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GOOD PRACTICE GUIDE

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**Supported decision-making maximises an individual's ability to ensure that their rights, will and preferences are at the centre of all decisions that concern them**

## **1. Introduction**

Everyone has the right to equal recognition before the law and respect for their choices. This guidance sets out why supported decision-making is an important concept. It explains how adults with mental illness (including dementia), learning disabilities and other related conditions, who may have difficulty making decisions, can be supported to ensure that decisions made, by or about them, genuinely reflect their choices.

### **1.1 Why is this guidance necessary?**

In the last few years, there has been increasing international interest in the idea of supported decision-making. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) sets a clear expectation that signatories (including the UK) 'shall take appropriate steps to provide access by persons with disabilities to the support they may require in exercising their legal capacity'. Some countries have passed laws which give formal legal recognition to supported decision-making.

This has not yet happened in Scotland, but Scots law already reflects many of the key ideas behind a supported decision-making approach. The principles underlying the Adults with Incapacity (Scotland) Act 2000 (the Adults with Incapacity Act), Mental Health (Care and Treatment) (Scotland) Act 2003 (the Mental Health Act) and the Adult Support and Protection (Scotland) Act 2007 (the Adult Support and Protection Act) all seek to ensure respect for a person's capacity and autonomy, even if they have some impairment or disability.

The Commission believes it is important that everyone involved with individuals with decision-making difficulties is aware of the importance of support for decision-making and thinks about how best it can be provided.

There is a considerable amount of research underway about different types of supported decision-making and their operation and effectiveness. But there are already many practical, simple steps that can be taken to keep a person's rights, will and preferences at the centre of decisions concerning them.

## 1.2 Using this guidance

This guidance discusses:

1. What supported decision-making is and why it is relevant and important.
2. The human rights framework that supports autonomy and supported decision-making.
3. The role that supported decision-making can play in reinforcing principles that underpin Scottish legislation.
4. What must be taken into account when providing supported decision-making.
5. Examples of supported decision-making.

In doing so, existing literature examples of supported decision-making in the field and information gathered during four stakeholder consultation events hosted by the Commission on supported decision-making in November and December 2015 have been taken into account.

## 1.3 Who is this guidance for?

This guidance will primarily be of assistance to health and social care staff. It will, however, also be relevant to individuals with mental disabilities, their families and those, including welfare and financial attorneys and guardians, who support or work with them.

Importantly, the protections of the UNCRPD and the principles of the Adults with Incapacity Act do not only apply in health and care settings, but are also relevant to issues such as operating a bank account, or renting property, or making other important financial and welfare decisions. So this guidance may also be helpful to other organisations and businesses that sometimes deal with adults with difficulties making decisions.

## 1.4 What do we mean by decision-making capacity and exercising legal capacity?

**Decision-making capacity:** An individual's decision-making capacity relates to their ability to make decisions about things that affect their life. To have decision-making capacity means that the individual can understand a decision, the available choices, the consequences of any decision they make and can communicate this decision.

**Legal capacity:** Legal capacity is the ability to hold rights and to make decisions that are respected and capable of being enforced under the law (e.g. signing contracts and agreeing to medical care and treatment).

Some people have impaired decision-making capacity or, in extreme cases (for example, a person in a coma) may have no decision-making capacity at all. But the

UNCRPD states that everyone with a disability should enjoy 'legal capacity on an equal basis with others in all aspects of life.' For that to happen, they need support – either to help them make a decision for themselves or, if that is genuinely not possible, to ensure that a decision is made on their behalf which respects their rights, will and preferences.

Of course, decision-making capacity is not an all-or-nothing issue. A person may be able to make decisions even if they are not able to personally exercise legal capacity themselves. An adult may lack capacity to make certain decisions for themselves, but have capacity to make other decisions. For example, they may have capacity to make decisions about everyday issues such as what to wear or what to eat, but lack capacity to make more complex decisions about financial matters.

## 2. Supported decision-making

### 2.1 What is supported decision-making?

'Supported decision-making' has no formal definition, and different people use it differently. We use it to refer to any process in which an individual is provided with as much support as they need in order for them to be able to:

- 1) Make a decision for themselves; and/or
- 2) Express their will and preferences within the context of substitute decision-making (for example, guardianship or compulsory treatment for mental disorder).

In both cases, the purpose of supported decision-making is to ensure that the individual's will and preferences are central to and fully respected in decisions that concern them.

Substitute decision-making for an adult should only happen where there is specific legal authority. The main pieces of legislation that authorise substitute decision-making in Scotland are:

- The Adults with Incapacity Act, which provides for guardians and attorneys, and sets out procedures to authorise medical treatment where a person lacks decision-making capacity.
- The Mental Health Act, which allows for detention and compulsory treatment linked to significantly impaired decision-making ability
- The Adult Support and Protection Act, which allows for short term interventions for 'adults at risk'.

This guidance will demonstrate how it is possible to nevertheless ensure that the individuals' choices can be reflected in all decisions made concerning them whether these decisions are made under Scottish procedures for substitute decision-making or outside them.

## 2.2 Benefits of supported decision-making

The benefits of supported decision-making are:

- It protects individual autonomy and the universal nature of personhood.
- It benefits individuals, families and society.
- It helps individuals to be less isolated, increases their independence and enables them to be better integrated in the communities where they live.
- Individuals are more likely to be happy with outcomes where opportunities to express their views have been provided in the decision-making process.

**Supported decision-making enhances an individual's ability to participate in decisions concerning them**

Supported decision-making enables the individual to participate as effectively as possible in decisions relating to them. It helps the individual to be properly informed and their voice to be better heard in decisions that concern them.

### 3. Human rights

**Everyone, regardless of disability, is entitled to have their rights respected on an equal basis with others**

As noted above, the principles that underpin relevant Scottish legislation promote respect for an individual's autonomy and their legal capacity. These principles are in turn reinforced by human rights standards in various international treaties. The most relevant human rights treaties for the purposes of this guidance are the European Convention on Human Rights and the UN Convention on the Rights of Persons with Disabilities. Appendix 2 gives more detail about the relevant legislation.

#### 3.1 The European Convention on Human Rights (ECHR)

In Scotland, the Human Rights Act 1998 and the Scotland Act 1998 require that ECHR rights must be reflected in devolved legislation and policy and are legally enforceable against public bodies (for example, government departments, hospitals, prisons, care facilities, local authorities, the police and the courts).

The state is also responsible for any violations of ECHR rights by individuals and non-state bodies where the state has a regulatory role regarding such individuals or bodies or colludes with the violation.

##### 3.1.1 Articles 5 (right to liberty) and 8 (right to respect for private and family life) ECHR

The ECHR does not identify a specific right to hold and exercise legal capacity. However, it does identify the right to liberty (Article 5) and the right to respect for private and family life (Article 8). These rights may be limited, but only in exceptional circumstances and subject to certain legal and procedural safeguards. The ECHR and its case law recognise that depriving someone of their right to respect for private and family life and/or liberty has serious implications for their autonomy and the exercise of their legal capacity. This is reinforced by the Council of Europe Committee of Ministers Recommendation R (99) 4 on principles concerning the legal protection of incapable adults, which although not legally enforceable is influential.

The ECHR further identifies a prohibition against discrimination (Article 14). This means that individuals with mental disabilities are entitled to enjoy the rights in Articles 8 and 5 ECHR on an equal basis with others.

### a) Article 5: the right to liberty

The rulings in the *Bournewood*<sup>1</sup> case and the *Cheshire West*<sup>2</sup> case have made it clear that a person who lacks capacity to consent to a deprivation of liberty will require the protection of legal and procedural safeguards if their Article 5 right is not to be violated. On the other hand, where a person has capacity to give valid consent to a deprivation of liberty then Article 5 is not engaged and these safeguards will not be necessary. It may therefore be that, with appropriate support, an individual may be able to give valid consent to arrangements which would otherwise be a deprivation of liberty. It is, however, crucial to ensure that they have given full, free and informed consent in such circumstances.

### b) Article 8: the right to respect for private and family life

The European Court of Human Rights has stressed that a person's mental capacity should be presumed. If such capacity is questionable then capacity must be assessed according to the particular matter that needs to be decided (a 'functional capacity assessment'). Moreover, it has stated that the fact that someone is considered to lack the ability to exercise their legal capacity does not mean that they are unable to understand their situation.

**The European Court of Human Rights has stated that the fact that someone is considered to lack the ability to exercise their legal capacity does not mean that they are unaware of their situation**

## 3.2 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The United Kingdom is a party to the UNCRPD. It is therefore expected under international law to comply with this treaty. The rights in the UNCRPD are not legally enforceable within the UK and Scotland in the same way that ECHR rights are but it is nevertheless an important and influential treaty.

The UNCRPD recognises that persons with disabilities have the same rights as those who do not and are entitled to enjoy rights on an equal basis with others. The right to equal recognition before the law (identified in Article 12 UNCRPD) is fundamental to this.

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<sup>1</sup> *HL v UK* (2005) 40 EHRR 32 (often referred to as 'the Bournewood ruling')

<sup>2</sup> *P (by his litigation friend the Official Solicitor) (Appellant) v Cheshire West and Chester Council and another (Respondents); P and Q (by their litigation friend, the Official Solicitor)(Appellants) v Surrey County Council (Respondent)* [2014] UKSC 19 (often referred to as 'the Cheshire West ruling').

### **3.2.1 Article 12 UNCRPD - equal recognition before the law**

Article 12 UNCRPD recognises the right of persons with disabilities to exercise legal capacity on an equal basis with others (Article 12(2)). In order to ensure that this is a reality for persons with disabilities it requires that states must provide them with access to support, in order to exercise their legal capacity. Importantly, safeguards must be in place to ensure that any such support arrangements 'respect the rights, will and preferences of the person' (Article 12(4)).

This is reinforced by General Comment No. 1 of the UN Committee on the Rights of Persons with Disabilities, which oversees the implementation of the UNCRPD in its interpretation of Article 12. It sees supported decision-making as being an integral part of support in the exercise of legal capacity.

