

Scottish Government

Rights for Persons with Cognitive Disabilities

Making Decisions - My Rights

**Creating a National Overarching Supported
Decision-making Framework for Scotland**

Autumn 2018

Creating a National Overarching Supported Decision-making Framework for Scotland

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Creating a National Overarching

Supported Decision-making Framework

1 Introduction

“What we are seeking to achieve is an over-arching support mechanism which will maximize the autonomy and exercise of legal capacity for persons with impaired capacity so that genuine non-discriminatory respect is afforded for individuals with rights and preferences”. Scottish Government (January 2018) Adults with Incapacity (Scotland) Act 2000. Proposals for Reform. January 2018

The Scottish Government is committed to the implementation of domestic human rights legislation and international instruments including United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the European Convention on Human Rights (ECHR) designed, to ensure that people with disabilities are not discriminated against and have support to exercise the same legal and civil rights as other citizens.

The policy intention to realize the fulfillment of disability rights is embedded in the ‘Fairer Scotland for Disabled People – Our Delivery Plan to 2021 for the UNCRPD’ and reflected in a range of progressive policies and strategies. The overarching supported decision-making strategic approach proposed here builds on these and links with other frameworks. At its heart is the simple core value that each of us, regardless of disability, has an equal right to make decisions affecting our own life.

Legal capacity is an inherent right, and as such is the key to meaningful participation in society. UNCRPD Committee, General Comment No 1 (2014)

The UNCRPD Art 12: 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’.

In this report the term ‘**supported decision-making**’ (**SDM**) refers to the **means** by which adults with cognitive disability may be assisted to access their right to exercise their legal agency. It is not any ‘one thing’. The UNCRPD Committee lists a potential range of support available including formal and informal support arrangements of varying types and intensity. (see section 4)

SDM is based on the human rights principle that everyone has legal agency regardless of disability. This shift in thinking represents a change in focus from 'can the person make decisions' to 'what support is needed to assist them to make a specific decision?'

SDM is a crosscutting right which threads invisibly through our equality and disability laws, policies and strategies. The introduction of a national, overarching SDM framework will highlight the centrality of this neglected right. The strategic approach proposed here has implications for structures, processes and practice across sectors and agencies, both public and private - not only health and social care, but finance, social security, justice, housing, education, employment and civil society.

The term '**Support for decision-making**' is used to describe the **practice** of providing decision-making support for a person with cognitive disabilities, whether legal or otherwise (day to day decisions). Fundamentally it is the process of finding out what the person wants and assisting them to make their own decision. The factors, which contribute to effective decision-support, are described in section 5.

Although the right of people with disabilities to independent living, choice, respect and dignity are central tenets of government policy, there is evidence that this is not happening as intended for a number of complicated reasons. (see section 6).

It is recognised across jurisdictions in the UK and internationally, that informal carers, i.e. family members, partners and friends, provide the main source of decision support but are, so far, in Scotland, bereft of the opportunity to develop the skills and capacity to enable the cared for person to make their own decisions as far as possible¹.

This report provides a starting point for the development of an overarching approach to the implementation of supported decision-making for adults with cognitive disability in Scotland.

Support for decision-making is a new field of practice internationally, with a growing body of research into the development of resources and models for effective delivery. Evaluated projects in Australia have evidenced the benefit of SDM to decision makers and their decision supporters. In addition, research has evidenced the detrimental effects on individuals who lack support to make decision affecting their lives. (See section 6). However, evaluations have found that trials gave insufficient attention to analyzing delivery systems and the relationship with SDM practice and outcomes for individuals. Scotland is well placed to take on board the learning from Australia and develop a '**whole systems**' approach to SDM delivery.

¹ Killeen J. Dementia: Autonomy and Decision-making. Putting Principles into Practice (2012) Alzheimer Scotland.

The strategy proposed here builds on existing rights based laws, policies and disability strategies, including the over-arching policy to facilitate a personal outcomes focus through changes in practice advocated in the Christie Commission Report and enshrined in The Public Bodies (Joint Working) (Scotland) Act 2014. The principles, which underpin 'person-centred, personal outcomes' approaches, are closely aligned with Art.12 rights. This is exemplified by Self Directed Support and Realistic Medicine policies, both being based on the principle to give individuals more control and choice over decisions affecting their own health and welfare. The monitoring and inspection of 'personal outcomes focused approaches' takes a whole systems approach to creating change. The 'Health and Social Care Standards. 'My support, my life'. (June 2017), provides the criteria for inspection and regulation.

Proposed reforms to Adults with Incapacity (Scotland) Act 2000, currently under consideration, aim to clarify and give strength to the rights of people with cognitive disability to have their will and/or preferences respected as far as possible. Proposed reforms aim to reduce the need for substitute decision-making, even where guardianship may be required in specific circumstances for the most vulnerable individuals. AWI reforms have the potential to drive forward the paradigm shift towards an inclusive culture which recognises the legal and status of people with cognitive disabilities.

Making this shift happen is, of course, complex and goes beyond AWI reforms. Government recognition of SDM as a disability rights policy priority and the adoption and development of the proposed national SDM strategic framework would make a considerable impact.

2 Summary: making Supported decision-making work

The Overarching SDM Framework comprises five core inter-linked components:

1. Legal Provisions
2. Education and training
3. Service Delivery Systems
4. Disability Strategies
5. Research

An analysis of the role of each component and what needs to happen is discussed in more detail in section 7

2.1 National SDM Resource Centre

To effectively inform, support and sustain a 'whole systems' approach to implementation, both nationally and locally and to facilitate transfer of learning within the wider international SDM community, it will be essential to develop an easily accessible, highly collaborative, dedicated resource base. Whilst a base may take different forms, it should aim to fulfill the following functions:

- Develop and support implementation of a national SDM education strategy (section 7 Core component B)
- Provide an Information and resource base –tools and technologies to assist SDM.
- Co-ordinate a SDM practice network.
- Provide consultation to NHS and local authority Lead Commissioners etc. and other providers.
- Create a research database
- Network internationally to share ongoing learning from policy development, research and practice.

2.2 Factors to enable effective implementation of Supported Decision-making.

a) Policy priority and leadership - the requirement to comply with UNCRPD Art 12 has implications for the implementation of multiple equality and disability strategies, suggesting the need for a Ministerial cross-cutting lead group with responsibility for driving the strategy forward.

b) An SDM Action Programme in collaboration with public bodies at a national and local level with responsibility for ensuring delivery of SDM (duty holders), with the full involvement of people with lived experience of cognitive disability (rights holders).

A common understanding of Art.12 rights, principles and means of providing support, is a prerequisite to ensuring consistency and for all stakeholders/task groups to start with the same information base.

c) Resources - to provide:

- a National Resource Centre/hub to enable workforce development (skills and knowledge) and expansion (to allow time to facilitate decision-support and respond to increasing numbers).
- Expansion of Independent Advocacy Services to provide SDM - to ensure equality of access to SDM rights for persons with cognitive disabilities.
- Support/education/advice for informal carers (family members/friends with powers of attorney/ guardianship / registered supporter status (if introduced in AWI).
- Education and training across the professions and public awareness raising.

3 The equalities and human rights policy context

The Scottish Government is committed to the implementation of domestic human rights legislation and international instruments, including the European Convention on Human Rights (ECHR) which, along with the Human Rights Act (1998) is judicially enforceable, and the United Nations Convention on the Rights of Person's with Disability (UNCRPD), which the UK government

ratified in 2008. The Convention is designed to ensure that people with disabilities are not discriminated against and have support to exercise the same legal and civil rights as other citizens.

In 2012 The Scottish Human Rights Commission published a report of its in-depth analysis of the human rights landscape and made recommendations ('Getting it Right? Human Rights in Scotland')ⁱ which prompted Government funding for subsequent work on the development of the Scottish National Action Plan for Human Rights, launched in 2013. SNAP sets out a roadmap 'where everyone can live in dignity,' the concept of 'dignity' encompassing the right to self-determination.

At the launch of '**A Fairer Scotland for Disabled People – Our delivery plan to 2021 for UNCRPD**' (2 Dec 2014) Jeane Freeman, Minister for Social Security stated: 'We will...

- empower disabled people to know and claim their rights...
- promoting independent advocacy and advance statements ...
- work with disabled people and the organisations that represent them to develop changes to AWI ... to assess compliance with UNCRPD by 2018... and review policies and identify opportunities in which supported decision-making can be promoted.' (Extract)

The Christie Commission Report and recommendations (2011) had a pivotal role in influencing social policy reforms and led to the introduction of The Public Bodies (Joint Working) (Scotland) Act 2014 which aims to put 'personal outcomes' at the centre in order for everyone to be able to live longer and healthier lives at home or in a homely setting'.

This 'Personal Outcomes focused approach' represents a major shift in the provision of public services and in effect embeds the statutory requirement to ensure provision of supported decision-making. National health and well-being outcomes are a key part of monitoring and performance of Joint Boards. The overarching shift is away from a 'Deficit approach' to an 'Assets approach' in the delivery of health and social care, embodied in the concept and practice of 'Realistic Medicine, which aim to put the 'patient in the driving seat.'²

These developments are intended to be inclusive. However resources, such as time and appropriate tools and training to enable practitioners to facilitate self-determined outcomes for people with cognitive disabilities, need to be addressed.

In recognition of the issues affecting the implementation of the human rights principles which underpin Scottish Government welfare policies, the Scottish Government has created a new 'National Outcome' on human rights within it's draft National Performance Framework (5 April 2018) and will be launching a

² Bruce D. and Parry B. 'Community Oriented Personal Outcomes Work. A Scottish Perspective. London Journal of Primary Care (2015)

human rights leadership programme to drive this forward later in 2018. The draft 'Outcome' states,

'We respect, protect and fulfill human rights and live free from discrimination'.

The SHRC gives a helpful explanation as to why the wording is important, and significant to the task in hand.

'Scotland has obligations and duties under international law to respect, to promote and to fulfill human rights.... The obligation to fulfill means the state must take positive action to facilitate the enjoyment of basic human rights. Protection and fulfillment require policy, action and resource. Without these, we will have access to rights in theory, but they will not be delivered in practice'.

4 United Nations Convention on the Rights of Persons with Disabilities Article 12: Equal Recognition before the law.

The Convention's Art.12 right to equal recognition before the law is inherent in all other socio-economic and civil rights. Hence the imperative to implement across public services and sectors:

- health and social care
- social security
- justice
- finance
- housing
- education
- employment.
- civic society

UNCRPD Art 12 Equal Recognition before the law

Art 12 (1) States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law. Respect for the full range of rights, will and preferences of everyone must lie at the heart of every legal regime. That must be achieved regardless of the existence and nature of any disabilities.

Art 12 (2) 'States Parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life'

Art. (3) States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity i.e. any needed support to enable people to exercise their legal capacity to make their own decisions.

