowledge or involvement of the individual and their background.[41] People First have pointed out that approaches vary depending on who assesses the individual, the type of test used, and the assessors' subjective views about capacity and disability.[42]

The Case for Reform report also cited concern amongst some that an 'all or nothing' approach is being taken to assessment of capacity with respect to the AWI Act.[43] Indeed, whilst the limiting of legal agency in Scotland is meant to be decision-specific and based on a functional basis, people with learning disabilities are often referred to as either 'having capacity' or 'lacking capacity' in a global sense.

People First suggest that this impacts individuals adversely and can create a

37 CRPD, 'General comment No. 1: Article 12: Equal recognition before the law' (2014) UN Doc CRPD/C/GC/1, para 7

38 ibid, para 8

39 ibid, para 13

40 Independent Review of Learning Disability and Autism in the Mental Health Act (2019)

41 Mental Welfare Commission for Scotland and Centre for Mental Health and Capacity Law (Edinburgh Napier University), Mental Health and Capacity Law: the Case for Reform (2017)

42 People First (Scotland), 'Does it matter? Decision-making by people with learning disabilities' (People First Scotland 2017)

43 ibid

stigma that enforces and ingrains negative attitudes towards people with learning disabilities. Furthermore, Burch argues this can reinforce stereotypes which[44] undermine respect and dignity and, in turn, cause self-stigma.[45] This can have a negative impact on self-esteem, well-being, and the life chances of people with learning disabilities.[46]

There has been a significant increase in guardianship orders over the last decade. The Mental Welfare Commission for Scotland's figures show that as of March 2024, a total of 19,078 people are living under a guardianship order. This figure has more than doubled since 2014.[47] And it has been noted by People First that parents of children with learning disabilities are being actively encouraged to seek guardianship orders before their children reach the age of 16.[48] They have argued that there remains a prevalent view that people with learning disabilities are inherently vulnerable and need to be protected from risk.[49]

People First (2017) have also outlined that people with learning disabilities have reported decisions consistently being made without them, with the majority of people being told that they were not allowed or were not capable of making decisions.[50] This was especially prevalent with difficult or more complex decisions such as finance and medical decisions. These scenarios led to negative impacts on people with learning disabilities creating feelings of 'powerlessness,' 'frustration' and 'not feeling valued'.[51]

People First (2021) have argued that any new approach to structuring a legal framework based on SDM must work from the assumption that people with learning disabilities are citizens who happen to have an impairment and may require support to access their right to independent living or the exercise of their legal capacity.[52] They argue that no impairment should be used as grounds for the denial of that capacity and that there is a need to reconceptualise the way learning disability and capacity are understood.[53]

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44 People First (Scotland), 'Does it matter? Decision-making by people with learning disabilities' (People First Scotland 2017)

45 Matthew Burch, 'Autonomy, Respect, and the Rights of Persons with Disabilities in Crisis' (2017) 34 Journal of Applied Philosophy 389, 392.

46 ibid, 392.

47 'Over 19,000 Scots living with welfare guardianship orders - more than ever at an increasing rate' (Mental Welfare Commission for Scotland, 25 September 2024) <Body> accessed 5 December 2024.

48 People First (Scotland), 'Supported Decision-Making: A Framework' (People First Scotland 2017) 2.

49 ibid, 3.

50 People First (Scotland), 'Does it matter? Decision-making by people with learning disabilities' (People First Scotland 2017) 7.

51 ibid, 7.

52 People First (Scotland), 'The case for a new legal framework to cover the lives of people with learning disabilities in Scotland' (People First Scotland 2021) 3.

53 ibid, 3.

6. Approaches to SDM

Key components of SDM, both within and outside formal structures, include knowing the supported person as well as possible, ensuring they feel heard, and respecting and giving effect to their will and preference. Effective SDM processes also require good levels of communication, the avoidance of undue influence, the provision of information in suitable formats; as well as affording individuals sufficient time, emotional support and a providing range of options.[54]

Bigby stresses that all decision-making involves several different components including information; number of options; awareness of the consequences; personal confidence; understanding of connections between decisions; communication of information and attitudes towards risk. A supporter's role may be to provide information and guidance to help someone make a decision. They may also assist someone to weigh up the consequences and constraints of certain types of action and think through how their will and preferences can be best be achieved.[55] As such, all SDM needs to be adapted to the person and there is no one-size-fits-all approach.