As indicated earlier, Scottish law reflects ECHR requirements but does not entirely reflect those found in the UN Committee on the Rights of Persons with Disabilities' General Comment No.1. This guidance therefore looks at supported decision-making within the context of arrangements permitted under Scottish and ECHR law.

## 4. Principles underlying Scottish legislation and supported decision-making

**Supported decision-making has an important role to play in ensuring that the principles that underpin Scottish legislation are properly implemented**

Support with decision-making can be used even where individuals do not have decision-making difficulties and use of interventions under Scottish legislation are not being considered. This would encompass outlining the decision to be made in a manner that the adult could best understand, with the resulting benefits and/or consequences. Supported decision-making should also be applied where interventions under this legislation are being considered and even when the individual is subject to interventions under the Acts.

The principles that underpin the Adults with Incapacity Act, the Mental Health Act and the Adult Support and Protection Act reflect the need to respect the choices of an individual with decision-making difficulties.

All three Acts proceed from the position that mental capacity is presumed and assessed on a decision-specific basis, that interventions are a last resort (and must benefit the individual), and specifically direct that the individual's present and past wishes and feelings must be taken into account and the individual to participate, where reasonable and practicable, in any decisions about her or him. Supported decision-making can be used to apply these principles.

The following identifies situations in relation to the three Acts where regard must be had for the wishes and feelings of individuals who are, or may potentially be, subject to the legislation. In these cases, appropriate support with decision-making will assist in ensuring that their wishes and feelings are fully reflected in any outcomes.

**Scottish legislation recognises and respects the right of individuals to make choices concerning their lives even where interventions are in place.**

## 4.1 Using supported decision-making to reinforce Adults with Incapacity (Scotland) Act 2000 principles

### Stop and think!

How can **you** support the individual to make a decision and exercise their rights, will and preferences?

#### 4.1.1 Determining whether intervention under the Act is required

An Adults with Incapacity (Scotland) Act intervention is unnecessary if a person has capacity or the intervention can be most effectively achieved in some other way. It also specifically states that if human or mechanical support is available to overcome communication problems then the adult will not be considered to be “incapable”.

The need for substitute decision-making intervention may be avoided or delayed by supporting an individual to make decisions concerning all or part of their financial and property affairs, and personal welfare.

Even where an individual lacks capacity, supported decision-making can be used to influence what kind of intervention is appropriate. For example, a Practice Note for the sheriff courts in Lothian and Borders states that an application for guardianship:

“must include averments as to the present and past wishes and feelings of the adult so far as they can be ascertained. If it is not possible to ascertain them, the writ must include averments (1) as to why this is not possible and (2) as to the steps taken, if any, (including any assistance and/or support provided) with a view to ascertaining them”.<sup>3</sup>

#### 4.1.2 Encouraging the exercise of autonomy and legal capacity when interventions are in place

Whilst interventions are in place there is a legal requirement to take into account the adult's present and past wishes and feelings. In addition, any guardian, attorney or manager of an establishment exercising functions under the Adults with Incapacity Act or a sheriff's order must, where it is reasonable and practical to do so, encourage the adult to exercise and develop their skills relating to their property or financial affairs or personal welfare.

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<sup>3</sup> Sheriffdom of Lothian and Borders Practice Note No 1 of 2016: applications under the Adults with Incapacity (Scotland) Act 2000, available at [https://www.scotcourts.gov.uk/rules-and-practice/practice-notes/sheriff-court-practice-notes-\(civil\)](https://www.scotcourts.gov.uk/rules-and-practice/practice-notes/sheriff-court-practice-notes-(civil))

The Adults with Incapacity Act Codes of Practice for persons authorised under intervention and guardianship orders (paras 1.10-12) and for continuing and welfare attorneys (paras 1.12-1.14 and Annex 1: *A Guide to Communicating with the Person with Impaired Capacity*) stress that it is important that:

- a) The adult's present and past wishes and feelings are taken into account.
- b) The adult be supported to be involved in making decisions about their own lives as far as they are able to do so.
- c) The adult should be offered appropriate assistance to communicate and give effect to their views; recognising that a person may have opinions about something but not necessarily be able to give effect to this.
- d) Special efforts may be made to communicate with a person, such as interpreters, memory aids, pictures and non-verbal communication or advice from a speech and language therapist.

The Adults with Incapacity Act Code of Practice for practitioners authorised to carry out medical treatment and research under Part 5 of the Act states that *it is compulsory to take account of the present and past wishes of the person where these can be ascertained.*

#### **4.2 Using supported decision-making to reinforce Mental Health (Care and Treatment) (Scotland) Act 2003 principles**

**Stop and think!**

How can **you** support the individual to make a decision and exercise their rights, will and preferences?

When considering, and implementing, interventions (for example, emergency detention, short term detention and related treatment and compulsory treatment orders) authorised under the Mental Health Act:

- a) Regard must be had for the patient's present and past wishes and feelings (relevant to the discharge of the function).
- b) The patient must be permitted to participate as fully as possible in the discharge of any function under the Act and be provided with such information and support as is necessary to do this.
- c) The patient's abilities, background and characteristics (including their age, sex, sexual orientation, religion, racial origin, cultural and linguistic background and membership of any ethnic group) must also be taken into account.

The Act's Code of Practice (Volume 1, paras 3 and 5) reinforces the participation and provision of information, including principles such as information being provided in a form that is most likely to be understood by the patient. It also states that where the patient needs help to communicate (for example, translation services or signing) this should be considered and that any unmet need of this nature should be recorded.

### 4.3 Using supported decision-making to reinforce Adult Support and Protection Act (ASPA) principles

**Stop and think!**

How can **you** support the individual to make a decision and exercise their rights, will and preferences?

When considering an intervention under the Adult Support and Protection Act, consider how supported decision-making will help determine the necessity and type of action to be taken. How will supported decision-making assist the individual to participate in such decisions and make their will and preferences central to all decisions made?

When any public body or office holder is considering whether to take action under the ASPA:

- a) The adult's past and present wishes and feelings must be taken into account.
- b) The adult must be encouraged to participate in the process and they must be provided with such information and support as is necessary to enable them to participate.
- c) The adult's abilities, background and characteristics (including the adult's age, sex, sexual orientation, religious persuasion, racial origin, ethnic group and cultural and linguistic heritage) must be taken into account.

The Act's Code of Practice (Chapter 3, paras 6 and 8) reinforces the above principles. It specifically states that:

- a) Efforts must be made to assist and facilitate communication using whatever method is appropriate to the needs of the individual (for example, if the adult has an advance statement this should be given due consideration).
- b) The Act seeks to provide support additional to the networks that may already be in place and so it is important that the adult has the choice to maintain existing family and social contacts.
- c) So that the adult can most effectively participate in any decisions being made it is essential that they are provided with information to help that participation (in a way that is most likely to be understood by the adult). If help to communicate is required (for example, translation services or signing) then these needs should be considered and any unmet need should be recorded.

## 5. Requirements for supported decision-making

**The primary objective of any supported decision-making arrangement is to ensure that the views of an individual with decision-making difficulties are fully respected**

### 5.1 Stages of decision-making

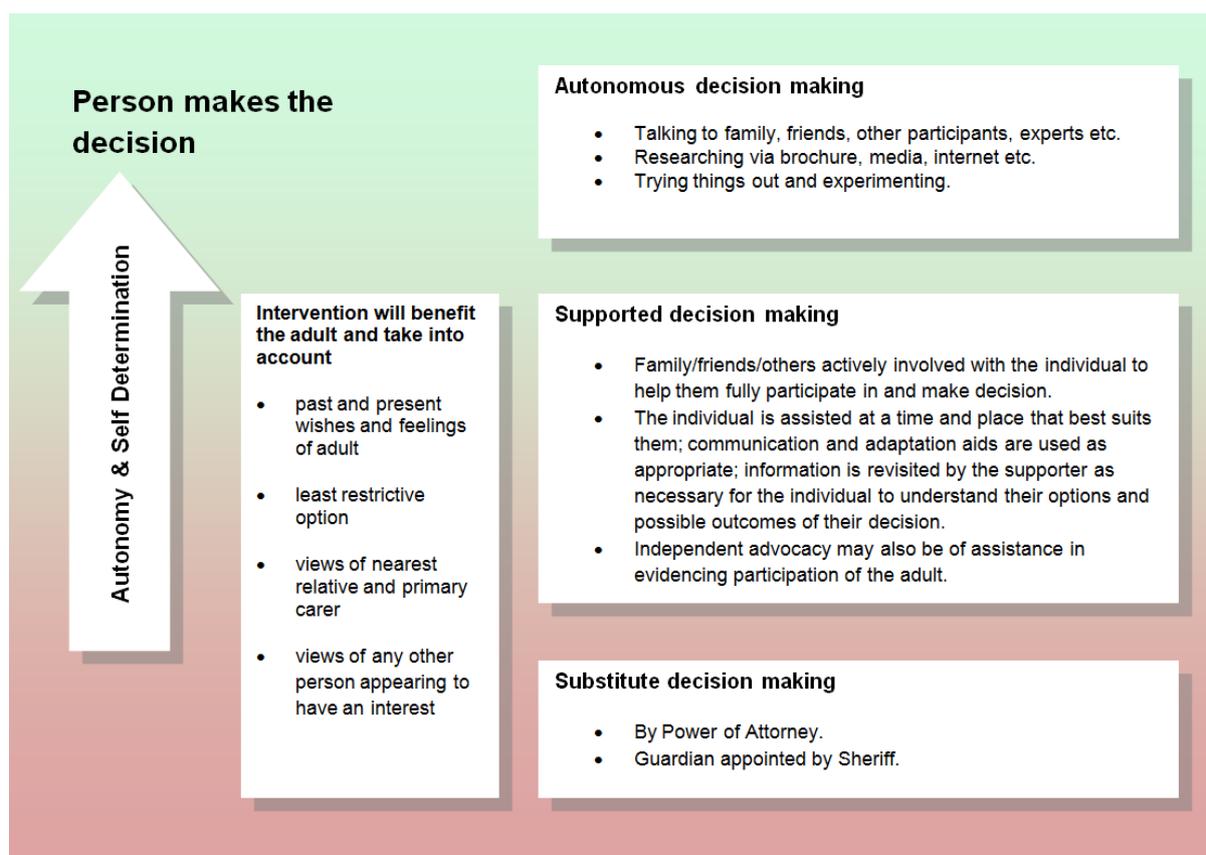
At any given time an individual may need different types and levels of support to make decisions and give effect to them, or no support at all. It may be that they need no support to make decisions about certain things, such as what they want to eat and where they want to live, but require it for others, such as how they handle their financial and property matters.