Art 12 (4) 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. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent, impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interest.

Art. 12 (5). Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of person's with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

The UNCRPD Committee in General Comment No.1 (2014) refers to 'supported decision-making' in relation to the legal right of persons with cognitive disabilities to access support for the exercise of their legal agency and sets out the informal and formal means by which support which may be provided.

- By one or more trusted persons, peer support and advocacy (including self advocacy)
- Assistance with communication, as appropriate to the needs of the individual... , especially for those who use non-verbal forms of communication to express their will and preferences.
- Advance Care planning ... including support to a person to complete an advance planning process.
- Special support in legal and administrative proceedings
- Communities and support that can be gained from these

In Scotland, the legal provision to appoint one or more persons with power of attorney is also included as a means to support a person's will and preference should their decision-making capacity become impaired.

The current review of Adults with Incapacity (Scotland) Act 2000 includes a proposal which would enable the decision-maker to appoint an officially recognised supporter with authority to access personal data-protected information on their behalf (on the same basis as anyone else). This is a key equalities issue, recognised in other judiciaries including Northern Ireland and certain states in Canada and Australia.

The MWC, Scottish Human Rights Commission, The Scottish Independent Advocacy Alliance and Public Guardian have each articulated the need for concerted action to fulfill UNCRPD Art.12 rights.

5 Understanding Supported Decision-making.

5.1 Who it is for and why it is needed

UNCRPD Art 1 describes persons with disabilities as those with:

‘long term physical, mental, intellectual or sensory impairments, which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.’

UNCRPD Art 12 requires support to be accessible to people with mental or intellectual disability, regardless of cause or degree. This includes people with lived experience of learning disability, autism, neurological conditions of which dementia is the most prevalent, psychosocial conditions, severe traumatic brain injury and other disabling conditions, which affect decision-making.

As explained, earlier, supported decision-making is not any ‘one thing’ – the nature and level of support required will depend on a multiplicity of factors which are unique to the individual and the specific decision/s to be made.

5.2 About decision-making

It is normal for us all to seek assistance from friends and family plus the internet for information when making big or small decisions. Sometimes we turn to experts for advice on important decisions, such as health care or financial matters. The decisions we make are influenced by our relationships, culture, beliefs, values, past experiences of decision-making and socio-economic circumstances. What we decide is often swayed by our emotions, rather than a weighing up of the options. How we make decisions is a unique process for each of us and is central to our sense of self-identity.

People with cognitive disabilities are no different but may need additional support to make and act on certain decisions. Many face challenges due to the nature of their condition and barriers in society, including risk-averse systems and assumptions by others that they are not capable of making ‘safe’ decisions for themselves, despite laws and policies which aim to empower and enable them. The prevailing culture continues to be ‘risk averse’ and discriminatory.

Research has also shown that decision-making capacity is affected by a person’s emotional state; for example, feelings of insecurity, anxiety, fear, and tiredness will impact on the ability to respond to an assessment process and may lead to wrong assumptions and decisions being made. This is exemplified by Brown and Marchant’s³ research involving people living with dementia in relation to making complex decisions. The impact of anxiety on

³ Brown H. & Marchant L. ‘Best interests decision-making in complex cases: report of a study commissioned by the Office of the Public Guardian (2011)

decision-making ability has been highlighted in recent research involving the participation of people with a learning disability or a mental health problem⁴. In both projects, participants have identified what factors have helped to support their decision-making as well as the factors which have created difficulties.

5.3 Decision-support for people living with different sources of cognitive disability.

In addition to individual influences which affect decision making in all our lives, responses will need to take into account the impact of a person's cognitive difficulty, requiring condition specific skills and knowledge e.g. communication skills and assistive technology.

- People with learning disabilities may have grown up with limited experience of decision-making but have the capacity to learn decision-making skills. There is considerable knowledge and experience to inform practice, with the growth of tools and resources both in the UK, Australia and elsewhere.
- People with dementia will have a life-time of decision-making but find themselves challenged by the progressive nature of the illness and its impact on cognitive ability. Different types of support will be needed as the illness progresses and in relation to different types of decision/s to be made over time.

'Research indicates that adults with progressive dementia are more likely to retain cognitive function when they use their cognitive skills. In the absence of an approach like SDM when deprived of self-determination they experience low self-esteem, passivity and feelings of inadequacy and incompetence and decrease inability to function.'⁴

- People with psycho-social conditions experience fluctuations in their ability and motivation to make decisions. A recent survey⁵ of the views of people with lived experience of supported decision-making has confirmed the value of Advance Statements and named person provisions in the Mental Health Act.

4 Beyond Guardianship: Towards Alternatives that promote greater self-determination. National Council on Disability, Washington DC. (9March 2018)

5 Mental Welfare Commission 'Views and experiences of people with lived experience on: Supported Decision-making and people with mental illness. Some practicalities. 2018. Also, Webb. P et al. 'Supported decision-making, experiences, approaches and preferences. (2018) Queen's University.'

- People with traumatic and severe brain injuries will have experience of making decisions throughout their lives but need to re-learn the skill through rehabilitation

5.4 Supported decision-making: what it is and what it is not

The concept of SDM includes but goes beyond the right to be treated with dignity and encompasses the principles of autonomy and choice. This is exemplified by Scottish Government's new Health and Social Care Standards 'My choice, my life' and is explicit under Standard 2 'I am fully involved in all decisions about my care and support'.

The nature and intensity of support may be seen on a continuum, from assisting with self-generated decisions e.g. about every day activities, to shared decision-making, if requested by the person (where others may be involved or a decision is complicated). The UNCRPD Committee recognises that there may be circumstances in which, after every appropriate means of support have been tried and the person lacks the ability to make a decision, then a 'best interpretation' or 'construction' of their will and/or preferences needs to be made on the basis of what is known about the person's values and choices.

The concept of 'autonomy' is sometimes interpreted as a state of complete independence in decision-making. However, this is rarely true for any of us and is a poor test of a person's ability to make a decision. As mentioned earlier, it is normal for all of us to discuss/consult on/gather the views of a range of others before making up our minds. In understanding decision-making processes there is a need to articulate the place of 'relational decision-making' at any point in the continuum i.e. the involvement of a significant other in making key decisions affecting both parties. This might be different from the role of co-decision-making or shared/joint decision-making in relation to providing support for reaching a specific decision. The principle underpinning each concept is that the arrangement is wanted by the person requiring decision support.

UNCRPD Art 12 and General Comment 1 refer to the centrality of 'rights, will and preferences'. However, an analysis by the Essex Autonomy Project⁶ identifies several pertinent issues i.e. that the concepts of 'will' and 'preference' are often conflated i.e. interpreted by others as being the same and not therefore explored with the individual. However a person's apparent choice may be based on a false premise (see case example no. 5 and 6). In addition, a person's right to protection from abuse may conflict with their 'will' where capacity to understand the extent of risk to self or others is lacking.

Without a common understanding of SDM rights and principles, unintentional abuse may occur due to unconscious bias leading, for example, to the

⁶ Essex Autonomy Project 'Three Jurisdictions Report' Towards Compliance with UNCRPD Art. 12 in Capacity/Incapacity Legislation across the UK. (2016)

imposition of undue pressure, or failure to explore potential conflicts of interest between the decision-supporter and the decision-maker.

A common misunderstanding is that SDM is the same as person-centred care, which focuses on the offer of choices from a list of services available. SDM is much more closely aligned with the achievement of 'personal outcomes' which is predicated on the 'conversation' with an individual about what they want to happen that would improve their quality life, which may or may not involve a 'service' as a solution to meeting their 'will and preference.'

An appreciation of these different concepts and how they interact is an essential component of SDM education.

In addition, it is important to distinguish between an individual's need for support to:

- make a specific decision i.e. support to exercise legal capacity to make decisions with legal implications e.g. signing a tenancy agreement, and
- make every-day decisions e.g. leisure activities
- build decision-making capacity skills and/or confidence, to facilitate autonomous or shared decision-making.

Importantly, UNCRPD General Comment No.1 makes it clear that one of the objectives of support in the exercise of legal capacity is that of building confidence and skills so that less support is required, if desired, to exercise legal capacity in the future. It also stresses that arguments about resourcing should not determine the level of support in the exercise of legal capacity.

5.5 Supported Decision-making: principles and practice

- Support for decision-making starts from the premise that: Everyone has a right to decide as far as they are able.
- The right to decide can be exercised with support.
- There is respect for the rights, will and/or preferences (which may be the same or different) of the person requiring decision support.
- The decision-maker has a right to decide if they want decision-making support in any specific instance.
- The decision-maker has a right to choose who they want to support them to make decisions (this may be one or more persons).
- The decision-supporter must respect the decision-maker and their decisions i.e. be able to respect their values, experiences and goals.

- The decision-supporter should give only as much support as is needed so that the decision-maker remains active and engaged in their decision.
- The decision-supporter should facilitate action necessary for the decision to be met.
- Assessment of support needs must not be dependent on assessments of mental capacity.
- There must be protection from potential abuse in any supported decision-making arrangements.

(Compiled from UNCRPD, the Australian Law Reform Commission's Report No 124, Equality, Disability and Capacity (2014), Bigby & Douglas 'Supported Decision-making – A Practice Framework (2015).

Safeguards for the SDM process should:

- Ensure that SDM practice is consistent with the principles.
- Include a quality framework
- Provide oversight of SDM processes and review mechanisms and identify responsibility for monitoring and review.
- Ensure a balance between SDM and duty of care in relation to proportionate response to risk. This requires a change of focus from deficit-based assessment to an asset-based assessment of supports required to facilitate decision-making and acting on a decision.
- Consider the need for independent decision support within the care planning process and be monitored by the lead practitioner.
- Involve an independent supporter/advocate where there is a conflict of interests e.g. service providers being gatekeepers to resources; family members/carers with their own needs.
- Provide readily accessible information, education and support for formal and informal decision-supporters.
- Register 'official' decision supporters' (if provision is made in AWI reforms)

Benefits of supported decision-making

Effective support is seen to compensate for difficulties with decision-making. Research indicates that involvement in decision-making, with appropriate support, enables people with cognitive disabilities to have greater control over their own lives, improving their self-identity, psychological well-being and quality of life.

Positive outcomes for people with cognitive disabilities and their supporters have been demonstrated by a critical review of evaluationsⁱⁱ⁷ of a series of

⁷ Bigby C Douglas J. Carney T. Wiese I. Smith E. 'Delivering Decision-making support to people with cognitive disability – what has been learned from pilot programmes in Australia from 2010-2015. (2016) La Trobe University & Sydney University.