Indeed, Gillespie and McCusker point to the need for tailored approaches to SDM to suit different needs. They highlight 'support circles', as an example of an informal SDM practice model, which consists of a group of family members and friends, working together to support someone to make their own decisions. They stress the importance of members of the 'support circle' knowing the individual well, understanding their communication methods, and being able to support them to understand information and communicate their wishes.[56] They also highlight 'Talking Mats' which is a decision-making tool which was developed in Scotland and uses specially designed images to help someone express their views and opinions. Talking Mats has been shown to be effective in assisting people with learning disabilities to communicate more effectively.[57]

54 Gillespie L and McCusker P, 'Supported decision making' (Insights 73, Iriss 2023) 10

55 Christine Bigby and others, '"I Used to Call Him a Non-Decision-Maker - I Never Do That Anymore": Parental Reflections about Training to Support Decision-Making of Their Adult Offspring with Intellectual Disabilities' (2022) 44 Disability and Rehabilitation 6356, 6357.

56 Gillespie L and McCusker P, 'Supported decision making' (Insights 73, Iriss 2023) 10.

57 Ibid, 10

People First point out that individuals who have less experience or confidence of making their own decisions may require greater support.[58] They also stress that people communicate in a variety of different ways, and for people with profound and multiple learning disabilities (PMLDs), who may have significant communication barriers, the role of the supporter can be to help to interpret someone's will and preference.[59]

The Mental Health (Care and Treatment) (Scotland) Act 2003 gives everyone with a learning disability the right to access independent advocacy support and requires local authorities and health boards to provide access to this. There is also formal support available, to a limited extent, for those with significant communications barriers through the provision of non-instructed advocacy. The Scottish Independent Advocacy Alliance (SIAA) Non-instructed Advocacy Guidelines[60] explain that non-instructed advocacy involves:

- Spending time getting to know the person, observing how they interact with others and their environment and building a picture of their life, likes and dislikes
- Trying different methods of communicating
- Gathering information from the person through a variety of measures including identifying 'past wishes' or any Advanced Statement
- Speaking to the significant others in the person's life
- Ensuring that the person's rights are respected
- Ensuring that account is taken of the person's likes and dislikes when decisions are being made and that the person is enabled to make choices as far as is possible
- Ensuring that all options are considered and no particular agenda is followed.

Then and Bigby have highlighted that traditional binary notions of capacity can preclude people with profound and multiple learning disabilities (PMLD)

58 ibid, 1283-1287.

59 People First (Scotland), 'Supported Decision-Making: A Framework' (People First Scotland 2017) 10

60 SIAA, Non-Instructed Advocacy Guidelines (2009)

from accessing the necessary support to assist with decision-making and expression of will and preference.[61] However, a study by Watson which interviewed carers of people with PMLD and others in their supportive network showed that individuals communicate in a variety of different ways: body language, vocalisation, facial expressions, or head and eye movements.[62] Bigby has argued that people with PMLD's decision-making ability is not clear-cut and there is scope to build the capacity of supporters to enable people with PMLD to express their will and preferences both within and outside formal SDM structures.[63]

Therefore, SDM takes many different forms and challenges conventional understandings of capacity and what this means for individual decision-making.[64] However, as Webb points out there remains a widespread lack of understanding and some distrust about what SDM entails.[65] Gillespie and McCusker have highlighted a need for more research on SDM, alongside increased education and training to embed SDM in professional practice.[66]

61 Shih-Ning Then and Christine Bigby, 'Supported Decision-Making and the Disability Royal Commission' (2024) 11 Research and Practice in Intellectual and Developmental Disabilities 86, 96