Many people can make **autonomous decisions** by informally accessing, where necessary and wanted, their own support from friends, family or specialists, written, oral and internet information and drawing on their own past experiences.

Others may require **additional and a higher degree of support** that may be both informally or formally available but which is more tailored to their particular circumstances. This could include appropriately formatted and presented information, help with communication, the use of technology, formally recognised supporters, greater time spent with the individuals explaining options or professional advice.

It is important that supported decision-making is incorporated into all care planning arrangements.

Figure 1 Decision-making spectrum



Adapted from Disability Services Division of the Victorian Government Department of Human services<sup>4</sup>

## 5.2 Key elements of supported decision-making arrangements

Whatever form of supported decision-making is used, its primary objective is to ensure that the individual's rights, will and preferences are central to any decision-making process and reflected in, and given effect to, by the decision that results. Effective supported decision-making must therefore incorporate the following key elements:

<sup>4</sup> Victorian Government Department of Human Services (2012), *Supporting decision making A guide to supporting people with a disability to make their own decisions.* [http://www.dhs.vic.gov.au/\\_data/assets/pdf\\_file/0011/690680/dsd\\_cis\\_supporting\\_decision\\_making\\_0212.pdf](http://www.dhs.vic.gov.au/_data/assets/pdf_file/0011/690680/dsd_cis_supporting_decision_making_0212.pdf)

### 5.2.1 Adherence to relevant legislative principles and human rights

The principles underpinning the Adults with Incapacity (Scotland) Act 2000, Mental Health (Care and Treatment) (Scotland) Act 2003 and Adult Support and Protection (Scotland) Act 2007 and related human rights must be kept in mind at all times.

### 5.2.2 Presumption of capacity and functional capacity assessments<sup>5</sup>

An individual's capacity must be presumed unless there is strong evidence to the contrary, assessed on a functional capacity basis and regularly reassessed. It must be remembered that capacity can fluctuate. Confusion or consciousness may determine whether or not an individual has capacity to make a decision. Even where a person is considered to lack capacity, their rights, will and preferences must still be taken into account and strenuous efforts must be made to ascertain what these are.

### 5.2.3 Absence of “undue influence” and conflict of interest

There is a need to be mindful of undue influence and of actual and potential conflicts of interest in relation to supporters and others around the individual and the impact this might have on the individual's decision-making.

#### **Case example 1: Peer and community supported decision-making and undue influence**

Jane is a young woman with a mild learning disability. She has recently been “befriended” by a group of young men and women who are heavily influenced by “heavy rock”. Jane decided that she wanted a tattoo because her new group of friends all have them and have been urging her to do this.

Jane went to a tattoo artist who is the partner of one of the group. He persuaded her to have several large tattoos at a high cost over the next six months. Jane is only in receipt of benefits and does not have much money so she agreed to pay the tattooist in instalments. However, this will have an impact on her ability to pay her bills and have any other disposable income. She says that she is not bothered by this as she wants to be like the rest of the group and they have told her she can only stay with them if she gets the tattoos. It may be that the Jane's new friends and the tattooist have subjected her to undue influence for financial gain.

In this situation, it is important that steps are taken to ascertain whether or not she has been presented with all the options and the benefits and disadvantages of getting the tattoos, and a suitable place and amount of time to reflect on these, so that she was able to make a fully informed decision.

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<sup>5</sup> See section 3.1(b) of this guidance for a definition of ‘functional capacity assessment’.

#### **5.2.4 Family involvement**

The role that family members should play is a very important theme but there is also a need to be mindful of the wishes of the individual about family involvement. Clear and transparent records must be kept documenting the role of family members and/or individual's reasons for not wishing them to be involved.

#### **5.2.5 Acceptance and use of support is in the individual's discretion**

It is important to respect the fact that the seeking and acceptance of support is entirely voluntary on the part of the individual. The individual can refuse such support if they so wish although the consequences of not accepting the support should, where appropriate, be explained to the individual.

#### **5.2.6 Clarity regarding support provider**

It is essential to be clear about who actually is providing the support and what type of support this is. Situations where this is unclear and why it is unclear must be recorded.

#### **5.2.7 Honesty**

There must be honesty with the individual about what each type of support can and cannot achieve.

#### **5.2.8 Options and alternatives**

All available and appropriate options and alternatives must be presented to the individual both in terms of types of support available to assist with decision-making and choices to actually be made. This allows the individual to make a full and informed decision.

### **Case example 2: Professional supported decision-making and risk-taking**

Keith is a young man with a mild learning disability. He lives in supported accommodation and a welfare guardianship is in place which is managed by the local authority social worker. The guardianship order does not include a power over 'dress or appearance'.

Keith's appearance is very important to him and he has decided he wants to get his tongue pierced. His mother has said that if he gets that done she will not speak to him or visit. However, Keith is adamant that he wants to get his tongue pierced. To help him come to a fully informed decision the community nurse has set up three meetings to discuss the pros and cons with Keith of his taking this decision. She has also arranged for him to visit the dentist who will be able to present the facts around oral health if he goes ahead with the piercing.

This is a good example of supported decision-making by professionals. Whatever Keith decides it is clear that they have helped him to look at the impact of getting his tongue pierced so that he can make a fully informed decision.

### **5.2.9 Allow for risk taking**

Risk taking is an important aspect of decision-making. In general, an adult should be entitled to take risks and learn from the consequences of them. In supporting a person, supporters may need to explain the nature and consequence of any potential risk to the individual. However, people have the right to learn from experience, to revisit decisions and change their minds and make decisions that others do not agree with.

The assessment, management, and enablement of risk poses particular challenge to the practitioner implementing supported decision-making principles. "Enabling people to exercise choice and control over their lives, and therefore the management of risk, is central to achieving better outcomes for people."<sup>6</sup> It is inevitable that promoting choice will lead to moral dilemmas, as well as fears around complaints or litigation. Supported decision-making should be used to promote choice while managing risk proportionately and realistically. Trying to remove risk altogether can have a detrimental impact on the quality of life and benefits to the individual, including independence, confidence, self-esteem, and choice.

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<sup>6</sup>Page 7 of Independence, Choice and Risk: a guide to best practice in supported decision making by the Department of Health. Available at: [http://www.thinklocalactpersonal.org.uk/\\_library/Resources/Personalisation/Direct\\_Payments/Risk\\_Management/DH\\_074775.pdf](http://www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/Direct_Payments/Risk_Management/DH_074775.pdf)

Some individuals may choose not to seek or accept support; or will only accept limited support that is not sufficient for the individual to subsequently exercise their legal capacity.

If decision-making support is not sought or accepted or the individual suggests a wish to place themselves or others in a situation of danger, exploitation or abuse, appropriate safeguarding steps should be considered, as per the Adult Support and Protection Act. Support for making decisions may also have its limitations in a crisis situation, when acting under ASP procedures or under duty of care for public bodies may be required. Similarly, a local authority has a statutory duty of care and a responsibility not to agree to support a care plan if there are serious concerns that the individual's needs will not be met or there will exist a significant risk of harm to the individual or others.<sup>7</sup>

Perceptions of risk are different for different people. Perceived risk should be tested and assessed against the likely benefits of taking an active part in the community, learning new skills and gaining confidence. There is “an important distinction to be made between putting people at risk and enabling them to choose to take reasonable risks.”<sup>8</sup>

Ultimately, existing arrangements for safeguarding people will continue, as required. But supporting an individual to manage the process of choice and understand the potential consequences of their decision encourages empowerment and responsible decision-making. In keeping with CRPD Article 12 aims, safeguards must be proportional, effective, person-centred, applied for the shortest time possible; the measures must be regularly reviewed.

Retaining accurate, transparent records of discussions, choice, and risk is essential. Where relevant, records should include evidence of debate about risk and balancing risk-aversion with empowerment and supported decision-making.

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<sup>7</sup>Page 4 of Independence, Choice and risk: a guide to best practice in supported decision making by the Department of Health.

<sup>8</sup> Page 22 of Independence, Choice and risk: a guide to best practice in supported decision making by the Department of Health.

People with capacity to make autonomous decisions may make unwise decisions. It is important for practitioners to consider when the need for protection would override the supported decision of the individual.

Good practice:

- Considers the consequence of an action
- Considers the likelihood of harm occurring
- Supports the person to look at all options, even if they would differ from one's own choices
- Supports the person to take any action to protect themselves
- Ensure that any other people involved are protected
- Ensures procedures for safeguarding are implemented if there is a need for protection
- Ensures that the person knows how to report incidents promptly
- Liaises regularly with safeguarding bodies and has a good knowledge of their policies
- Ensures clear accountability for actions
- Ensures that carers and relevant others are involved in decision-making, when appropriate, and that their issues and concerns are heard
- Clearly documents all options that have been considered

### **5.2.10 Record keeping**

A person-centred approach should be taken to keeping records before, during and after the decision is reached. This should include reasons for why support may not be available and why a decision does not fully reflect the individual's will and preferences. Evidence in relation to all points below (5.3) should be included in written records.

## **5.3 Providing supported decision-making**

When providing support for an individual to make decisions it is important to appreciate the following:

### **5.3.1 Taking time**

Effective supported decision-making is often a process that requires time and patience. It is very important to realise this and make sure that sufficient time is provided.