SDM pilot projects in Australia. The following relational factors were found to have contributed to enabling the decision-maker to express their will and preferences and to act on them. A key feature of the pilots was the requirement for decision-supporters to attend a short training course, with access to mentoring for a short period after. The support person/s were:

- freely chose by the decision-maker
- knew the decision-maker well
- understood SDM principles
- took a positive approach to risk
- had positive expectations about what the decision-maker could achieve with support, going beyond the exercise of choice to the actual implementation of decision
- had time to provide support
- had skills to identify formal sources of assistance and informal supports in the community to help the individual to achieve their goals.

Positive outcomes for decision-makers

- increased confidence in decision-making – which for some extended beyond the specific decisions/goal chosen
- greater experience in decision-making;
- increased autonomy
- participation in a wider range of activities.

Positive outcomes for supporters

Formal and informal supporters reported:

- satisfaction from increased autonomy of the person they supported
- changes in work practices to encourage autonomy i.e. to engage the person in building up their experience of making choices
- offering the individual more choices in day-to-day life
- revocation of guardianship (small number of cases recorded);
- increased involvement of a guardian – demonstrated the feasibility of including people under guardianship as participants in SDM projects.

The small-scale pilots evaluated in Australia and elsewhere have mainly involved people with learning disabilities and a few with lived experience of severe and traumatic brain injury and psychosocial conditions. Only a very few new pilots involve people with dementia.

5.6 Research and practice

The La Trobe University research team used findings from the six pilots and other qualitative SDM research to inform the basis of a generic practice framework⁸ for the provision of effective decision-making support.

The framework focuses on the actual practice of SDM regardless of legal context. It describes a process of support encompassing SDM principles and seven steps in support for decision-making.

- 1 Knowing the person
- 2 Identifying and describing the decision
- 3 Understanding the person's will and preferences for the decision
- 4 Refining the decision and taking account of constraints
- 5 Deciding whether self-generated, shared or substitute decision
- 6 Reaching the decision and associated decisions
- 7 Implementing the decision and seeking advocates if necessary.

The aim of a major new longitudinal research project,⁹ which commenced in 2017, is to develop and evaluate the effectiveness of an education programme for people who provide decision-making support so that the quality of their support improves and results in better outcomes for the person requiring decision-making assistance. Participants include people with lived experience of intellectual disability, people with acquired brain injury, and their supporters. The project aims to publish findings in 2019/2020

6 Why Scotland needs a National Overarching Supported Decision-making Framework.

6.1 Evidence of problems with policy implementation

There is wide acceptance of evidence that social policies to empower people with disabilities to make their own choices and take more control of their lives are not delivering as intended. A not infrequently made observation from the field is that whilst pockets of excellence do exist, this is due to the dedication of practitioner teams rather of systems.

Knowing where, why and how things have gone wrong is a key part of the process in finding out what needs to be done. The following is a list of issues which have been documented:

- The absence of a legal duty to ensure the provision for supported decision-making was highlighted in the UNCRPD Committee's review of UK compliance with the Convention. The Committee's Conclusions were highly critical of the UK's failure to fulfill the right to live independently and be included in the community (Article 19) and of the

⁸ Bigby C. & Douglas J. 'Support for Decision-making – A Practice Framework'. (2015) La Trobe University, Living with Disability Research Centre.

⁹ 'Effective Decision-making Support'. La Trobe University, Living with Disability Research Centre, University of Sydney, Queensland University of Technology (ongoing)

incapacity/capacity laws in Scotland and England/Wales which require a pivotal shift away from substitute decision-making regimes to supported decision-making (Article 12). Evidence was published in a comprehensive research report based on an analysis of compliance with the Convention's Art. 12 (3) and (4) within the UK's three jurisdictions¹⁰.

- A common understanding of human rights in general and Art. 12 (3) and (4) rights in particular is generally lacking amongst professionals, politicians and the general public.¹¹
- In general, the operation of Self-directed Support has been widely criticized. Audit Scotland's review of Self Directed Support (2016) plus evidence submitted to the Scottish Parliamentary Legislative Scrutiny Committee; MWC annual statistics on guardianship and other sources).
- Adults with Incapacity (Scotland) Act 2000 – a number of implementation issues have been identified e.g. evidence that the legal principles are not well understood by legal, health and social care practitioners. Capacity assessments are widely regarded as problematic, with poor practice serving to undermine the actual or potential capacity of individuals and their right to be as involved as possible in making decisions about how they wish their own support, care and treatment needs to be met.¹² People with cognitive disability are often denied due process rights in guardianship proceedings e.g. attendance for the hearing; access to an independent advocate.
- Discriminatory barriers to exercising legal capacity, simply because the language of legal contracts, is unnecessarily complex. A typical example being tenancy agreements for adults with learning disability. Although a model contract was produced by a specialist mental health lawyer some years ago, it is not in general used by housing associations, resulting in applications for guardianship being necessary in order to secure accommodation.
- Equalities and resource issues – anecdotal evidence of differences between 'Adult Services' and 'Older People's Services,' –e.g. in relation to assessments, processes and service provision - learning disability services focus on achieving quality of life outcomes, whilst services for older people focus on 'what services will reduce risk.'
- Employment data on disability – high levels of unemployment amongst people with disabilities in general has become a high 'equalities' priority (there is no data on employment rates for adults with a cognitive disability and, again, it is possible that the rights of this group have become invisible).
- Consent to treatment - The Public Service Ombudsman's themed report, Informed Consent (March 2017) exposes failings by the medical

¹⁰ Essex Autonomy Project 'Three Jurisdictions Report' Towards Compliance with UNCRPD Art. 12 in Capacity/Incapacity Legislation across the UK. (2016)

¹¹ Mental Welfare Commission & Centre for Mental Health and Capacity Law, 'Scotland's Mental Health and Capacity Law: the Case for Reform.

¹² Ormiston R. et al. 'Improving Outcomes for people with learning disability- opportunities and challenges for housing. 2017 SCLD.

profession to put into practice the legal requirements post Montgomery Case, 'Complaints show that good policies and guidance are not enough,' even with training and tools available. Key findings were: the need for tools and information to be readily available at the time they are needed; time to engage in meaningful conversations; and, patients need to be better informed about what the consent process means. The PSO report found recurring themes including:

- lack of time for discussion, time for consideration and questions
- different understandings of what had been agreed
- individual communication needs not met
- inadequate record keeping
- in some cases the right to choose was not respected (patient choice being overridden)
- a number of cases related to consent involving adults with incapacity raised a number of issues including failure to contact the attorney.
- The lack of time for the conversation about consent issues was seen to be due to inadequate planning and resources, also unexpected changes or multiple clinicians were involved

These findings are not confined to the medical profession. The lack of time and availability of tools to exercise best practice to achieve personal outcomes have been highlighted by hospital discharge systems which allow the patient very limited time to make a major decision affecting their life style and future care. Overarching austerity cuts also have also been identified as having a major impact on the implementation of progressive disability strategies.

However, issues with implementation are recognised at a national and local level. Pilot projects, research and other initiatives are underway to progress the delivery of personal outcomes approaches to health and social care. The potential for integrating support for decision-making practice is high and does not need to wait until a reformed legal framework is in place. However such reforms are needed to ensure that national and local government makes proper provision for compliance with Art. 12 rights.

6.2 How an Overarching Framework for Supported decision-making will work to improve implementation of human rights based policies

The overarching framework proposes a strategic approach which focuses on the need to adapt systems and practices, so as to maximize the ability of people with cognitive disabilities to make decisions affecting their own lives.

1. UNCRPD Art 12 is inherent in all human rights, impinging on every aspect of our lives and as such requires a 'whole systems' approach to change, which incorporates SDM principles. The breadth of the impact of SDM indicates the need for a national framework to align responsibilities across multiple disciplines and disability strategies.

2. UNCRPD Art. 12 rights are central to the delivery of a wider human rights agenda. The Scottish government and Scottish Parliament hold the aspiration for human rights to be recognized and understood as integral to the fabric of society. Human Rights is a new 'National Outcome', which will be monitored and measured.
3. The Framework is constructed of inter-connected components which, with the intention of working together, have the potential to create the paradigm shift in culture the Scottish government is seeking to achieve.
- 4 Responsibility for the implementation of equalities, human rights and disability policies and strategies for people living with disability is shared across multiple ministries and directorates. The Framework aims to facilitate greater collaboration and consistency. Inconsistencies in provisions for the right to access decision-support need to be addressed, e.g. the definition of those with disability who may be eligible for decision-support through access to advocacy.
4. A function of the Framework is to articulate a common language and understanding of SDM, which will enable a consistent, repeatable and accessible practice throughout Scotland.
5. UNCRPD Article 12, has the potential to educate the wider public about the universal nature of human rights because the right to make our own decisions is fundamental to us all and easily grasped. It is the single most obvious right that each of us has and exercises every day and also when more significant decisions need to be made.

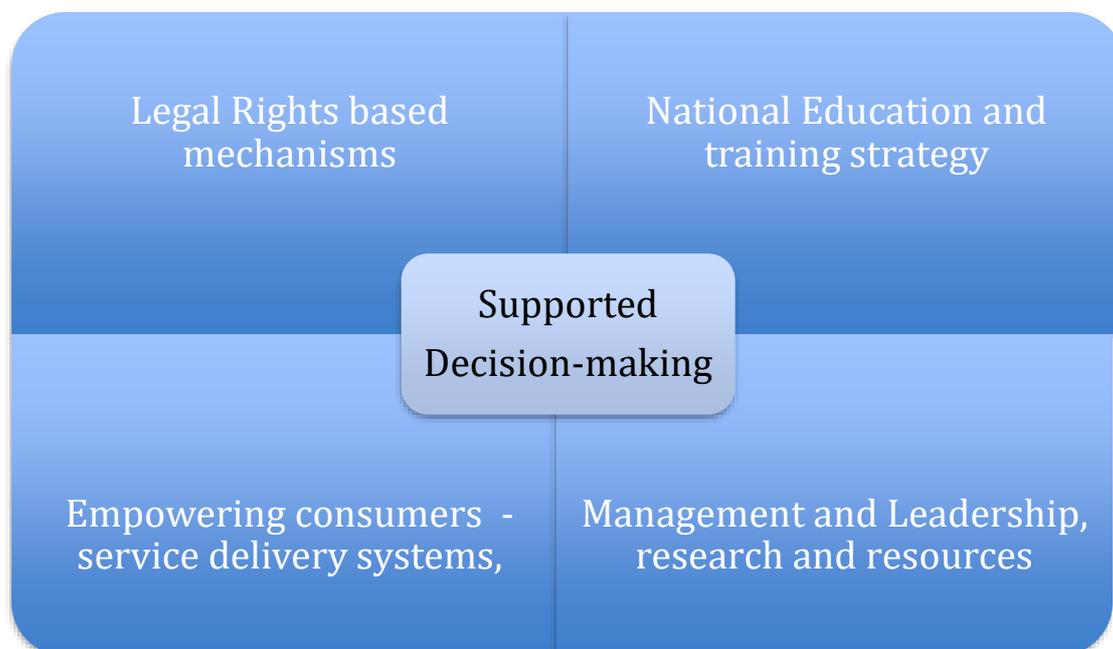
7 Constructing an National Overarching Supported Decision-making Framework: Core Components

This section identifies the core components of an overarching strategic framework. The components are not 'stand alone' but essentially interconnected. The complexity of the task requires strong leadership to spearhead and coordinate a cross-cutting SDM action programme, with shared accountability for the effective implementation of the integrated approach proposed in this paper.