62 Joanne Watson, Erin Wilson and Nick Hagiliassis, 'Supporting End of Life Decision Making: Case Studies of Relational Closeness in Supported Decision Making for People with Severe or Profound Intellectual Disability' (2017) 30 Journal of Applied Research in Intellectual Disabilities 1022, 1082

63 Christine Bigby and others, '"I Used to Call Him a Non-Decision-Maker - I Never Do That Anymore": Parental Reflections about Training to Support Decision-Making of Their Adult Offspring with Intellectual Disabilities' (2022) 44 Disability and Rehabilitation 6356, 6357

64 ibid, 10

65 Paul Webb and others, 'Service Users' Experiences and Views of Support for Decision-making' (2020) 28 Health & Social Care in the Community 1282, 1283

66 Gillespie L and McCusker P, 'Supported decision making' (Insights 73, Iriss 2023) 17.

7. Barriers to implementing SDM in Scotland

There is a degree of tension between demands for greater decision-making autonomy, and the current legal framework in Scotland and associated practice. The current legal framework in Scotland is based on the medical model of disability which views disability as resulting from individual impairment, in contrast to the human rights based model of disability, which views interactions with societal and environmental barriers as disabling individuals.[67]

This medicalised approach to disability can be criticised for legitimatising people with learning disabilities' inclusion in the Mental Health (Care and Treatment) (Scotland) Act 2003 which provides a legal basis for detaining people with learning disabilities for 'care and treatment.'[68] There is an ongoing debate surrounding the extent to which current mental health and capacity law undermines the objectives of the CRPD as well as concerns that the CRPD's approach to legal capacity, could put people at risk of not receiving necessary support, care and treatment.[69]

Harding has critiqued approaches to testing functional decision-making abilities through capacity assessments for leading to substituted decision-making when the context becomes more complex. Indeed, People First have highlighted that decision-making relating to medical and health care professionals, financial transactions and legal tools such as wills, and power of attorney for future planning is not supported to the extent that some people with learning disabilities have demanded.[70]

The Mental Health (Care and Treatment) (Scotland) Act 2003 requires local authorities, health boards and HSCPs to ensure the availability of independent advocacy services in their area. It gives everyone with learning disability the right to access independent advocacy support. However, the Scottish Mental Health Law Review (SMHLR) report stated that only around 5% of people who have a right to independent advocacy

67 Jill Stavert, 'Supported Decision-Making and Paradigm Shifts: Word Play or Real Change?' (2021) 11 Frontiers in Psychiatry 1, 7.

68 ibid, 21.

69 ibid, 2.

70 ibid, 2.

access it. They highlighted a number of reasons for this including:

- a lack of knowledge about what independent advocacy is and how to access it
- limited levels of funding for independent advocacy organisations
- a lack of awareness or understanding of independent advocacy among health and social care staff. [71]

The Scottish Independent Advocacy Alliance (SIAA) have reported on the precarious funding position of independent advocacy organisations which they say is making it challenging for independent advocacy organisations to meet the current demand for independent advocacy.[72]

Furthermore, thresholds for access to local authority services have increased over the past decade to the extent that, frequently, only individuals assessed as having 'critical need' are eligible. Local authorities also face financial challenges in providing support for people with learning disabilities to develop skills, access employment, and engage actively in the community and develop relationships. [73] This restricts people with learning disabilities' autonomy by limiting their choice and control and impacting their ability to assert the right to independent living and inclusion in the community. [74]

The question of how to manage potentially harmful decision-making by individuals with learning disabilities is an important consideration for the effective implementation of SDM in Scotland. Risk averse practice poses a potential challenge to supporting and enabling people with learning disabilities to make informed calculations of risk.[75] However, in such situations, People First have argued that a supporter's role should be to try to identify alternatives and assist the person to manage the risk and assess any possible harm.[76]

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71 Mental Welfare Commission for Scotland, The Right to Advocacy (2023)

72 Mental Welfare Commission for Scotland, The Right to Advocacy (2023)

73 People First (Scotland), 'The case for a new legal framework to cover the lives of people with learning disabilities in Scotland' (People First Scotland 2021) 11.