### Case example 3: A good practice example of supported decision-making

Mr L has advanced dementia and is incapable within the meaning of the Adults with Incapacity (Scotland) Act 2000. He also suffers from parkinsonism connected to his form of dementia and as a result uses a wheelchair. He was recently diagnosed with cancer.

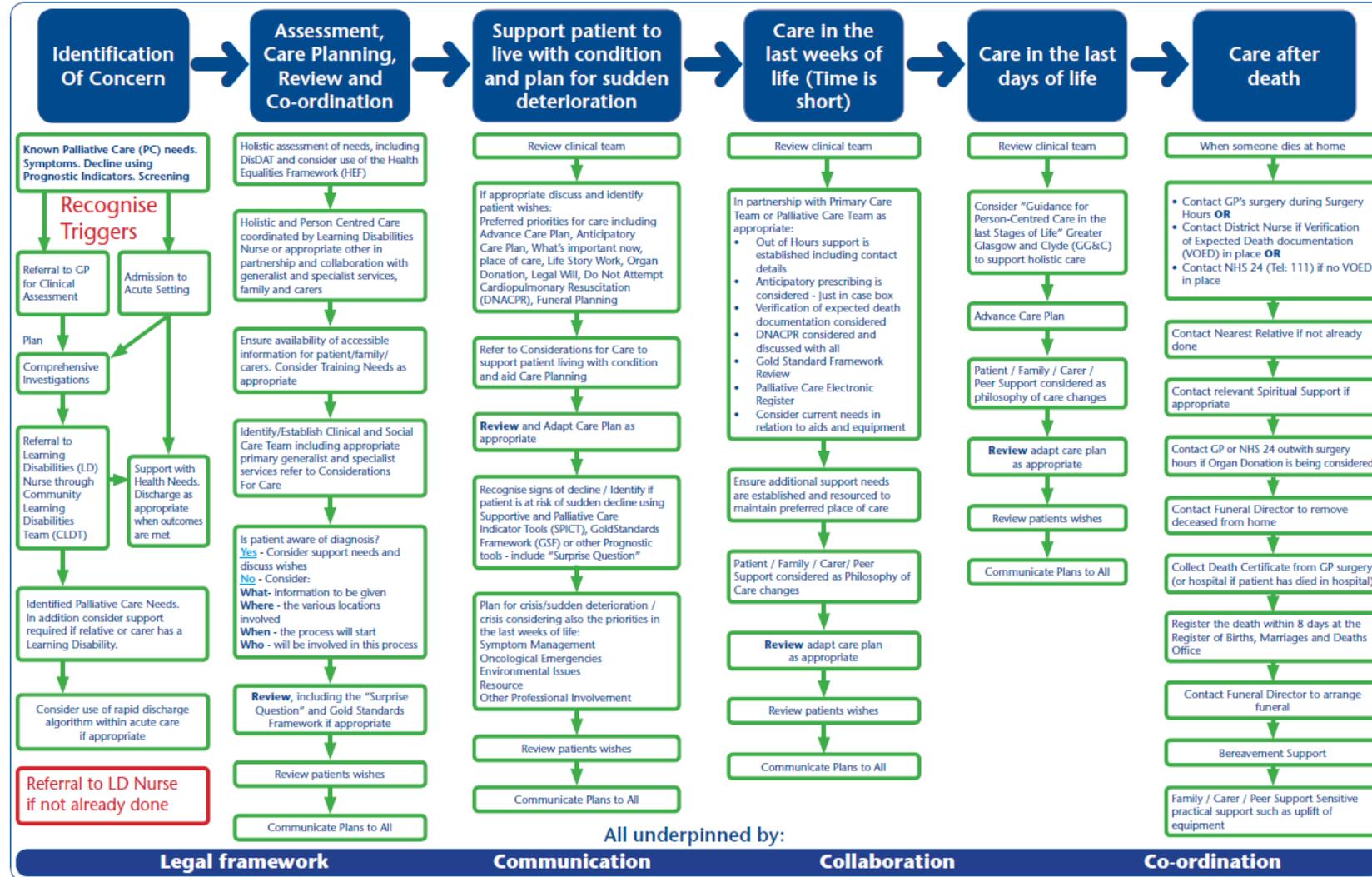
When considering treatment options for the cancer the following examples of good practice in terms of supported decision-making were used by the medical team. These ensure that Mr L was able to exercise his legal capacity on an equal basis with others and that his rights, will and preferences were reflected in the decision made.

1. All medical staff directly addressed Mr L. They did not speak about him to others or over him as he sat in the wheelchair. They took time to explain things in a way that he may understand and without patronising him.
2. The surgeon explained the various treatment options to Mr L at a pace that was right for him. This included outlining all the advantages and disadvantages of these options. He asked if Mr L had any questions and gave him time to formulate these.
3. Mr L did ask a question which was difficult to understand but the surgeon did not dismiss this and respected Mr L's right to seek additional information. Mr L's daughter, who has knowledge of the sort of things that are likely to worry her father and can ascertain this from his gestures, was able to offer her best interpretation of what he was asking. The surgeon replied directly to Mr L and not to the daughter. The surgeon's response seemed to be sufficient for Mr L because he settled thereafter.

Figure 2 Example of care pathway inclusive of supported decision-making

## Supporting people with learning disabilities through the palliative care journey

NHS Greater Glasgow and Clyde Learning Disabilities and Palliative Care Pathway



m1269615

### **5.3.2 Building and developing relationships**

Supported decision-making is most effective within the context of consistent and trusting relationships, which take time and patience to develop.

### **5.3.3 Education and training**

Those involved in giving or facilitating support for decision-making should be adequately trained and informed about what supported decision-making is, including where and in what context it is appropriate. Training should emphasise the human rights that underpin supported decision-making, its objectives, and the types of support available and their respective limitations.

### **5.3.4 Choosing appropriate times and environments**

A person-centred approach should be taken in selecting an appropriate time and to enhance the individual's full participation in decision-making. For example: an individual may be calmer and better placed to make such decisions at a particular time of the week or during the day; or they find their home to be a more conducive than a formal office or hospital.

### **5.3.5 Specialist advice and information**

In some circumstances it will be best practice to obtain specialist advice and information. The supporter should understand how the individual's particular disability might manifest and present itself. Specialist information will aid the supporter to utilise the most effective and meaningful approach with the individual.

#### Case example 4: Seeking specialist advice and information

Mr A suffered a traumatic brain injury as a result of a road traffic accident. His injury left him in a coma for three weeks and he required around the clock care. Following five weeks in an intensive care unit (ICU), he has been well enough to be able to be transferred out of the ICU to a different ward but communicating with him is very difficult in relation to all care and treatment decisions.

**Supported decision-making comment:** [See Checklist in Appendix 1] At the outset, Mr A's mental capacity must be presumed and assessed on a functional basis. In order to establish his will and preferences and give effect to them regarding his care and treatment, amongst other things (such as ascertaining whether he has an advance statement and speaking with family members and friends) it would be appropriate to seek specialist advice on brain injuries and how these may affect his decision-making and how he communicates his will and preferences. Such information might, for example, be obtained from one or a combination of a medical consultant, psychologist, occupational therapist, brain injury social worker and specialist nursing staff.

## 6. Examples of supported decision-making: General

Supported decision-making can take various forms and be formally or informally provided. At any given time, one or a combination of different forms of supported decision-making may be appropriate.

Supported decision-making includes accessing the necessary support so that an individual can make a decision and supporting them in ensuring that that decision is respected and, where relevant, given legal effect.

Support must be person-centred and informed. As already stated, it is important to ascertain the best way that the individual can communicate their will and preferences. This may involve obtaining specialist information about an individual's condition and how it might present itself in that individual, an individual's particular characteristics and background, and when and where is the best time to provide support.

### Important

Effective supported decision-making is often a process that requires time.  
It cannot be rushed.

The following are broad examples of approaches to supported decision-making that might be used. These should each bear in mind the requirements laid out in Section 6.

### **6.1 A trusted person or persons**

This might include professionals, such as health and social care staff, the police, social workers, lawyers and the judiciary as well as family members, partners, guardians and attorneys and others.

### **6.2 Peer support**

This might include friends or other individuals or groups with similar lived experience.

### **6.3 Advocacy**

Advocacy can be instructed – sought by the individual themselves; or non-instructed where, despite significant attempts to do so, it is not possible to ascertain the person's will and preferences. It is important that non-instructed advocacy always gives the best interpretation of the individual's will and preferences (see Section 9: Supported decision-making in 'difficult cases').

Advocacy can also include collective advocacy whereby a peer group, or a wider community of shared interests, represent their will and preferences.

Advocacy may also, of course, include and involve self-advocacy which is what in many cases should ultimately be aspired to as the individual gains in confidence and feels able to make, express and give effect to their decisions.

The Scottish Independent Advocacy Alliance specifies that a principle of independent advocacy is that services should be directed by the individual concerned and should assist the person in exercising control over their life.

Scottish Government guidance states that independent advocacy has two main themes:

- Speaking up for and with people who are not being heard, and helping them to express their views and make their own decisions and contributions; and
- Safeguarding individuals who are at risk.<sup>9</sup>

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<sup>9</sup> Page 5 of The Scottish Government's Independent Advocacy Guide for Commissioners. Available at <http://www.gov.scot/Resource/0044/00441045.pdf>.

Independent advocacy is recognised under the Mental Health (Care and Treatment) (Scotland) Act 2003 (see later in Section 8). People with mental illness, learning disability, dementia and related conditions have a right to independent advocacy.

#### **6.4 Community and neighbourhood support**

This includes support from members of the individual's community whether informally or formally and provided on an individual or group initiative basis.

#### **6.5 Assistance with, and clear, communication**

It is important that information is clearly presented in either oral, written and/or pictorial form. This might be achieved by providing information in a format that is understandable to the individual, using professional sign language interpretation, speech and language therapy and/or the development and recognition of diverse, non-conventional methods of communication (especially for those who use non-verbal forms of communication to express their will and preferences). Such methods may also be used to help an individual revisit previous decisions they have made to assist their current decision-making.