- Legal provisions
- National Education and training
- Service Delivery
- National disability strategies
- Research

An analysis of each component aims to identify both 'enable's' and 'barriers' for improving compliance with Art.12 rights. An assessment of resource issues is not addressed in this report although implications for resources are identified. It is anticipated that an SDM action plan will interact with

programmes designed to deliver the objectives related to other 'over-arching frameworks' e.g. to meet National Health and Welfare Outcomes and the new National Human Rights Outcome.



7.1 Core Component A: Legal Provisions

Scotland is widely recognised as having progressive legislation to promote and protect the rights of adults with mental disabilities through the Adults with Incapacity/Mental Health/Adult Support and Protection Acts. Together these provide a strong basis for taking forward reforms to improve compliance with UNCRPD Art. 12. (A fusion of these laws in the longer term, will enable a more comprehensive approach).

The UK government, as a signatory to the UNCRPD has a statutory duty to ensure access to support for the exercise of legal capacity as required by Art 12. This fundamental gap in our legal framework is yet to be addressed.

Whilst the need for a radical overhaul of Scotland's mental health and capacity laws is recognised, proposed reforms to Adults with Incapacity (Scotland) Act 2000, (AWI), currently under consideration would go some way towards improving the legal framework to promote compliance with SDM.

Legal changes to comply with UNCRPD Art. 12

- Enhanced legal principles to reflect the need for the adult to have support for the exercise of legal capacity
- Provision for the appointment of an 'official supporter';

- Measures to ensure support and education for non-professional guardians and attorneys to comply with SDM principles (to include 'official supporters).
- Code of Practice on Supported Decision-making
- A statutory duty to provide access to independent advocacy (as provided in the MHA)
- Legal status for Advance Statements
- improved safeguards to protect from potential abuse – with particular reference to deprivation of liberty and powers of attorney/guardianship.
- Art 12 rights to be clarified and strengthened within MHA/ASP laws (see forthcoming research report by Jill Stavert, CMHCL, Napier Edinburgh University, commissioned by MECOPP).

AWI principles and implementation

A recently published report of a European-wide survey of powers of attorney and advance directives for incapacity conducted for the Council of Europe, by Adrian Ward¹³, puts forward six proposals to improve compliance with UNCRPD Art 12. As noted earlier, it is not well understood by attorneys that grantors continue to have the right to self-determination and that it is a duty of the attorney to support that right except in certain prescribed circumstances.

This issue was explored in an earlier study by Killeen¹⁴ into the support needs perceived by family members/friends with power of attorney or guardianship for someone with dementia. A key finding was that participants lacked awareness of the principles and felt that such information and support on how to use them would have helped to assist the cared for person with decision-making, especially when challenged by professionals.

The case for statutory provision of education, advice and support for lay proxies was identified in the majority of responses to the recent AWI consultation. However, it was also recognised that many professionals across the disciplines failed to implement AWI principles. Strengthening the law is not enough, hence the need for greater accountability and SDM educational modules to support AWI reforms.

SDM and Independent Advocacy Services

Whilst family members/partners/friends comprise the majority of decision-supporters, there are many socially isolated, vulnerable individuals across Scotland with no such relationships. These groups and others may be subject to a serious conflict of interests or undue pressure, with no access to independent support. However, access to independent advocacy should be an unconditional legal right for everyone under AWI.

¹³ Principles concerning continuing powers of attorney and advance directives for incapacity. Recommendation CM/REC (2009)11 and explanatory memorandum. Council of Europe

¹⁴ Killeen J. Dementia: Autonomy and Decision-making. Putting principles into practice. Research summary and recommendations. 2012. Alzheimer Scotland.

Current provision is severely limited and focused mainly on detained patients in hospital. The extension of independent advocacy and SDM provision in the community requires an investment of resources by Joint Boards (the 'duty holders').

There is evidence from The ADACAS¹⁵ independent advocacy service in Canberra, Australia, of the value of combining SDM and independent advocacy within the same service, thus enabling a person-centred, flexible response to individuals and/or their informal decision-supporters. The knowledge and skill required of independent advocacy is closely aligned to SDM practice. This model is worth exploring and piloting in Scotland. Independent advocacy services provide a strong base for the delivery of supported decision-making and an appropriate one for Scotland given the structure and system already in place. The Scottish Independent Advocacy Alliance is currently preparing SDM practice guidelines for advocacy services, including peer advocacy. It is suggested that this would be an effective means of meeting the 'equalities gap'.

Advance Statements

Advance Statements are an important means of empowering people with psycho-social conditions to make decisions in advance of fluctuations in their mental state. Recent campaigns by the Mental Welfare Commission and local groups to raise awareness of the value of making an Advance Statement have been welcomed. Proposals for giving Advance Statements legal status in the AWI consultation would appear to receive a significant level of support.

Named Person

The MHA includes a provision for the appointment of a 'Named Person'. An adult who needs treatment under the Act can choose someone to help protect their interests and make decisions on their behalf if they are not able to decide for themselves.

This option, also open to people with dementia, gives 'official status' to a supporter. It is an important mechanism within the range of potential supports. However awareness raising about this and the potential range of supports available is vital.

Reframing Capacity Assessments – this controversial issue is also to be addressed within the AWI reform programme. UNCRPD Committee General Comment 1 requires States signatories to abandon a 'deficit' model based on the assessment of legal capacity to an assets based approach which assesses the supports available to facilitate decision-maker to make an autonomous decision – legal agency being an inherent right and therefore not open to an assessment. Decision-support is integral to an asset-based model. Best practice dictates that time is needed for the assessor to get to know the

¹⁵ www.adacas.org.au. www.support-my-decision.org.au.

person, develop a trusting relationship and find out what decision-support is appropriate to enable the person to make their own decision/s as far as possible. There is a need to develop tools to the support needs of different groups who are vulnerable to guardianship or compulsory detention.

Legal Agency, equality and ‘reasonable adjustments’.

The legal agency of people with a diagnosis of mental disability is often misunderstood by non-statutory agencies providing public services. Examples are often drawn in relation to the banking system or the legal processes of housing associations. Systems and practices are often unintentionally discriminatory, with a failure to make reasonable adjustments or to understand what this might entail for adults with cognitive impairments. ‘Reasonable adjustments’ require an investment in systems change and customer care. Bodies responsible for monitoring and regulating these services should be made aware of and act on disability equality issues.

The requirement to make ‘reasonable adjustments’ to assist decision-makers with cognitive difficulties applies across community services and a targeted awareness raising campaign should form part of the wider SDM education and training strategy.

7.2 Core Component B: National SDM Education and Training

A wide reaching SDM education and training strategy will be needed to respond to the ‘whole systems’ approach to effective delivery of SDM advocated by the Overarching Framework’

Investment in an SDM Centre/hub, ideally over an initial period of 5 years, would support workforce development from commissioners to practitioners across disability strategies and personal outcomes focused approaches. A short-term priority would be to support the implementation of AWI reforms to improve compliance with Art.12 rights.

Educational functions:

- Provide an Information and resource base for: educational resources, tools and technologies to assist SDM across the professions (including legal and financial); an open catalogue of SDM educational and training from international sources.
- Develop/pilot/evaluate educational modules (generic and specialist for professionals in collaboration with NES, SSSC, etc).
- Develop and pilot or evaluate models of education and support for decision-supporters (family members with powers of attorney, guardianship or informal decision-supporters).
- Develop decision-capacity building programmes for and in collaboration with people with lived experience.
- Provide training for trainers.

- Develop standards of practice and produce a National SDM Practice Framework National Practice Framework to ensure that policies and practice for SDM are aligned across sectors i.e. Realistic Medicine, SDS, social care assessments and service delivery.
- Develop/support a SDM Community Awareness Campaign
- Co-ordinate an SDM practice network.
- Provide a resource for undergraduate professional training institutions (health and social care professionals, legal education etc).
- Network internationally.

A strategic approach would ensure consistency in how Art12 rights and principles are understood and articulated through education and awareness raising programmes.

The strategy would identify areas for collaboration with existing programmes to support an understanding of UNCRPD Art 12 in the context of wider human rights principles and approaches, including 'personal outcomes' focused approaches in health and social care. Key collaborators (duty holders) with responsibility for workforce development include NHS Education Scotland. SSSC; also other agencies supporting human rights education i.e. SHRC and MWC

Approaches to integrating SDM training and initiatives.

In Scotland, 'Promoting Excellence. Education Framework for Dementia' (2011) NES/SSSC provides a useful model for how to meet the educational needs of staff with different roles and levels of responsibility for supporting decision-making. There is potential to include SDM knowledge and skills learning within this framework.

Integrating SDM skills learning within existing educational programmes would be practical and cost effective.

Carers as decision-supporters

The support needs of family members with responsibilities to assist the cared-for person with decision-making is well documented across judiciaries from the US, Australia, Canada and across Europe and has been highlighted in responses to the AWI reform. Consultation indicates strong support for family members with powers of attorney and guardianship to be provided with education about how to use their powers in compliance with the legal principles in the Act. However a number of different ways of providing such support were put forward.

The Scottish Human Rights Commission response importantly emphasizes the duty of government (under UNCRPD) to ensure the provision of rights based decision-making training for adults with decision-making difficulties as well as for guardians and attorneys.

“We believe that advice and support for both guardians and attorneys is crucial. This should focus on developing an understanding of their role in supported decision-making, how to apply CRPD principles and AWI principles. Since Article 12 represents a paradigm shift, it is crucial that this shift takes place in communities and day-to-day interactions, rather than being confined to legal processes. General Comment No.1 is clear about the pivotal role that legal capacity plays in accessing other rights and a cultural understanding of the paradigm shift that must be built. This should extend to all those providing support for decision-making (e.g. Official Supporters, informal supporters) as the real mark of success would be if adults were being supported to make decisions and exercise their legal capacity on a daily basis without recourse to legislation. The models highlighted in ‘Supported Decision-Making: Learning from Australia’ evidence the importance of building the knowledge and skills of family members and friends as an effective way to support and sustain decision-making ability. We believe there is potential in developing such models in a Scottish context. It is also important to provide advice and support for adults who may require supported decision-making as, in terms of General Comment No.1, “State parties have an obligation to provide training for persons receiving support so that they can decide when less support is needed or when they no longer require support in the exercise of their legal capacity.” SHRC response to AWI Reform consultation

Learning from Australia

With regard to skills development for decision-supporters (informal and formal) a major longitudinal training initiative is currently being tested, based on a National SDM Practice Framework developed by Bigby and Douglas at the Center for Disability, La Trobe University in Melbourne; ‘Effective Decision-making support for people with cognitive disability’ (Phase 3 Australian Research council Linkage Grant Funding. Living with Disability Research Centre, La Trobe University).