74 People First (Scotland), 'Does it matter? Decision-making by people with learning disabilities' (People First Scotland 2017) 6.

75 ibid. 14

76 ibid. 26

There is potential for SDM to help people with learning disability to navigate systems and processes and have a stronger voice in many other areas of life, where currently they can have their decision-making autonomy and legal capacity restricted. For example, challenging systemic barriers which exist for people with learning disabilities who are parents [77] and navigating the criminal justice system.[78]

The potential value of SDM for people with learning disabilities has been highlighted in a study published by People First Scotland. Participants with learning disabilities reported feeling very positive about making their own decisions. Gillespie and McCusker have highlighted, that SDM can increase the confidence of people in their decision-making over time and result in a greater willingness for supporters to step back from decision-making support and seek new ways to enable the participation of the people they support. [79]

However, the reality for many people in Scotland is often very different. People with learning disabilities frequently have decisions made for them based on their perceived 'best interests', and as such, the development of their decision-making skills, and their will and preferences can be overlooked or ignored.[80] People First have suggested that any new approach to decision-making in Scotland and the establishment of formal SDM structures must be led and informed by people with lived experience. This arguably needs to be accompanied by widespread change at a legal and cultural level including a fundamental shift in how learning disability and capacity are understood.[81]

77 ibid, 16

78 ibid, 17

79 Gillespie L and McCusker P, 'Supported decision making' (Insights 73, Iriss 2023) 10

80 People First (Scotland), 'Does it matter? Decision-making by people with learning disabilities' (People First Scotland 2017) 6.

81 People First (Scotland), 'Does it matter? Decision-making by people with learning disabilities' (People First Scotland 2017) 35.

8. International Learning

Australia

Several studies in Australia provide useful learning for the implementation of SDM in Scotland. There is evidence that the provision of training and support mechanisms for both formal and informal supporters alongside the development of community networks, can enhance decision-making autonomy for people with learning disabilities across all aspects of their lives.

A study by Bigby with eighteen parents of children with learning disabilities, highlighted the impact that parental attitudes can have on children's level of self-esteem and decision-making abilities. The parents were given training in a SDM model called the 'La Trobe Support for Decision-making Practice Framework', and parental reflections were recorded.[82] The framework consists of seven steps: knowing the person; identifying and describing the decision; understanding the person's preferences for the decision; refining the decision and taking account of constraints; considering if a formal process is needed; reaching the decision and associated decisions; and implementing the decision and seeking advocates if necessary.[83]

It was found that the training acted as a catalyst for parental reflections and encouraged parents to enact more deliberative approaches to SDM.[84] In many instances, there was a perceived increase in the confidence of their children in expressing their will and preferences.[85] It was also noted that parents valued the mentoring sessions following training in the framework which they believed helped to develop their reflective skills on their practice. As well as this, the study concluded that any SDM training should be paired with individual mentoring or other strategies to assist parents to discuss and solve more difficult issues they face in offering SDM to their children. In turn, it was suggested that supporters' respect for the will and

82 ibid, 6356

83 ibid, 6358

84 ibid, 6456

85 ibid, 6456

preferences of the supported person depends on the decision being made and the context. Therefore, it is important to focus on the capacity of the supporter to deliver that support for both formal and informal decision-making.[86]

For many of the parents this was their first exposure to SDM, and they reported that the training helped them reflect back on past decision-making, and to stop and think about the types of support they are going to provide to assist decision-making.[87] The training helped parents understand the perceptions that their children had when making decisions, and to be more aware of the different ways in which they express themselves.[88]

The framework also aided parents and family to have a shared language for SDM and improved confidence in their role. In these ways the framework helped in transferring theoretical understandings of SDM into practice.[89]

The overall effect of training for parents resulted in an increase in the level of confidence of their children's decision-making skills. [90] The study helped highlight the value of decision-making for quality of life, and the potential for people with learning disabilities to be supported to develop their decision-making skills.[91]