#### **6.6 Technological support**

This might include the use of iPads, talking mats, life story books, other applications that support communication, using technology to record decision-making processes and decisions made and video testimony (in legal and administrative proceedings). These methods of support might also be used to support an individual to revisit previous decisions they have made to help with their current decision-making.

### **Case example 5: Supported decision-making with persons with learning disabilities**

Ms B, Ms C and Mr D are three individuals with mild to moderate learning disabilities who live in a residential unit that is soon to be de-registered. This will require the signing of tenancy agreements with a housing association for each of the residents, though nothing will change in their actual environment or support. Each resident is reported to be very happy with their homes and the support they receive.

It is unlikely that the residents are able to understand, in full, the technical jargon and language used in the full-length tenancy agreement. The housing association is therefore refusing to accept the clients' signatures and is insisting that the local authority apply for guardianship to sign on their behalf.

**Supported decision-making comment:** [See Checklist in Appendix 1] At the outset, the mental capacity of these individuals must be presumed and assessed on a functional basis. Appropriate forms of supported decision-making should be identified, for example, clearly presented information in a way that is understandable to each individual and the involvement of a trusted person or persons. It may be that with such support all or at least some of the three individuals will be able to understand what is required of them under the new tenancy and its implications and therefore be able to exercise their legal capacity to personally sign the tenancy thus avoiding the need to apply for guardianship.

**At all times, and even where interventions are in place, all attempts must be made to maximise the exercise of the individual's autonomy and the exercise of their legal capacity.**

### **6.7 Advance planning**

The UN Committee on the Rights of Persons with Disabilities in General Comment No. 1 makes clear their view that one form of supported decision-making is advance planning:

“For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others. All persons with disabilities have the right to engage in advance planning and should be given the opportunity to do so on an equal basis with others.”<sup>10</sup>

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<sup>10</sup> General Comment No. 1, para 17.

There are a range of mechanisms for advance planning, including anticipatory care plans, personal statements and specific decisions about types of medical treatment (such as a statement as to whether a person should receive CPR should they experience a cardiac arrest).

Not only are these forms of supported decision-making in themselves, the principles of supported decision-making should apply in relation to them. In other words, people who may have some difficulties in decision-making should be given the necessary support to decide whether they wish to make any advance planning should they become more impaired in future.

Some forms of advance planning, such as advance statements and Powers of Attorney are recognised and regulated under Scottish legislation (see later in Section 7).

### **Case example 6: Supported decision-making with persons with a mental illness**

Ms E is the single mother of a four year old daughter who she says is the most important person in her life. Ms E has a diagnosis of bipolar disorder.

Ms E has been subject to compulsory care and treatment under the Mental Health (Care and Treatment) (Scotland) Act 2003 Act in the past but has not made an advance statement. She has a close family network but occasionally breaks contact with them.

She works full time as a housing development officer at the local authority. Ms E is determined to maintain her job and values the independence it gives her very highly. She relies on her parents for the childcare that she is unable to secure at her daughter's nursery.

In recent months she has stopped taking her medication complaining of its side effects and saying that she has been well for a long time and therefore probably no longer requires it. However, over the past few weeks she has started to become progressively unwell and is not sleeping properly. She is becoming very argumentative and confrontational with her parents and with her employers. In light of this there are concerns that she may require to be cared for and treated under the Mental Health (Care and Treatment) (Scotland) Act and about the impact this might have in terms of caring for her daughter and on her job.

**Supported decision-making comment: [See Checklist in Appendix 1]** At the outset, Ms E's mental capacity must be presumed and assessed on a functional basis. In terms of possible care and treatment under the Mental Health (Care and Treatment) (Scotland) Act this would be a presumption that, unless there is persuasive evidence to the contrary, she does not have significantly impaired decision-making ability because of her mental disorder.

In terms of treatment for her mental illness, consideration should be given as to whether Ms E could be provided with support from a trusted person or persons, peer support, a social worker and, importantly, an independent advocate (note that she is entitled to receive this support under the Mental Health (Care and Treatment) (Scotland) Act). This may assist Ms E to take a decision to accept appropriate care and treatment without the need for compulsion. If Ms E has the capacity of properly intending the wishes specified in it at this time she might be encouraged to make an advance statement. If she does not have such capacity but regains this later then it might be suggested that she makes one then for the future.

**Continued on next page**

## Continued from previous page

In terms of arrangements for Ms E's daughter and maintaining her employment, again consideration should be given as to whether Ms E could be provided with support from a trusted person or persons, peer support, social worker and, importantly, an independent advocate. If Ms E makes a personal statement or anticipatory care plan then she might want to express her preferences about what happens regarding her daughter when she is unwell.

## 7. Examples of supported decision-making specifically recognised under Scottish legislation

Many of the above types of supported decision-making are recognised and provided informally across Scotland. Scottish legislation also recognises support in the form of advance planning and independent advocacy (links to examples of forms of supported decision-making in other jurisdictions can be found in the Appendix 4 to this guidance).

### 7.1 Advance planning

#### 7.1.1 Powers of Attorney

The Adults with Incapacity (Scotland) Act 2000 allows for Powers of Attorney and regulates their use. Powers of Attorney are a means by which an individual can seek to ensure that their choices are central to any actions when they lose capacity to make decisions and act for themselves. They permit any individual with capacity to put in place arrangements for the future management of their financial (continuing) and/or welfare affairs by appointing an individual or organisation to act on their behalf.

Financial powers of attorney may come into effect either before or when the individual (the granter) becomes incapable, as defined by the Act. Welfare powers of attorney only take effect when the individual become incapable. The individual can specify:

- 1) Who the attorney or attorneys will be;
- 2) When and how a financial power of attorney will operate whilst they retain capacity;
- 3) Exactly how, and by whom, incapacity will be assessed for a financial and/or welfare power of attorney to become operational; and
- 4) The powers that the attorney or attorneys will have.

There are virtually no limitations on the choice of attorney or the powers granted and any limitations largely protect the granter's autonomy. Solicitors acting for granters must be satisfied that the granting of the power is the result of an autonomous decision and this is reinforced by the Law Society of Scotland's *Vulnerable Clients Guidance* (2013).

A welfare attorney may not:

1. Place the granter in hospital for treatment for mental disorder against their will.
2. Consent to medical treatment excluded from the scope of the Act's Part 5 general power to treat.

The Act's Code of Practice relating to powers of attorney encourages the individual granting the powers to discuss their feelings and wishes regarding the exercise of the powers with the proposed attorney or attorneys. It also recommends that detailed discussions between the granter and the proposed attorney or attorneys take place so as to ensure the attorney or attorneys has an in-depth knowledge of the granter's likes, dislikes and values.

Importantly, an attorney must act with the Adults with Incapacity (Scotland) Act's principles and human rights in mind at all times. If the granter is therefore, with support, able to take decisions for themselves they must be provided with such support and permitted to do so and effect must be given to these decisions.

For further guidance on powers of attorney see the Mental Welfare Commission for Scotland's *Common Concerns with Power of Attorney: Good Practice Guide* (July 2015), *Power of Attorney Guide for Hospital and Care Home Staff* (September 2015) and *Power of Attorney Guide for General Practitioners* (August 2015). Information can also be found on the website of the Office of the Public Guardian (Scotland).

### **7.1.2 Advance statements**

Advance statements cannot force medical staff to provide specific treatments. That being said, they are widely acknowledged as a way which allows for an individual's autonomy to be respected. Studies suggest that they empower patients, enhance their capacity, improve patient/clinician relations and even reduce the need for involuntary detention. They are a way in which an individual can set out in writing how they wish to be cared for and treated in the event of them being unable to effectively communicate their will and preferences to medical staff and others. Careful checks should always be made to ascertain whether or not a person has made an advance statement.

### **a) Advance refusals**

In Scotland there is no relevant case or statute law relating to advance refusals for treatment for physical health matters. However, it seems likely that the approach adopted by the English courts and in the Mental Capacity Act 2005 will be followed in that such a refusal will normally be respected if it clearly covers the situation which has arisen and there is no reason to believe the person has changed their mind or was under undue influence when they made the statement.

### **b) Advance statements**

The Mental Health (Care and Treatment) (Scotland) Act 2003 specifically recognises written advance statements. These are defined in the Act as being a statement that complies with the Act's requirements that specifies the ways in which the maker wishes to be treated, and not to be treated, in the event of their decision-making ability becoming significantly impaired because of mental disorder.

The Mental Health Tribunal and any person giving medical treatment under the Act are only required to "have regard" to their contents. However, when deciding to override wishes stated in advance statements they must apply the Act's principles and related human rights and record their reasons for overriding such wishes.

At present it is not always easy to ascertain whether or not an individual has an advance statement. However, in all cases, whether or not an individual is being treated under the Mental Health (Care and Treatment) (Scotland) Act, it is imperative that extensive enquiries are made to find out if a valid advance statement exists. In terms of psychiatric advance statements amendments to the Mental Health (Care and Treatment) (Scotland) Act (made by the Mental Health (Scotland) Act 2015) will shortly come into effect that will make this task easier. These amendments will require health boards to place copies of patients' advance statements in their records and inform the Mental Welfare Commission. Health boards will also be required to publicise the support they have given for the making of or withdrawing advance statements. The Mental Welfare Commission will monitor this.

It is also a good idea to include a personal statement to accompany the advance statement. A personal statement can be used to let health and social care staff and others know about things that are important to the individual and what their will and preferences are about these (for example, caring responsibilities, pets and bills). Although these have no legal standing, they are good for allowing the adult to convey their wishes on personal matters, e.g. care of pets, keyholding, etc. This is another example of participation.

For more information about advance statements and personal statements see Mental Welfare Commission *Advance Statement Guidance* (January 2016). See also the Mental Welfare Commission webpage ‘Advance Statements’ for more information and guidance <http://www.mwcscot.org.uk/get-help/getting-treatment/advance-statements>

## 7.2 Advocacy

The Mental Health (Care and Treatment) (Scotland) Act Code of Practice (Vol 1, para 97) states that “independent advocacy can enable a patient to express their needs and thoughts and to make these known to those who are making decisions about the patient’s care and welfare”.