The research focuses on a large cohort across several States and invites participation from people with a learning disability and people with an acquired brain injury together with their formal or informal supporters. Following pre-training interviews in which current decision ‘behaviours’ are explored with both the supporter and decision-maker, decision-supporters are provided with two days of workshops with the offer of mentoring in the short-term and regular phone calls over 12 months. The final stage of the research is to measure the impact of the interventions on decision-making behaviours. The research is expected to report by 2020.

SDM empirical research in Australia is more advanced than anywhere else globally with knowledge and skills acquired over the past 10 years currently being used to inform the development of new SDM models for delivering SDM and training relevant for older people and people with psychosocial conditions who have been under-represented in research to date.

It will be vital to develop and maintain links to ensure that Scotland is able to benefit from the learning to adapt within our own policies and service delivery systems¹⁶.

7.3 Core Component C: Service Delivery Systems

The introduction of the Public Bodies (Joint Working) (Scotland) Act 2014, underpinned by a 'personal outcomes' approach; represents a major shift from the traditional provision of public services to one which is intended to respond to and respect the choices and preferences of individuals, impacting on the orientation of delivery across sectors. This policy intention is closely aligned with SDM principles. Access to SDM is integral to the effective delivery of personal outcomes approaches.

Joint Boards (duty holders) responsible for the delivery of the 'National Health and Wellbeing Outcome'¹⁷ which embeds a human rights based approach. Compliance with equalities and human rights principles will be a factor in the monitoring of performance of the Boards by the Scottish Government. It is important that UNCRPD rights and specifically Art.12 rights are articulated and included in approaches to assessing performance on the basis of human rights measures. It is recognised that this is a new and complex area in terms of identifying performance indicators.

Funding for workforce development and education has been provided to NES and SSSC to support organisational change and practice, moving from a 'deficit' to an 'assets' approach. This has included learning resources to support joint strategic commissioning by Joint Boards. It is at this level that the concept of SDM needs to be incorporated into existing learning resources.

A key message for lead commissioners and senior management in health and social care (duty holders) is that supported decision-making is not just another approach to good practice for adults with cognitive difficulties, but a human right which informs the design of delivery systems which aim to facilitate personal outcomes focused and other person-centred interventions, including self-directed support, realistic medicine, self-management and anticipatory care planning.

Personal Outcomes Focused Approaches and SDM

Self-directed support provides an important vehicle for the delivering supported decision-making. Legislation provides for a recipient or potential recipient to have an independent supporter assist them through the assessment process and thereafter. However anecdotal evidence suggests this is right is little known or exercised.

¹⁶ Killeen J. Supported Decision-making: Learning from Australia. (2017) WCMT.

¹⁷ Scottish Government, 'National Health and Wellbeing Outcomes. A framework for improving the planning and delivery of integrated health and social care', 2015

SSSC has led the field in supporting personal outcome focused development and has an extensive work programme to support organisations and individuals to ‘understand what a personal outcomes approach is and embed this approach in day-to-day practice.’

‘Person outcomes’ are described as referring to ‘things that are important to people in their lives... it requires linking holistic practice with a whole system approach so personal outcomes are built into support, planning, performance and commissioningthe values and principles underpinning personal outcomes should be routinely modeled by managers, in for example, supervision, team meeting and continued professional development’.

Effective personal outcomes focused practice should include an assessment of the decision support an individual may require. This may result, for example, in the need to involve a decision-supporter of the person’s choosing, technical assistance or specialist help with communication. The Personal Outcomes approach uses an ‘Exchange Model ‘ to identify ‘desired outcomes’ – with a focus on ‘agreed outcomes’ resulting from a negotiation emerging from the views of the person, their relative, practitioners and organisations. It is unclear who provides decision-support in this model given the inevitable power imbalance and potential for a conflict of interests and undue pressure (however unintended).

Learning from a review of person-centred approaches to health and social care is relevant to considering issues for the implementation of effective support for decision-making¹⁸. The review has identified a number of issues which challenge the shift in practice including:

- yet to be resolved differences in the value bases of traditional quantitative, target focused performance management as opposed to relationship-centred practice, which requires a qualitative approach to assessing outcomes for individuals against their own ‘self-defined’ objectives. Time is the biggest resource needed to facilitate personal outcome focused approaches and SDM
- complexities of recording and evidencing personal outcomes for individuals
- different interpretation of what an ‘outcome focus’ means, and confusion around different approaches e.g. personalisation, person-centred care, self-management, personal outcomes. (To this list can be added the terms: supported decision-making; support for decision-making).

Realistic Medicine

Realistic medicine is described as presenting ‘a new ‘paradigm’ in delivery of person-centred care where the patient is in the driving seat... it shifts power

¹⁸ Barrie K. & Miller E. ‘Personal outcomes, person-centred working and personalization. Thinking about different approaches in health and social care in Scotland’. 2018 SSSC

from the doctor to the patient... Primary objective is to maximize value that the patient derives from their own care and treatment and the value the whole population derives from investment in their health care.' Scottish Government, practicing realistic medicine CMO 3rd Annual Report (20/4/18)

'Empirical evidence shows that this approach results in more effective health and well-being outcomes for the patient. The Royal College of Surgeons has produced a good practice guide, which focuses on the new requirement for 'tailored individual consent discussions.' 'Consent: Supported decision-making. A Guide to Good Practice (November 2016)

Empowering patients requires skills development and a shift in mind-set as well as a recognition of the time investment required to enable all patients to be involved in making health care decisions. Adults with cognitive disability will make greater demands on the communication skills and time of the health care profession. It is essential that allowance be made for the additional resources required, including technical aids, so that these patients are not subject to discrimination.

To support this major change in culture and practice in the NHS, the Scottish Government is funding 'Leads' in Realistic Medicine.

These 'Leads' will need to have a good grasp of the SDM skills development and access to resources that practitioners will need to achieve person-focused outcomes for patients with cognitive disabilities. The implications for Clinical Commissioning are also being considered and need to take account of the growing number of patients who will need decision-making support. (see ref. to the Ombudsman's report).

Prof. Muir Grey, leading the 'Right Care Programme' for the NHS in England, identified the need for clinical commissioning groups to look at a range of resource and technical issues in relation to different sub-groups in the population and included the need to look at 'personal value' to determine how well medical decisions relate to the values of each individual.

The Scottish Government's 'Making it Easier – a Health Literacy Action Plan for Scotland 2017 – 2025 focuses on practice in terms of 'Making good decisions in collaboration... how to embed good practice in shared decision-making' 'and for people with cognitive disabilities that includes the health care professional, patient and their carer.

Current Scottish Government funded pilot projects are focusing on adults with specific chronic conditions. **It will be important to pilot, monitor and evaluate how realistic medicine can operate effectively for adults with cognitive disabilities.**

The CMO report refers to the 'triangle of care' i.e. the patient, carer and health care professional. The carer is recognised as having an important role as a source of support for patients. Whilst many patients will turn to their carer for support, an unintended consequence may be a power imbalance, with the

patient under pressure from the practitioner and carer to make the decision they want to hear.

The development of tools and resources to support person-centred practice is to be aided by the development of on-line NHS human rights portal. This should include a module on UNCRPD Art 12 rights and address ethical issues for practice including dealing with conflicts of interest.

Anticipatory Care Planning (ACP)

ACP is a process, which is introduced over time to enable people living with a long-term condition to plan for expected changes in their health including improvements as well as palliative care. It puts people at the centre of the decision-making process about their own health and care needs¹⁹. As such it is a tool, which aligns with Realistic Medicine and provides a means of identifying personal outcomes and working towards them. NHS Inform provides on-line information about ACP, the benefits, and how to make an anticipatory care plan. ACPs are not legally binding but provide an important means of SDM provided they are introduced at an early enough stage for the person to fully understand how it will be used to inform their care and treatment at a later stage.

A new ACP toolkit: 'My Anticipatory Care Plan... Let's Think Ahead' states 'if you have mental health issues, learning Disability or dementia an independent advocate can talk with you about what you want in your care plan'.

7.4 Core Component D : Disability/equality Strategies, implementation

Disability strategies provide a major driving force for the fulfillment of the rights of people with cognitive disabilities. They have the potential to deliver supported decision-making within identified priorities. This section recognises existing building blocks and aims to highlight opportunities for developing SDM.

Key disability strategies are:

- National Dementia Strategy (2010 – 2013; 2013-2017, 2017 – 2020)
- National Mental Health Strategy (2017-2027)
- Keys to Life – Learning Disability Strategy and Autism Strategy (under review)

Lead teams at national and local level have a duty to ensure that the strategies and their implementation are compliant with UNCRPD. A dedicated analysis of each strategy through an Art. 12 lens, involving people with lived experience in the process, would identify gaps, barriers and opportunities for change.

¹⁹ NHS Inform. Making an Anticipatory Care Plan. Health Improvement Scotland (May 2018)

A model for analysis and planning which lends itself to adaptation for such an exercise is exemplified in a report published by the Mental Welfare Commission and Human Rights Commission (2015)²⁰ in relation to progressing Commitment 5 of the Scottish government's National Mental Health Strategy 2012 – 2015, the focus of which was on the rights of people with mental illness.

The report and recommendations were produced on the basis of consultation with a wide range of stakeholder groups including people who use services. What followed was the development of a 'Logic Model', which shows 'intended outcomes (changes) in the short-, intermediate- and long-term and the activities expected to produce these. (See Logic Model – working version' page 31).

It is noted that The Carers Act, which focuses on an assessment of needs of the carer, fails to recognise the support and learning needs of carers as decision-supporters for the cared-for person. This gap should be rectified in the Code of Practice and guidelines on assessment, with decision-making rights information for carers and cared-for persons.

National Mental Health Strategy (2017-2027)

Commitment 34 states that AWI reforms should fully reflect the requirement of the UNCRPD, with particular emphasis on the provision of SDM, addressing issues around deprivation of liberty and the interaction of AWI legislation with legislation on mental health and support and protection.