Watson has highlighted the value of building knowledge and support of family and friends of people with learning disabilities, who can also be termed informal supporters or 'naturally occurring' supporters. This type of support from someone who knows the person well is regarded as a highly effective way of providing SDM for people with learning disabilities, particularly for individuals with the most complex needs.[92] Watson points to a shift in attitudes around capacity towards a more asset-based

86 ibid, 6357
87 ibid, 6359
88 ibid, 6360
89 ibid, 6360
90 ibid, 6362
91 ibid, 6362
92 Joanne Watson, 'Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability' (2016) 5(1) Laws 1, 1.

understanding focussed on quality of support and building supporter capacity.[93]

In terms of more formal SDM processes, various states in Australia have implemented or considered similar reforms to those recommended in Scotland, including greater incorporation of SDM into guardianship structures. However, research by Then and Bigby has noted that public guardians are underfunded and under resourced which has made providing effective SDM for people with learning disabilities a challenge.[94] The research emphasised that it takes significant time to develop effective support structures and that confidence in the supporter is key to this.[95] Where supporters have not received sufficient training, it highlighted an absence of formal processes to ensure good practice by supporters or guardians.[96] Additionally, while recognising that there is no one size fits all model, the research highlighted that SDM must be well funded and that there is a need for best practice guidance which is co-produced with people with learning disabilities.[97]

Then and Bigby have recommended that training is required for all those who interact with people with learning disabilities in order to assist communication, change attitudes and develop skills.[98] This includes embedding an understanding of SDM in private enterprises, the health system and public sector accompanied by guidance on how to implement SDM at a delivery level.[99] Furthermore, it has been recommended that those who do not have natural forms of support or networks around them should be prioritised in accessing SDM.[100]

Watson has highlighted that SDM with people with PMLD was more effective when there was a close relationship to the supported individual and active knowledge of their personal life stories.[101] The study highlighted

93 ibid, 3.

94 Shih-Ning Then and Christine Bigby, 'Supported Decision-Making and the Disability Royal Commission' (2024) 11 Research and Practice in Intellectual and Developmental Disabilities 86, 91.

95 ibid, 93.

96 ibid, 93.

97 ibid, 94.

98 ibid, 102.

99 ibid, 102.

100 ibid, 103.104.

101 Joanne Watson, Erin Wilson and Nick Hagiliassis, 'Supporting End of Life Decision Making: Case Studies of Relational Closeness in Supported Decision Making for People with Severe or Profound Intellectual Disability' (2017) 30 Journal of Applied Research in Intellectual Disabilities 1022, 1022.

that responsiveness of a supporter is multifaceted, in that it involves acknowledging, interpreting and acting on the expression of the will and preferences of the supported individual.[102] The study suggests that supporters' effectiveness, regardless of whether they are formal or informal, improves based on the level of responsiveness attained which is based on the relational closeness to the supported individual.[103] The study recommended that there needs to be improved training of paid supporters, and that training should not just be restricted to the 'classroom' but through supervision and on the job training. Furthermore, it said that peer support as well-managed relationships are vital.[104]

Sweden

Sweden has actively sought to develop the decision-making skills of people with learning disabilities through their education system, helping to build confidence in decision-making skills for individuals and enabling people with learning disabilities to make their own decisions but also to determine when they need support.[105]

The Swedish education system has a 'democratic objective', which aims to instil both theoretical knowledge and practical skills that people need to make decisions about their lives and actively participate in society including when transitioning into adulthood.[106] There is an acknowledgement, however, that students with learning disabilities may need support to achieve this level of self-determination in everyday decision-making, and this is where SDM is utilised.[107] Although the Swedish education system has both state and 'special schools', active participation between schools is promoted, and the curriculum for 'special schools' is kept very similar to state schools.[108] Furthermore, there is active

102 ibid, 1028.
103 ibid, 1032.
104 ibid, 1032.
105 Magnus Tideman, Lars Kristén & Kristina Szönyi (2022): The preparation for entry into adulthood - supported decision-making in upper secondary school for students with intellectual disability, European Journal of Special Needs Education
106 ibid, 156.
107 ibid, 156.
108 ibid, 156.