Whilst independent advocacy is an important means of supported decision-making for all individuals with decision-making challenges it is specifically referred to in the Mental Health (Care and Treatment) (Scotland) Act 2003. The Act requires that health boards and local authorities must provide and secure access to independent advocacy services for any person with mental disorder, whether or not they are subject to compulsory measures. Amendments to Mental Health (Care and Treatment) (Scotland) Act (made by the Mental Health (Scotland) Act 2015), which will shortly come into force, will hopefully strengthen health boards’ (including the State Hospital board) and local authorities’ compliance with this. They will have to provide the Mental Welfare Commission with information regarding their provision of independent advocacy.

For more information and guidance on advocacy see Mental Welfare Commission for Scotland. *Working with Independent Advocates—Good Practice Guidance for Working with Independent Advocates* (2015).

## 8. Supported decision-making in ‘difficult cases’

In some situations it might be very difficult or impossible to ascertain what an individual’s will and preferences about a particular matter are because they are unable to communicate in any apparently meaningful sense. For instance, the individual might be in a coma or suffering from acute psychosis or a brain injury and have not provided any indication beforehand about what they would want in such a situation, or they have had profound mental impairment since birth. These situations clearly provide serious challenges to discovering, understanding or giving effect to the individual’s will and preferences.

In its General Comment No. 1 the UN Committee on the Rights of Persons with Disabilities states that where significant efforts have been made to work out the individual’s will and preferences but have been unsuccessful then a ‘best interpretation’ of that person’s will and preferences should be used.<sup>11</sup>

Care must be taken in such circumstances not to assume that the individual has no identifiable views simply because they appear to be beyond communication. It is recommended that such an interpretation can be achieved by, for example, speaking to those who know the individual (for instance, family, friends, partners, carers, etc.), by considering the individual’s values and beliefs, looking for subtle non-verbal indications of will and preferences and taking into consideration any relevant past views expressed by the individual.

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<sup>11</sup> General Comment No. 1, para 21.

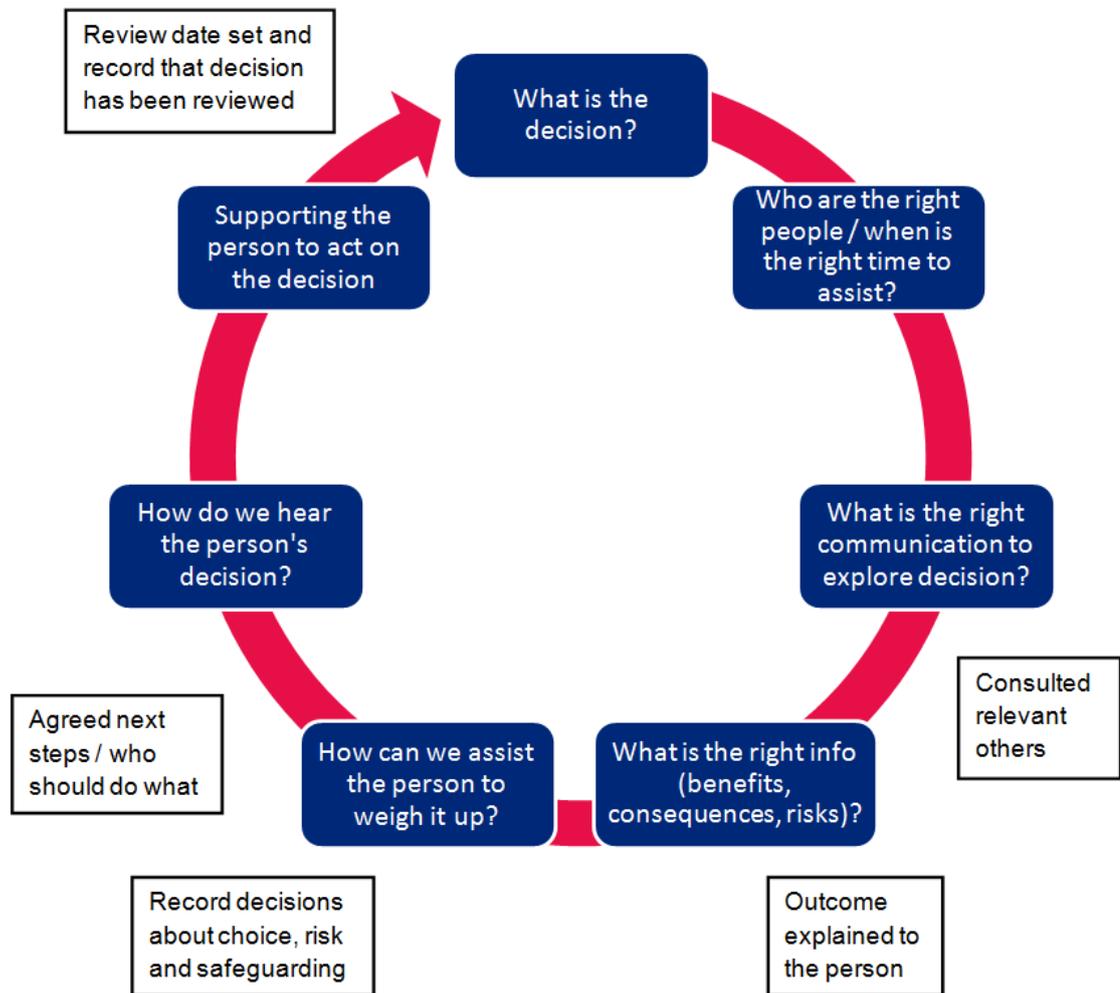
## Appendices

### Appendix 1: Checklist for delivering support for decision-making

***Starting point: Individuals with mental disabilities have the right to make choices and exercise their legal capacity on an equal basis with others***

- 1) Have you presumed that the individual has mental capacity to start with?
- 2) Is there any indication that the individual's mental capacity is in issue?
- 3) If so, have you adopted a proper functional capacity assessment using, where necessary, appropriate expert advice? If the individual is incapable of exercising legal capacity have you checked whether or not they are still capable of making any decisions?
- 4) Have you identified an appropriate method or methods of support for decision-making and exercise of legal capacity and who will provide this support? See Sections 7 and 8 of this guidance.
- 5) Have you ensured that such support is provided in accordance with 'Key elements of supported decision-making arrangements'? See Section 6 of this guidance.

Figure 3 Supported decision-making process map



Adapted from WA's Individualised Services<sup>12</sup>

<sup>12</sup> Page 4 of Supported Decision Making by WA's Individualised Services. Available at <http://waindividualisedservices.org.au/wp-content/uploads/2014/11/Supported-Decision-Making-Project-Resources-Supporting-Decision-Making.pdf>

## Appendix 2: Human rights information

### Human rights, autonomy and legal capacity

Certain human rights standards underpin respect for a person's autonomy and legal capacity and these are reflected in various international treaties, the most relevant for the purposes of this guidance being the European Convention on Human Rights and the UN Convention on the Rights of Persons with Disabilities.

#### 1. The European Convention on Human Rights (ECHR)

It is clear from the rulings of the European Court of Human Rights (the Court) that that it views any restrictions placed on lives and choices of persons with mental disorder very seriously and that these must only occur within very limited perimeters. The ECHR does not identify a right to exercise legal capacity as such. However, the rights in Articles 8 (the right to respect for private and family life) and 5 (the right to liberty and security) are very much associated with autonomy and the exercise of legal capacity<sup>13</sup>.

Supported decision-making is particularly relevant in the context of the exercise of these rights. It ensures that the rights, will and preferences of the individual with decision-making difficulties are central and respected at all times. It also helps to ensure that any limitations of the individual's rights are proportionate and take into account their wishes.

##### 1.1. Article 8 – the right to respect for private and family life

Article 8(1) ECHR states that:

‘Everyone has the right to respect for his private and family life, his home and his correspondence.’

This has been interpreted by the Court as encompassing the right to respect for physical and moral integrity and autonomy<sup>14</sup>.

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<sup>13</sup> The right identified in Article 14 ECHR (prohibition of discrimination) can also be used to reinforce the fact that individuals with decision-making difficulties are entitled respect for, and to exercise, the rights in Articles 8 and 5 without discrimination and on an equal basis with others.

<sup>14</sup> *Bensaid v United Kingdom* (44599/98) (2001) 33 EHRR 10, para 46.

### 1.1.2. Restrictions of the exercise of the right to respect for private and family life

Article 8(2) does permit the lawful and proportionate restriction of private and family life in specified circumstances:

‘There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.’

Restricting or denying the right to exercise the right in Article 8 has serious implications for a person’s autonomy and the exercise of their legal capacity. It is important that even where restriction of this right is considered to be appropriate the person retains as much of their decision-making ability and ability to exercise their legal capacity as possible. This is where supported decision-making can be invaluable.

The Court has emphasised the need for necessity and proportionality and that the indiscriminate and all-encompassing denial of legal capacity and the imposition of guardianship for persons with mental health issues violates Article 8<sup>15</sup>. It has stressed that there must always be a presumption that a person has capacity and that where someone’s capacity is questionable then a functional approach to the assessment of capacity must be adopted<sup>16</sup>. Noting that removing someone’s ability to exercise their legal capacity is a serious interference with their private life it has also directed that strict and careful scrutiny is called for where limitations are being considered concerning a person whose mental capacity may be at issue<sup>17</sup>. The Court has further importantly acknowledged that just because someone is considered to lack the ability to exercise their legal capacity does not mean that they are unable to understand their situation<sup>18</sup>.

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<sup>15</sup> *Alajos Kiss v Hungary* (App no. 38832/06) (2010) ECHR 692; *Stanev v Bulgaria* (App no 36760/06) [2012] ECHR 46; *D.D. v Lithuania* (App no 13469/06) [2012] ECHR 254; *Sýkora v The Czech Republic* (App no 23419/07) [2012] ECHR 1960; *Mihailovs v Latvia* (App no 35939/10) [2013] ECHR 65; *MS v Croatia* (App no 36337/10) [2013] ECHR 378; *MH v UK* (App no 11577/06) [2013] ECHR 1008;

*Shtukarturov v Russia* (44009/05) (2008) ECHR 223, para 29.