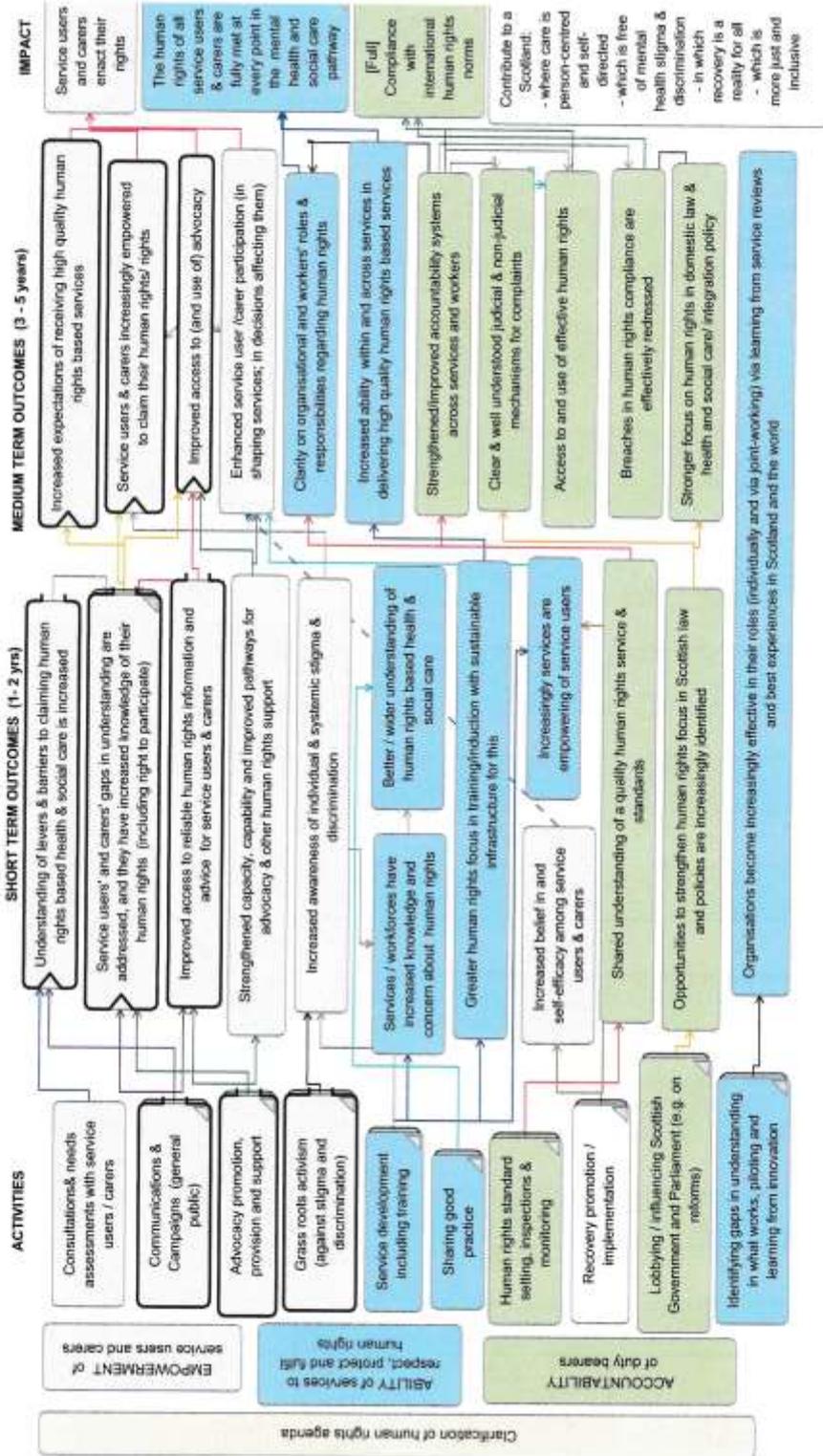
It identifies the need to address the ongoing shortage of Mental Health Officers who provide essential safeguards for the rights of people with cognitive disabilities under incapacity and mental health laws and address gaps in the provision of independent advocacy. People with cognitive disabilities under the MHA are entitled to independent advocacy. As mentioned earlier, access to an independent advocate is severely limited to people detained in hospital, yet has an vital role in providing advocacy and SDM for a wider group of vulnerable people living in the community, including their carers.

A recent MWC survey to gain the views on supported decision making of people with lived experience found that the support of a 'trusted' person who knew and understood them was valued more than any other factor; and concerns were expressed about the time pressures imposed by professionals.

Existing provisions for Advance Directives and Named Person to support self-determination were valued. However uptake is limited as these provisions are not widely known or understood.

²⁰ Human Rights in Mental Health Care in Scotland (September 2015) SHRC & MWC (Logic Model, page 17).

Logic model – working version



Keys to life – Scotland’s Learning Disability Strategy 2013 -2023 (under review/consultation)

The principles of choice, control and independence are at the core of this 10-year strategy with the Implementation Framework 2015-2017 including Strategic Outcome 2 – that people with learning disability are able to participate in all aspects of community and society. The revised implementation framework should include the provision of SDM. There is considerable expertise and resource to draw on from Australia and examples of good practice from with Scotland and across the UK.

National dementia strategies

Since 2010 the Scottish government has introduced three 3-year strategies underpinned by human rights principles set out in the ‘Charter of Rights for People with Dementia and their Carers in Scotland’. Priorities have been based on consultations with a wide range of stakeholders, including people living with dementia. The dementia strategies exemplify the range of provisions needed at different stages of the illness to facilitate self-determination and social inclusion.

Key elements of the strategy are designed to enable self-determination and empower decision-making. Of major significance has been the holistic approach to workforce development. NES produced ‘Promoting Excellence’ resources and training to support the introduction of the first Dementia Strategy. It was designed to meet four levels of skills development, recognising the different roles and responsibilities of all the staff involved in delivering care across the dementia journey. This key resource is currently being updated as NES and a training needs analysis is being carried out, with an appreciation of the need to integrate SDM knowledge and skills.

There is a growing capacity for dementia trained staff across the professions to facilitate people living with dementia to make their own decisions e.g. the Dementia Champions Programme; the introduction of community based dementia co-ordinators and dementia nurse consultants in hospital settings.

Recent initiatives with links to the NES workforce training programme include:

- a new pilot commissioned by the Scottish Government and led by Health Care Improvement Scotland ‘Focus on Dementia’ which aims to influence whole systems change. All training includes ethical and legal components and how to involve the person with dementia and retain their involvement as much as possible.
- Reforms to primary care, including a focus on the provision of post-diagnosis support and learning through a new advance level of training ‘Supporting people through a diagnosis of dementia’ taking a personal outcomes focused approach.

The increasing use of future care plans, powers of attorney, and anticipatory care planning are all means by which people with dementia can make their will and preferences known.

The addition of the ability to appoint an ‘official supporter’ (as proposed in AWI reforms) would fill a significant gap in the range of decision-making support mechanisms available to people living with dementia for whom this would be especially helpful in accessing personal data to make present day decisions.

7.5 Core Component E: Research

Developing a research agenda and priorities for SDM research in Scotland.

Empirical research into the effective delivery of supported decision-making is limited in this new field of policy and practice. To date, pilots have been small scale and focused mainly on people with learning disabilities and have evidenced the benefit to individuals and their decision-supporters.

The Centre for Mental Health and Capacity Law at Napier, Edinburgh University has developed a body of knowledge on SDM issues and research and has an ongoing commitment to seeking funding for research projects in this field.

The research agenda in Scotland will be influenced by a number of factors including the need to identify current related research initiatives in the UK and elsewhere. The creation of an **SDM research database** is needed to facilitate shared learning, opportunities for collaboration and the identification of gaps.

As this report has highlighted, Scotland has a number of progressive laws, policies and strategies which embed principles to empower people with disabilities to make their own choices with the introduction of a systemic approach to a ‘personal outcomes’ approach underpinning the delivery of integrated health and social care services. However, major issues with implementation have been identified. Current pilot projects designed to find ways to deliver ‘personal outcome focused approaches’ are being tested but appear to exclude people with cognitive disabilities, it would be important to extend research to include this group at the next stage to ensure equality issues are addressed.

Research priorities and gaps

Key areas for investigation and research have been recommended by the Mental Welfare Commission and Centre for Mental Health and Capacity Law, the Scottish Human Rights Commission and the Scottish Independent Advocacy Alliance.

Areas for investigation

- 1 Learning about what decision support works for people with lived experience, giving priority to populations under represented in research studies e.g. people with dementia and people with psycho-social conditions.
- 2 Piloting models of training and support interventions for decision-supporters (informal and formal i.e. powers of attorney and guardians)
- 3 Advance Planning: effective use of mechanisms to maximize control should decision-making capacity be affected at some future point: future care planning, powers of attorney, advance statements, nominated person, anticipatory care plan. (At the time of writing the Centre for Mental Health and Capacity Law (CMHCL) is seeking funding for a research project on this area).
- 4 Independent advocacy and SDM: development of a national framework.
- 5 Decision-capacity building programmes for adults with cognitive disabilities.
- 6 Reframing Capacity Assessments – developing models and tools to support the shift away from a deficit based ‘medical model’ to an assets based model.
- 7 Operation and impact of proposed provisions within AWI Act (if introduced):
 - Investigate how the reformed provisions are working from the perspective of all involved
 - what is the uptake and usage in practice of new provisions and safeguards.
- 8 Links with Australian research initiatives would be very fruitful with opportunities for collaboration.

For information about current SDM research see Appendix E

8 Creating Change – mainstreaming access to SDM

8.1 Aim

The over-all aim of the SDM strategic framework is to mainstream access to supported decision-making for all those who need it in compliance with UNCRPD Art. 12; and in so doing, effect a pivotal shift in our culture which recognises that people with cognitive disabilities have the same legal and civil rights as everyone else. The proposed framework is based on the concept that decision-making can’t easily be compartmentalized and that decision-support may be needed across many aspects of person’s life, including day to

day decisions which impact on a sense of well-being, independence and quality of life.

It is essential to elevate the status and profile of hitherto invisible ART.12 rights and raise awareness across national and local government and the wider community. The new Human Rights National Outcome and Leadership Programme provides the opportunity to highlight the centrality of UNCRPD Art.12 to accessing all other socio-economic and civil rights.

The status given to the SDM Overarching Framework will have a bearing on the level of commitment and resources likely to be awarded at regional and local levels.

8.2 Leadership roles: duty bearers

- **Scottish Government**

Given that responsibility for equality, disability and human rights policies is shared across several ministries, and bearing in mind that Art.12 rights are inherent in all other UNCRPD rights, it will be important to have an identified lead to spearhead and coordinate an SDM action programme.