cooperation with communities to prepare students with learning disabilities for life and jobs after education.[109] Therefore, education in Sweden is about adapting education to student's needs and there is a strong focus on the development of decision-making capacity.[110]

A study by Tideman conducted in Sweden 2023, examined the decision-making process through interviews with those who provided decision-making support in several different schools. They looked at two main groups in 3 different schools: young people with learning disabilities and teachers, student assistants and councillors. The research explored various approaches that gave students an opportunity to participate in decision-making and express their views, and develop clarity about the decision-making process.[111]

The research found that schools developed decision-making capacities of students with learning disabilities through encouraging active participation in democratic processes. For example, participation and involvement in student politics with student councils perceived very positively as areas where students could participate in decision-making.[112]

Schools were also found to be actively supporting the decision-making skills of young people with learning disabilities by promoting employment skills. The development of these skills was seen as important as it involved and supported students in decision-making about many aspects of working life.[113] The role of education was also found to be important in supporting young people with learning disabilities to manage and maintain close relationships. This included developing their skills at interpreting other's actions; making decisions from others' perspectives; and managing healthy relationships boundaries.[114]

Overall, the study highlighted the need for training and awareness for educational staff when it comes to developing student decision-making capacities. In addition, having the skills and support to make choices and weigh them up effectively are central to the wellbeing of individuals

109 ibid, 157
110 ibid, 157.
111 ibid, 8.
112 ibid, 9.
113 ibid, 10.
114 ibid, 10-11.

throughout their lives.[115] There is arguably an important role for schools to help student with learning disabilities develop decision-making skills in different contexts through the use of supportive materials and methods. Community support strategies can be central to this, where schools work together to pool information and materials to better support capacity building. Furthermore, schools can provide accessible learning environments that can be tailored to the different support needs of students. [116]

115 ibid, 11

116 ibid, 11.

9. Mapping a way forward for SDM in Scotland

There have been two national reviews in Scotland, the Independent Review of Learning Disability and Autism in the Mental Health Act, 2019 (Rome Review)[117] and the Scottish Mental Health Law Review, 2022 (SMHLR),[118] which have both considered SDM and the exercise of legal capacity in detail and have made recommendations to the Scottish Government.

The Rome Review (2019) recommended a statement of rights, will and preferences for people with learning disabilities with a right to challenge any professional decision that does not respect a person's will and preferences, and which may not be proportionate for their human rights.[119] A further recommendation was the provision of independent advocacy to all people with learning disabilities on an opt out basis, as well as non-instructed advocates for people with significant communication barriers alongside duties on Scottish Government and local public services to resource independent advocacy adequately. The review also recommended that Scotland set standards for accessible communication for people with learning disabilities.[120]

The SMHLR (2022) made further proposals designed to ensure people with 'mental and intellectual disabilities' can exercise greater choice and control over decisions around support, care and treatment decisions and have their will and preferences respected. A key proposal was replacing existing incapacity and 'significant impaired decision-making' (SIDMA) tests, in the Adults with Incapacity and Mental Health Acts, with a new test of autonomous decision-making (ADM) supported by a human rights enablement (HRE) approach, to help someone access the support and services they are entitled to, underpinned by a comprehensive SDM scheme.[121]

117 Rome Review, Independent Review of Learning Disability and Autism in the Mental Health Act (2019)

118 SMHLR, 'Scottish Mental Health Law Review: Final Report' (2022)

119 Rome Review, Independent Review of Learning Disability and Autism in the Mental Health Act (2019)

120 ibid

121 SMHLR, 'Scottish Mental Health Law Review: Final Report' (2022)

The review advocated for more sophisticated forms of advanced decision-making to better reflect and respect an individual's will and preference.[122] It also recommended that the Scottish Government should consider a national advocacy service.[123] Another recommendation was that assistance with communication appropriate to the needs of an individual should be a guaranteed right. The review said this is particularly necessary for those who use non-verbal methods of communication to express their will and preferences. The review highlighted that the establishment of an SDM system in Scotland necessitates effective training at all levels across care, support, law, and medicine.[124]