<sup>16</sup> *Shtukarturov v Russia* (Application No. 44009/05) (2008) ECHR 223, paras 93- 94.

<sup>17</sup> *Shtukarturov v Russia*, paras 87-89 and 93-94; *X and Y v the Netherlands* (1985) 8 EHRR 235, paras 102 and 109; *Sykora v Czech Republic* (Application No. 23419/07) (2012) ECHR 1960, paras 101-103.

<sup>18</sup> *Shtukarturov v Russia*, para 108; see also *Stanev v Bulgaria* (2012) 55 EHRR 22, para 130 and *Stankov v Bulgaria* (Application No. 25820/07) judgment of 17 March 2015, para 89.

## 1.2. Article 5 – the right to liberty

Article 5(1) ECHR (the right to liberty) identifies the right to liberty and also those situations where a deprivation of liberty is permissible such as where a person has mental disorder (Article 5(1)(e)).

### 1.2.1 Restrictions of the right to liberty

Again, depriving someone of their liberty also has serious implications for their autonomy and the exercise of their legal capacity and the role that supported decision-making plays here is important.

However, even where a deprivation of liberty is permitted under Article 5(1) certain legal and procedural safeguards must be present. A person who lacks capacity to consent to limitations placed on them and such limitations amount to a deprivation of liberty will require such safeguards<sup>19</sup>.

A person with capacity may give a valid consent to measures restricting their liberty, provided such consent is clear and unequivocal. In this case, Article 5 is not engaged<sup>20</sup> and the Article 5 ECHR legal and procedural safeguards will not be required. However, it is, of course, important to ensure that they have given full, free and informed consent to the deprivation of liberty<sup>21</sup>. The Court has repeated on several occasions that the right to liberty is too important for a person to lose the benefit of the ECHR protection for the single reason that he/she may have given himself/herself up to be taken into detention<sup>22</sup>.

In addition, and significantly, even if an individual has been lawfully detained it does not automatically follow that there is an entitlement to treat an individual without their consent as this may amount to a violation of their right to autonomy identified in Article 8<sup>23</sup>.

The Court has also specifically referred to support in the context of Article 5(2) ECHR which requires a person to be informed of the reason for their arrest. This also applies to mental health patients who are detained or they will not be able to effectively exercise their right to appeal<sup>24</sup>.

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<sup>19</sup> See, in particular, *HL v UK* (2005) 40 EHRR 32 (often referred to as ‘the Bournemouth ruling’) and *P (by his litigation friend the Official Solicitor) (Appellant) v Cheshire West and Chester Council and another (Respondents); P and Q (by their litigation friend, the Official Solicitor)(Appellants) v Surrey County Council (Respondent) [2014] UKSC 19* (often referred to as ‘the Cheshire West ruling’).

<sup>20</sup> *Storck* at paras 76-77 and *Stanev* at para 117.

<sup>21</sup> *Storck*, para 75; *M v Ukraine* (Application No. 2452/04) (2012) ECHR 732, para 77.

<sup>22</sup> See, for instance, *De Wilde Ooms and Versyp v Belgium* (1971) 1 EHRR 373 at paras 64-65, *HL* at para 90 and *Storck* at para 75. This was also reaffirmed in *Cheshire West* (per Lady Hale at 24).

<sup>23</sup> *X v Finland* (App No. 34806/04) (2012) ECHR 1371, paras 212-213.

<sup>24</sup> *X v UK* (App. NO. 7215/75) (1981) ECHR 6, para 66; *Van der Leer v The Netherlands* (1990) 12 EHRR 567, para 27.

If the patient is incapable of receiving ‘proper’ information then it must be given to persons who represent their interests<sup>25</sup>. There is also a duty to make ‘reasonable accommodation’ to assist a person to understand their rights including giving information to their legal or family representatives<sup>26</sup>.

## **2. Council of Europe Committee of Ministers Recommendation R(99) 4 on principles concerning the legal protection of incapable adults<sup>27</sup>**

Although influential only and not legally binding in the same way as the ECHR (see 4.4.3. below) the Council of Europe Recommendation R (99)4 also reinforces the need to respect a person’s legal capacity. Again, supported decision-making will assist the more effective implementation of these principles.

Principles 3 (Maximum preservation of capacity) and 6 (Proportionality) reinforce the functional approach to capacity and that any measure designed to protect a person should not automatically remove right to exercise legal capacity and, in particular, to make decisions of a personal nature. Principle 8 emphasises the paramountcy of interests and welfare and Principle 9 respect for wishes and feelings of the person concerned (which includes giving the person adequate information concerning any major decision about them in order they can express their own view).

## **3. United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)**

### **3.1. Article 12: Equal recognition before the law**

It is, however, in connection with the right to equal recognition before the law in Article 12 UNCRPD that the requirement for supported decision-making has been specifically emphasised.

Articles 12(1) and (2) UNCRPD reaffirms the universal right of persons with disabilities to exercise legal capacity. Articles 12(3) and (4) indicate how this can be achieved.

### **3.2. Article 12 and supported decision-making**

Article 12(3) requires that the states must provide access by persons with disabilities to support in order to exercise their legal capacity:

‘...shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.’

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<sup>25</sup> *X v UK*, para 66.

<sup>26</sup> *ZH v Hungary* (App No. 28973/11) (2014) MHLR 1, para 42-44, see also Articles 2, 13 and 14 UNCRPD which were also mentioned by the Court in *ZH*, para 43.

<sup>27</sup> Adopted by the Committee of Ministers on 23 February 1999 at the 660th meeting of the Ministers' Deputies

Article 12(4) then stipulates that safeguards must be in place to ensure that any such support arrangements ‘...respect the rights, will and preferences of the person...’

The UN Committee on the Rights of Persons (the Committee) that oversees the implementation of the UNCRPD has interpreted Article 12 in its General Comment No. 1<sup>28</sup>. This General Comment gives broad examples of types of support required in the exercise of legal capacity and a radical interpretation of the environment in which such support must operate.

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<sup>28</sup> UN Committee on the Rights of Persons with Disabilities, General Comment No 1 (2014) *Article 12: Equal Recognition before the Law*, CRPD/C/GC/1, adopted 11 April 2014.

## 4. General Comment No. 1

### a) Types of support for the exercise of legal capacity

General Comment No. 1 emphasises that the potential range of support available in the exercise of legal capacity includes informal and formal support arrangements of varying types and intensity<sup>29</sup>. This can, for example, include one or more trusted persons, peer support and advocacy (including self-advocacy)<sup>30</sup>. It can also include:

#### i. Assistance with communication

This could be in the form of provision of information in an understandable format, professional sign language interpretation and the development and recognition of diverse, non-conventional methods of communication (especially for those who use non-verbal forms of communication to express their will and preferences)<sup>31</sup>.

#### ii. Advance planning

Advance planning is identified as ‘an important form of support’ which allows a person to state their will and preferences that should be followed at a time when they are unable to communicate their wishes to others<sup>32</sup>. General Comment No. 1 also states that if the person so wishes support should be provided to a person to complete an advance planning process.

#### iii. Communities

Communities and the support that can be gained from these<sup>33</sup>.

#### iv. Special support in legal and administrative proceedings

In the context of judicial, administrative and other legal proceedings support could include recognition of diverse communication methods, the use of video testimony, in certain situations, procedural accommodation, providing professional sign language interpretation and other methods of assistance<sup>34</sup>.

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<sup>29</sup> General Comment No. 1, paras 17 and 29. This corresponds with, and reinforces, the requirement for respect for diversity identified in Article 3(b) UNCRPD and GENERAL COMMENT NO. 1, para 18.

<sup>30</sup> General Comment No. 1, para 17.

<sup>31</sup> General Comment No. 1, para 17.

<sup>32</sup> General Comment No. 1, para 17.

<sup>33</sup> General Comment No. 1, para 45.

<sup>34</sup> General Comment No. 1, para 39.

## b) Requirements for supported decision-making

General Comment No. 1 also stipulates various requirements of ‘supported decision-making’ regimes<sup>35</sup> which can be broadly summarised as follows:

- i. Any such regime must give primacy to a person’s will and preferences and respect human rights norms<sup>36</sup>. In this connection there is no hierarchy of rights and all have equal force<sup>37</sup>.
- ii. There must be protection from “undue influence” in any supported decision-making arrangements<sup>38</sup>.
- iii. Supported decision-making should not, however, over-regulate the lives of persons with disabilities.
- iv. The seeking and acceptance of support is voluntary on the part of the person with disabilities<sup>39</sup>. They can refuse such support if they so wish.
- v. Access to support must not be dependent on assessments of mental capacity.
- vi. Such support must never amount to substitute decision-making and must take place in the absence of substitute decision-making regimes (such as guardianship and involuntary psychiatric treatment laws). Indeed, General Comment specifically states that true respect for a person’s rights, will and preferences can only be effectively achieved where the complete absence of substitute decision-making regimes<sup>40</sup>.

General Comment No.1 also 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<sup>41</sup>. It also stresses that arguments about resourcing should not determine the level of support in the exercise of legal capacity<sup>42</sup>.

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<sup>35</sup> General Comment No. 1, para 29.

<sup>36</sup> See also E Flynn and A Arstein-Kerslake, ‘The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?’ (2014) 32 *Berkeley Journal of International Law* 134, 134.

<sup>37</sup> ‘including those related to autonomy (right to legal capacity, right to equal recognition before the law, right to choose where to live, etc.) and rights related to freedom from abuse and ill-treatment (right to life, right to physical integrity, etc.).’

<sup>38</sup> General Comment No. 1, para 22. See also W Martin, S Michalowski and C Caughey, Briefing Paper: *Safeguards against Undue Influence and Conflicts of Interest*, Essex Autonomy Project Three Jurisdictions Project, Edinburgh Roundtable 2 (December 2015).