Other statutory bodies with duties and responsibilities to ensure SDM delivery include:

- Joint IHSC Boards
- Lead commissioners – NHS and local authorities
- Adult Social Care and Older People's leads in local authorities.
- The Care Inspectorate
- SSSC

8.3 Change model

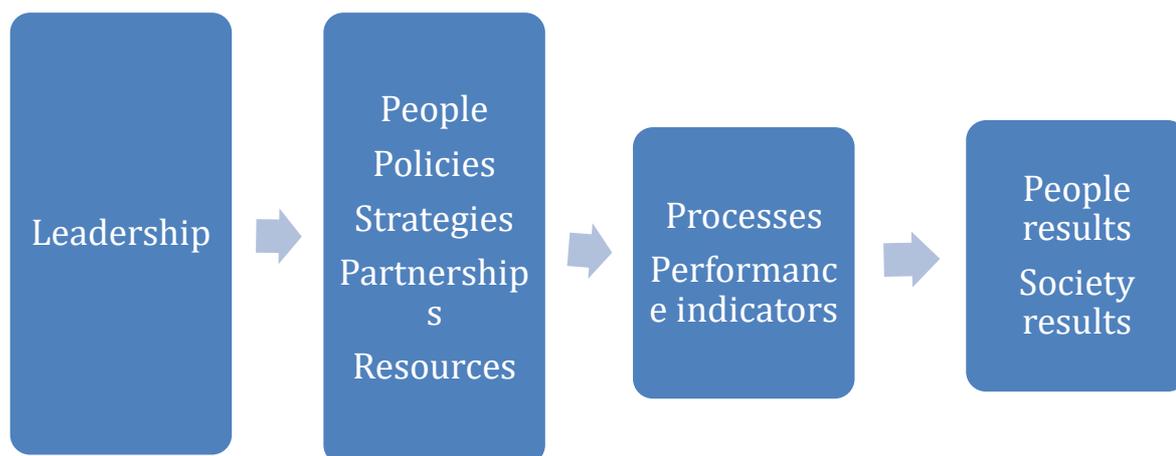
The SDM model for change proposed here is not based on the provision of new services but has sought to identify how existing policies, structures, delivery systems and practices can be reframed to support decision-making for people with cognitive disability. The process of organizational change to fulfill the Government's commitment to 'personal outcomes' is already in process and provides appropriate mechanisms to deliver UNCRPD Art. 12 rights. The SDM Overarching Framework approach focuses on 'enablers' and 'barriers', borrowing from The European Foundation for Quality Management (EFQM) improvement model lends itself well to the application of a 'whole systems' approach. (See below)

However, the detailed 'Logic Model – working version' set out in the MWC/SHRC report, 'Human Rights in Mental Health Care in Scotland' which provides a 'in-depth' approach to achieving a specific objective, relates more closely to what needs to happen to facilitate the implementation of the SDM Framework. The Logic Model shows intended outcomes (changes), in the intermediate and long term and the activities expected to produce these (in

relation to meeting commitment 5 of the Mental Health Strategy for Scotland (2015). Importantly the analysis identifies those roles and organisations with duties and responsibilities to act.

Barriers: structures, systems, processes, attitudes

ENABLERS



European Foundation for Quality Management (EFQM) improvement model

8.4 Next steps

Several areas where early action will be timely and fruitful. In summary:

- Identification of leadership roles at national level.
- Engage with disability strategy lead teams
- Engagement with people with lived experience (people with a cognitive disability and their informal carers).
- Awareness Raising Strategy
- Engage with SSSC, NES and the Care Inspectorate on workforce development, training and new quality framework; review of Commissioning Guidance for specific groups e.g. autism etc.
- Engage with 'personal outcomes' initiatives including Realistic Medicine and action to improve implementation of Self-directed support.
- Pilot collaborative SDM education and support models for informal carers with powers of attorney and guardianship/and other informal decision-supporters
- Establish an SDM centre/hub
- Developments leading to the expansion of independent advocacy services, providing decision-support.

Appendix A: UNCRPD ‘PANEL’

The PANEL approach endorsed by the United National underpins recent reforms. It emphasizes the rights of everyone to:

Participation in decisions which affect their lives

Accountability of those responsible for the respect, protection and fulfillment of human rights

Non-discrimination and equity

Empowerment to know their rights and how to claim them

Legality in all decisions through an explicit link with human rights standards in all processes and outcome measurements.

Appendix B

Laws, policies and strategies affecting people with cognitive disability.

Legislation

- Adults with Incapacity (Scotland) Act 2000 (currently under review)
- The Public Service Reform (Scotland) Act 2010
- Mental Health (Care and Treatment) (Scotland) Act 2003, (amended 2015)
- Adult Support and Protection (Scotland) Act 2007
- Education (Additional Support for Learning) (Scotland) Act 2004, amended 2009
- The Patient Rights (Scotland) Act 2011
- Social Care (SDS) (Scotland) 2013
- Public Bodies (Joint working) (Scotland) Act 2014
- The Community Empowerment (Scotland) Act 2015
- Carers (Scotland) Act 2018 (to commence 1st April).
- Social Security (Scotland) Bill (3rd stage at time of writing)

Key National Strategies

- A Fairer Scotland for Disabled People – Our delivery Plan to 2021 for the UNCRPD. Dec. 2016.
- National Dementia Strategies (3) 2010 – 2021
- Age, Home and Community. A strategy for housing for Scotland's Older People. 2012-21 (refreshed)
- National Mental Health Strategy 2017-2027
- Keys to Life – Scotland's Learning Disability Strategy 2013-2023 (under review)

- The Scottish Strategy for Autism 2011 – 2021

National Standards:

- Standards for Dementia Care in Scotland (May 2011)
- Health and Social Care Standards – My support, my life.
9 June 2017

Appendix C: Learning from Experience: case examples

1 Experiences of people living with a learning disability

Case 1: Elizabeth

Elizabeth lived with her parents in the family home but due to changes in her health she started using a wheelchair, which meant the house was no longer accessible. She made the decision to move out of the family home and attended an event about housing options for people with learning disabilities in order to look for advice on her options. At the event she was advised that she should speak to her local council about being rehoused. The council advised that, because Elizabeth was not homeless, there would likely be a long wait for a property. She was told that she would probably be offered a house sooner if she were prepared to move out of the area. Elizabeth knew she wanted to stay local to her parents. After talking the situation over with her parents she decided that waiting for a council house to come up was not an option.

Her mum helped her to look at her finances and to consider her options. There were not a lot of accessible properties available for private rental in the area and rents were expensive so, after discussions with her family, friends and a mortgage advisor, she decided that she would purchase a property. Because her family are owner-occupiers, she was familiar with the idea of home ownership; in addition, her parents were supportive of the idea of buying her own house.

Her parents and mortgage adviser both gave her advice and information that helped her decide on the kind of mortgage and length of loan would suit her best, and a bank approved a loan. The decision of which house to buy within these parameters was made by Elizabeth on her own. She identified a house on Good Moves that was accessible and met her other criteria. After visiting the property she submitted an offer, which was accepted.

The more difficult decisions came later. She found it difficult to understand some of the things that came with being a home owner. The local authority acts as a factor for the property and the information she got from them was difficult to understand. A number of adaptations, such as widening the doors in order to accommodate her wheelchair, needed to be made before she could move in. Elizabeth found it difficult to understand how to arrange for these adaptations to be made. She had thought that the council did these

things for you and that she would be able to get support to help her live independently.

Some other things needed to be fixed that she had not been aware of, as she had not been made aware of the importance of reading the home report. Her parents had last bought property before the system of home reports came in so they had not been in a position to advise on this. Elizabeth had found the language of the home report difficult to understand, and, not realising its importance had not sought help to understand it. This had highlighted some problems with damp and unsafe flooring that she had then only accidentally discovered. As a result she was unable to move into the property for several months after completing the purchase of the property. She also found that there are a number of physical tasks around the house that she was unable to do. She is trying to get some support for this from social work.

She contacted her local advocacy provider but they said the waiting list is very long and her issue was not viewed as a priority for them. Elizabeth did not want to wait so she found some informal support through an organisation she knows through her work. They put her in contact with another disabled person who had also experienced life as a home owner. This person was able to offer peer support to guide her through some of the things she had to do. This informal peer advocacy has been really helpful with her discussions with social work and occupational therapy, even though the issue has not yet been resolved.

Elizabeth is pleased to have moved, and pleased with the house she now owns. Many of the decisions she made resulted in good outcomes. However, she recognises, with hindsight, that she made some decisions without being fully-informed. Even a combination of friends, family and relevant professionals did not give her a realistic idea of the ongoing costs of owning a house.

A key factor that enabled Elizabeth to make the decisions she made was her social capital. She had a supportive family, helpful work colleagues and others in her wider circle that she could go to for advice. These contacts were also able to signpost her to relevant professionals such as mortgage advisers. Time will tell how good some of Elizabeth's decisions were but what she is sure about is that they were *her* decisions.

Case 2: Frank

Frank's mother had dementia. The local authority was in the process of assuming the role of financial guardian over her affairs. However, guardianship had not been finalised before she passed away. This left Frank with a number of financial issues. He inherited her house. However, her estate was left owing the council money for care charges she had incurred. In addition, the mortgage was not fully paid off and Frank was not able to make the payments. He, therefore was required to sell the house but knew, since it was in a bad state of repair, that he would have to contract a number of tradespeople to ensure it was brought up to a sellable standard. Frank had a lot of decisions to make about who to choose to complete the

work. He needed a joiner, a roofer, a landscaper, gas engineers, a cleaning firm, and an estate agent. In addition, he had to deal with lawyers to make the sale.

Frank had never had to do anything like this before and it was very difficult to get different quotes for the work and identify what work was to be done. Frank's personal assistant Gareth helped him to make the decisions he needed to make. Gareth was particularly well suited to help as he knew Frank well, and before becoming a PA, he had worked as a solicitor.

Gareth's skills and experience were very helpful to Frank as he was able to offer advice and support with things that Frank found difficult such as telephone calls to professionals and tradespeople. Frank asked Gareth to arrange an estate agent on his behalf and trusted that he would be able to do this. Frank says; 'he told me all the time that I was in charge and not to let myself be intimidated by the lawyer.'

There were some decisions that Frank wished he had been better supported to make. For example he paid for roof repairs because he did not know that he could have made an insurance claim for the damage. He also ran into some problems with contracting a landscape gardener. Frank had decided to put chippings on the front garden to make it easy to care for. The contractor asked for payment for materials and Frank decided to save time and pay the whole fee up front without talking to anyone else first. The contractor then did not complete the job. This was a mistake and cost him twice as much money as he had to find an alternative landscaper to redo the work.

Frank's only formal support is a small number of hours each week from Gareth. He felt fortunate that Gareth was able to help him make a significant number of informed decisions as another PA might not have had the same mix of skills, experience and empathy. However, there were at least a couple of occasions when Frank made decisions without the full facts or without appreciating the significance of those decisions.

2 Cases 3 & 4: Experiences of a professional guardian

The following cases studies have been contributed by a solicitor and are narrated in the first person. They are based on two people for whom she is financial guardian. The names are changed and other details to preserve anonymity.