The review also suggested a three-tiered approach to decision-making support: Decision-Making Supporter, Power of Attorney and Decision-Making Representative.[125]

The proposed role of Decision-Making Representative is similar to that of a Guardian. However, the Decision-Making Supporter is a new role, without formal powers, that would support an individual to arrive at a decision themselves including by providing information, assistance to express will and preferences and communication support.[126]

The Scottish Government has responded to the SMHLR and has produced a Mental Health and Capacity Reform Programme Delivery Plan 2023-25[127] which includes several objectives and actions with regards to enhancing support for decision-making. This includes reviewing existing SDM practices and approaches and considering whether a national framework or approach is needed. It also includes working with key stakeholders including organisations providing advocacy services to help identify and address gaps and/or improvements in provision and/or legislation. The current plan is due to run until April 2025 and it is not yet clear what progress has been made with respect to these different actions.

In developing any national strategy or approach for SDM, it is important to be cognisant that SDM does not only pertain to Article 12 and the right to

122 ibid, 145.
123 ibid, 135-36
124 ibid, 145.
125 Ibid, 722
126 Ibid, 722
127 Scottish Government, Mental Health and Capacity Reform Delivery Plan 2023-25

to legal capacity. It can also be seen as critical in realising the right to Article 19 and independent living in the community for people with learning disabilities. Indeed, SDM has a crucial role to play in supporting people across a wide range of areas (including education, employment, housing, social security, family life and sexual relationships) to participate fully as active citizens and to lead independent lives.

There is clearly growing recognition in Scotland that people with learning disabilities have a right to support to exercise their legal capacity and to be empowered to make decisions and exert choice and control over their lives.[128] However, genuine change for people with learning disabilities, may not only require changes to law and practice but also to the way we understand disability. [129]

As discussed, the current legal framework in Scotland is based on the medical model, which relies on restriction of rights as a means of 'protecting' people. [130] Defined as a 'mental disorder', learning disability has traditionally been understood as a medical condition, diagnosable by clinicians and requiring medical care and treatment. The CRPD challenges this understanding of learning disability.

In adopting a human rights based model of disability, the CRPD views disability as being caused by social and environmental barriers, which interact with impairments to hinder full and effective participation in society on an equal basis with others.[131] The Rome Review (2019) advocated for an understanding of learning disability aligned with the CRPD definition of disability. [132]

This new understanding is arguably strengthened and supported by Article 8 and awareness raising which requires states to promote a positive image of disability. This includes promoting an awareness of people with disabilities' skills, abilities and contributions to society as well as supporting awareness training across all sectors of society. [133] This is an area which arguably

128 People First (Scotland), 'Does it matter? Decision-making by people with learning disabilities' (People First Scotland 2017) 35

129 ibid, 36.

130 Jill Stavert, 'Supported Decision-Making and Paradigm Shifts: Word Play or Real Change?' (2021) 11 Frontiers in Psychiatry 1, 7

131 United Nations Convention on the Rights of Persons with Disabilities (adopted 12 December 2006, entered into force 3 May 2008) 3 UNTS 2515 (CRPD), preamble.

132 Rome Review, Independent Review of Learning Disability and Autism in the Mental Health Act (2019)

133 United Nations Convention on the Rights of Persons with Disabilities (adopted 12 December 2006, entered into force 3 May 2008) 3 UNTS 2515 (CRPD) art 8(2)(a)-(d).

deserves more attention in Scotland including scope for increased co-production with people with learning disabilities.

Therefore, going forward, effective implementation of SDM in Scotland may require changes not only to law and practice but also to how we view and value people with learning disabilities as a society. This can be seen as critical to providing the necessary support to empower people with learning disabilities to maximise their autonomy and enjoy full and active lives in the community. Delivering the required changes to law, practice and societal understandings will require strong leadership and sustained resourcing at a national and local level.

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