Case 3: HL living with dementia

HL is an 82 year old woman with dementia who lives in her own home with a lot of support from family and neighbours. She has significant savings and became a target for two individuals who befriended her and proceeded to steal around £15, 000 over a four week period. Following this she was assessed as lacking capacity to manage her financial affairs and I was appointed as her financial guardian.

HL has always been very independent and reluctant to accept help from others. She lacks insight into her vulnerability and memory loss and has been very resistant to any formal involvement. While she did not oppose the financial guardianship she strongly believes it is not necessary.

HL is used to managing her own money and is understandably offended by any suggestion she cannot manage on her own. I am registered on her bank accounts and can view activity online. She now has no access to her large savings accounts other than via myself. However, when I talked to her about her spending, it follows a very distinct pattern. Direct debits are paid, and she withdraws 30/50 twice a week for shopping, meals out etc. She rarely makes larger purchases but wishes to be able to pick up something if she sees it such as a painting, ornament, clothes, and furniture.

We agree that she has free access to her current account with the cash card in the same way she always did. I monitor this, so I can pick up any unusual transactions. Otherwise we keep her current account with a balance of £1500/£2000. She follows her established pattern of spending most weeks with occasional larger purchases. For example, she booked a holiday with her sister. Her sister provided informal support and they have a great relationship. She lets me know if HL wants anything larger, so I know to expect the transaction.

While I am a guardian and substitute decision maker we are trying to operate a Supported Decision-Making approach. From HL's point of view everything continues as it did before. She has autonomy over her money. She has some awareness that I check her accounts but views this as just making sure no one steals her money again. Despite having a guardian, she makes her own decisions about money. However, she is protected from theft and fraud.

Case 4:TP

TP is a forty-year-old man who lives in the community with his two sons. He has very limited understanding of the value of money and is vulnerable to pressure to spend from those he socialises with. His children also pressure him into purchasing things leaving him short of money.

I am his financial guardian, but he receives support from a care organisation as well. We have tried to respect his rights to make his own decisions but also keep him safe. For example, as he was not eating he has agreed online shopping is a good idea. His support staff help him plan meals but overall, he has control over what he buys and how much.

He also wants to gift money regularly to family and friends, and especially his sons. He has no understanding of normal social conventions or when someone is likely to pay him back so he is often exploited. His children are also aware of his vulnerability. It has been hard to act as his guardian. His generosity and wish to provide for his children is something he has in common with many parents. Even when he sees them making unwise choices about expensive items, holiday and clothes he sees it as his role to assist.

I have struggled with balancing his views and preferences with the guardianship rules. As far as possible I facilitate his decisions but I am also

aware these might be detrimental to him financially in future. It can often be hard to see the benefit to him.

There is no doubt he makes some questionable choices but I think these are within the realm of what many competent and capable adults do. I feel as financial guardian there are pressures on me to 'save' his money when it is not what he wants and not what others do

I have felt conflicted in justifying legally some of the things he wants to do with his money. If there was more of an emphasis on his own will and preference I think some of my decisions might be different.

3 Experiences of people living with dementia

Cases 5,6,7

These cases illustrate how different understandings of **rights, will and preferences**, can have very different outcomes for the individuals and highlight some of the ethical issues involved.

a) Ethel

First, the story of Ethel who died at the age of 97yrs.

I lived next to Ethel for 15 years and visited her most days. She lived all her life in a large house built by her architect grandfather, married at the age of 50, widowed by the age of 55, no children or other living relatives (apart from distant cousins in New Zealand). Ethel had a wicked sense of humour and I loved hearing her stories. She was Scottish high diving champion in 1928 – she trained as a cordon bleu chef and worked in a posh hotel until WW2 broke out, she organized the canteens for the armed forces across the south of Scotland, and drove ambulances.

As her dementia advanced she became unable to cook for herself and the local authority commissioned a private provider to supply care workers to visit 3 times a day. The meals they produced lacked nutritional value, and were unappetizing—often tinned sausages, baked beans and cheese sandwiches, which were left half eaten. Ethel complained to me and we agreed that I should raise the issue with the social work department on her behalf.

To my dismay, I was told: “we do not recognize what you are saying, you are imposing your middle class values”. They visited her and Ethel told them she was quite happy with the meals she was given, and they ‘fed’ that piece of information back to me. When I asked Ethel why she had told them this, she said, “I don’t know what would have happened if I complained, I thought I might be left with nothing to eat”. When I reported **this** back to social work they gave instructions to the provider for her to be cooked a fresh hot meal every day.

Social workers thought they were responding to her **'Will'** to eat tinned sausages day after day – but in fact, her **'Will'** was not to be left to starve – her **'preference'** was for a decent meal.

b) Mrs I

The next case focuses on a formal investigation by the Mental Welfare Commission, Scotland (MWC) which arose from an interrogation of a rise in statistics of the number of cases of people 80 and over who were detained under the Mental Health Act. The investigation looked into the circumstances which lead to a serious deterioration in the mental and physical health and well being of Mrs.I, resulting in her compulsory detention in hospital. The investigation found that well-meaning professionals and family believed that they **must** give primacy to Mrs I's strongly expressed wishes to remain independent, in her own home. There was no assessment of her decision-making capacity. They accepted her refusal of help, even when her behavior exhibited extreme distress and she was physically deteriorating to a life threatening degree. During her short time in hospital (she died after 3 weeks) she was recorded as becoming relaxed, happy and sociable).

The investigation found that the case notes were very poor, with no life history record. A reluctant daughter related the following crucial information:

Mrs I was born in Italy, brought up under the fascist regime - as a girl she took food to the resistance hiding in caves above her village. She married a Scottish soldier and moved to Scotland where they had 3 daughters. He left her when she was in her 60s and, by then, the daughters were married. Mrs I stayed independent, active and house proud until the onset of dementia.

Mrs I was monitored regularly. As her illness progressed she needed a lot of help with personal care but was difficult to manage – she tried day care once but objected to the food; her personal hygiene became very poor, she ate rotten out of date salami, was bitten by her dog more than once and had to be treated for infections in hospital. She became frightened of being left alone and clung onto the cars of the care workers as they drove away and, eventually, was found walking down the middle of the road at night – her stockings sticking to her feet and her toe nails cutting into her. Mrs I was regularly discussed in case meetings with no action taken to assess her decision-making capacity as there was a belief that services must respect her **'will'** to remain at home without interference and an assumption that she had always neglected her house and personal hygiene, and loved her dog. As she deteriorated rapidly, several discussions between professionals resulted in no decision but **'to wait until there was a crisis'**.

It is impossible to understand how staff did not see that they had an overwhelming ethical duty to respond to the severe self-neglect due to her progressive dementia.

The MWC's role is to use cases like this to promote best practice The investigation report identifies a number of failures and highlights key issues for the support and care of the person with dementia throughout the illness, including support needed for her daughters who held powers of attorney, who

had problems of their own and felt out of their depth. Action at an earlier stage under the Adults with Incapacity (Scotland) Act could have averted the tragedy and protected her right to the quality of life she had chosen for herself before the illness took hold.

Research on the role of emotion in decision-making by Professor Hilary Brown, Canterbury University, for the UK government in relation to the Mental Capacity Act, provides valuable insights into the impact of dementia in relation to refusal of support from services. She concludes that emotions seem to provide an essential driving force in deciding. The study explores the influence of a person's: history and memories, their drive and motivation, their mood and stability and their openness to influence.

What she describes can be related to the cases of Mrs I, and Ethel – it is as if the unknown can come to seem so frightening or unimaginable to the extent that a person would prefer to keep to the familiar routine and avoid new experiences at all costs. People with dementia may find themselves governed more by this kind of overwhelming fear than by their assessment of the possibilities. This, inevitably, affects their decision-making and locks them into a distressing situation. Such cases are not uncommon, being faced daily by health and social care professionals especially where vulnerable adults are prone to self-neglect.

c) Mrs R

A positive story of Mrs R, where the senior social worker and his team adopted the principle that no one in their patch was to be moved into a care home against his or her **will**.

Mrs R had severe dementia, lived alone in a large house, unable to care for herself without help, but lacked insight into her plight. She believed that her husband was still alive and looking after her. She was assessed as being at high risk and that it was not sustainable for her to continue to live alone for much longer. The senior social worker called regularly and found that at certain times of the day Mrs R was much more coherent and understood things better. He concluded that with gentle support she could be helped to understand her true circumstances, and then it would be possible to discuss care options with her.

A volunteer was found who called every day at a time she was most receptive and talked with her about her husband and the fact that he had passed away. Each time she grieved but, eventually, came to terms with his loss and decided that she did not want to live alone any more and did not want people worrying about her. She remembered she had a sister and said she would like to go and live with her. It was discovered that the sister lived in a care home in the adjacent local authority area and negotiations began for her to join her sister but, unfortunately she died.

Her '**Will**' was to live at home with her husband, but once she accepted he was no longer with her, her clear **preference** or 'altered will' was to go and live with a her sister.

Was it unethical to keep reminding the lady that her husband had died (because of the emotional pain this caused each time)? Would it have been ethical to collude with her? Collusion would eventually have led to the awful outcome of her being moved against her will, under a court order, perhaps believing she was leaving her husband in the house without her, or even believing that her husband had abandoned her.

Collusion of this nature with people with dementia is not at all uncommon and can have devastating consequences for the individual, yet it is often seen as 'respecting the person's will' even if it denies them other rights under UNCRPD. It is a controversial ethical issue, which again deserves more attention.

Appendix D Current research (this is not a comprehensive list)

- 1 Scotland: Chief Scientists Office – funding projects on Realistic Medicine objectives
- 2 The Mental Health and Justice Collaborative Interdisciplinary programme has 6 interrelated research strands:
 - 1 Enabling legal capacity through decision-making support
 - 2 Support and independence within the community
 - 3 Supporting Advance Directives
 - 4 Decision-making and Insight
 - 5 Decision-making and metacognition
 - 6 Contested Assessment

For details see: <https://mhj.org.uk>

Elsewhere

- 2 The Living with Disability Research Centre at La Trobe University has been leading the field and is currently conducting a major longitudinal research programme:
'Effective Decision-making support for people with cognitive disability' (Phase 3 Australian Research council Linkage Grant Funding. Living with Disability Research Centre, La Trobe University).
- 3 Queens University, Belfast: Supported decision-making - experiences approaches and preferences. Mental Capacity Act (Northern Ireland, implementation to start in 2019).
- 4 National Resource Centre for Supported Decision-Making <http://supporteddecisionmaking.org/> currently conducting qualitative and quantitative studies to document the nature, use, barriers and outcomes of SDM by older people and people with learning disabilities (results pending)

Appendix E. References

There is a growing literature, world-wide, on developments to progress UNCRPD Art. 12 rights. The following list comprises only some of the background used to inform this report.

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