<sup>39</sup> This is alluded to in several places throughout General Comment No. 1 but in particular in paragraph 19.

<sup>40</sup> General Comment No. 1, paras 17, 26, 28 and 42. It radically states that guardianship and laws permitting involuntary psychiatric treatment must be abolished (paras 7, 26 and 27).

<sup>41</sup> General Comment No. 1, para 24.

<sup>42</sup> In this it distinguishes the right to reasonable accommodation to exercise legal capacity (which need not be provided if it objectively results in disproportionate or undue burden) from the right to support to exercise legal capacity.

The state has an absolute and immediate duty to provide access to support in the exercise of legal capacity for persons with disabilities<sup>43</sup>.

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<sup>43</sup>General Comment No. 1, paras 30 and 34.

## Appendix 3: Links to supported decision-making resources: UK and Scottish

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### United Kingdom

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#### Scotland

##### Legislation and Codes of Practice

Adults with Incapacity (Scotland) Act 2000

Code of Practice for Continuing and Welfare Attorneys (2011)

<http://www.gov.scot/Resource/0048/00489797.pdf>

Code of Practice for Practitioners Authorised to Carry Out Medical Treatment or Research Under Part 5 of the Act (2010)

<http://www.gov.scot/Resource/Doc/327864/0105906.pdf>

Code of Practice for persons authorised under intervention orders and guardians under the Adults with Incapacity (Scotland) Act 2000 (2011)

<http://www.gov.scot/Resource/Doc/347717/0115820.pdf>

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

Code of Practice Volume 1 (2005)

<http://www.gov.scot/Resource/Doc/57346/0017038.pdf>

Adult Support and Protection (Scotland) Act 2007

Code of Practice (2009) <http://www.gov.scot/Resource/Doc/259161/0076850.pdf>

##### Guidance

Law Society of Scotland, 'Vulnerable Clients Guidance' (2013)

<http://www.lawscot.org.uk/rules-and-guidance/section-b/rule-b1-standards-of-conduct/guidance/b15-vulnerable-clients-guidance/>

Mental Welfare Commission for Scotland – Guidance and Information

*Power of Attorney for Staff in Hospitals and Care Homes* (September 2015)

[http://www.mwscot.org.uk/media/241253/poa\\_leaflet\\_care\\_homes.pdf](http://www.mwscot.org.uk/media/241253/poa_leaflet_care_homes.pdf)

*Power of Attorney under Adults with Incapacity (Scotland) Act 2000 for General Practitioners* (August 2015)

[http://www.mwcscot.org.uk/media/241261/poa\\_leaflet\\_general\\_practitioners.pdf](http://www.mwcscot.org.uk/media/241261/poa_leaflet_general_practitioners.pdf)

*Common Concerns with Power of Attorney: Good Practice Guide* (July 2015)

[http://www.mwcscot.org.uk/media/233718/common\\_concerns\\_with\\_power\\_of\\_attorney\\_final\\_2.pdf](http://www.mwcscot.org.uk/media/233718/common_concerns_with_power_of_attorney_final_2.pdf)

*Working with Independent Advocates : Good Practice Guide* (September 2015)

[http://www.mwcscot.org.uk/media/240668/working\\_with\\_independent\\_advocates\\_2015.pdf](http://www.mwcscot.org.uk/media/240668/working_with_independent_advocates_2015.pdf)

*Advance Statements webpage* <http://www.mwcscot.org.uk/get-help/getting-treatment/advance-statements/>

*Advance Statement Guidance* (January 2014)

[http://www.mwcscot.org.uk/media/128044/advance\\_statement\\_final\\_version\\_jan\\_2014.pdf](http://www.mwcscot.org.uk/media/128044/advance_statement_final_version_jan_2014.pdf)

Andrew Symonds, Mental Welfare Commission for Scotland, 'Guardianship Research, Analysis and Projects 2014' (April 2015)

[http://www.mwcscot.org.uk/media/220997/final\\_report\\_-\\_guardianship\\_related\\_research\\_and\\_analysis\\_-\\_2014\\_final\\_.pdf](http://www.mwcscot.org.uk/media/220997/final_report_-_guardianship_related_research_and_analysis_-_2014_final_.pdf)

Scottish Government, 'Independent Advocacy – Guide for Commissioners' (2013)

<http://www.gov.scot/Resource/0044/00441045.pdf>

Scottish Independent Advocacy Alliance, Principles and Standards for Independent Advocacy (2008) [www.siaa.org.uk/resources/publications-list/principles-standards/](http://www.siaa.org.uk/resources/publications-list/principles-standards/)

Scottish Independent Advocacy Alliance, 'Code of Practice for Independent Advocacy' (2008) [www.siaa.org.uk/resources/publications-list/code-practice/](http://www.siaa.org.uk/resources/publications-list/code-practice/)

Scottish Independent Advocacy Alliance, 'Non-Instructed Advocacy Guidelines' (2009)

<http://www.siaa.org.uk/resources/publications-list/non-instructed-advocacy-guidelines/>

NHS Greater Glasgow and Clyde, 'Learning Disabilities and Palliative Care Pathway – Supporting people with learning disabilities through the palliative care journey'

<http://www.ldpcproject.co.uk/palliative-care-pathway/>

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## England and Wales

House of Lords, Select Committee on the Mental Capacity Act 2005, 'Mental Capacity Act 2005: post-legislative scrutiny' (2014) HL Paper 139

<http://www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf>

Department of Health, 'Independence, choice and risk: a guide to best practice in supported decision-making' (May 2007)

[http://www.thinklocalactpersonal.org.uk/library/Resources/Personalisation/Direct\\_Payments/Risk\\_Management/DH\\_074775.pdf](http://www.thinklocalactpersonal.org.uk/library/Resources/Personalisation/Direct_Payments/Risk_Management/DH_074775.pdf)

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## International Law

European Convention on Human Rights

[http://www.echr.coe.int/Documents/Convention\\_ENG.pdf](http://www.echr.coe.int/Documents/Convention_ENG.pdf)

Council of Europe Rec 1999 on incapable adults

[http://www.coe.int/t/dg3/healthbioethic/texts\\_and\\_documents/Rec%2899%294E.pdf](http://www.coe.int/t/dg3/healthbioethic/texts_and_documents/Rec%2899%294E.pdf)

United Nations UNCRPD

<http://www.un.org/disabilities/convention/conventionfull.shtml>

Committee on the Rights of Persons with Disabilities, 'General Comment No 1 (2014) – Article 12: Equal recognition before the law'

<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf?OpenElement>

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## Appendix 4: Links to supported decision-making resources: Other countries

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### Australia

Australian Law Reform Commission, 'Equality, Capacity and Disability in Commonwealth Laws' Discussion Paper 81 (2014)

<http://www.alrc.gov.au/publications/disability-dp81>

Australian Law Reform Commission, 'Equality, Capacity and Disability in Commonwealth Laws' Final Report 124 (2014)

<https://www.alrc.gov.au/publications/equality-capacity-disability-report-124>

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### Victoria

Victorian Law Reform Commission, 'Guardianship Final Report 24' (2012)

[http://www.lawreform.vic.gov.au/sites/default/files/Guardianship\\_FinalReport\\_Full%20text.pdf](http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20text.pdf)

Victorian Government Department of Human Services, Disability Services Division, 'Supporting decision-making – A guide to supporting people with a disability to make their own decisions' (2012)

[http://www.dhs.vic.gov.au/\\_data/assets/pdf\\_file/0011/690680/dsd\\_cis\\_supporting\\_decision\\_making\\_0212.pdf](http://www.dhs.vic.gov.au/_data/assets/pdf_file/0011/690680/dsd_cis_supporting_decision_making_0212.pdf)

Office of the Public Advocate Victoria, 'Supported decision-making background and discussion paper' (November 2009) <http://www.publicadvocate.vic.gov.au/advocacy-research/supported-decision-making>

Office of the Public Advocate Victoria, 'Supported decision-making: Options for legislative recognition' (January 2010) <http://www.publicadvocate.vic.gov.au/advocacy-research/supported-decision-making>

Office of the Public Advocate Victoria, 'Project description – Supported Decision-making Pilot Project' <http://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/supported-decision-making/59-supported-decision-making-pilot-project-description/file>

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## South Australia

Office of the Public Advocate South Australia, 'South Australian Supported Decision-making Project Report of Preliminary 'Phase I'' (November 2012) [http://www.opa.sa.gov.au/resources/supported\\_decision\\_making](http://www.opa.sa.gov.au/resources/supported_decision_making)

Office of the Public Advocate South Australia, 'Evaluation of the Supported Decision-Making Project' (Independent Evaluation) (November 2012) [http://www.opa.sa.gov.au/resources/supported\\_decision\\_making](http://www.opa.sa.gov.au/resources/supported_decision_making)

Office of the Public Advocate South Australia, 'Developing a Model of Practice for Supported Decision-making' (June 2011) [http://www.opa.sa.gov.au/files/batch1376447055\\_supported\\_decision\\_making\\_practice\\_manual\\_v1-4.pdf](http://www.opa.sa.gov.au/files/batch1376447055_supported_decision_making_practice_manual_v1-4.pdf)

Dianne Chartres & John Brayley, Office of the Public Advocate, 'South Australia – Inquiry into Disability Care and Support – Submission to the Productivity Commission' (August 2010) <http://www.pc.gov.au/inquiries/completed/disability-support/submissions/sub0325.pdf>

## **Australian Capital Territory**

ADACAS Advocacy, 'Self-Determination and Cultural Change: A Report on Supported Decision-making for People Experiencing Psychosocial and Intellectual Disability' (2014) [http://www.adacas.org.au/decision-support/ADACAS\\_recommendations\\_SDM\\_psychosocial\\_and\\_intellectual\\_disability.pdf](http://www.adacas.org.au/decision-support/ADACAS_recommendations_SDM_psychosocial_and_intellectual_disability.pdf)

ADACAS Advocacy, 'Spectrums of Support – A Report on a project Exploring Supported Decision-making for People with Disability in the ACT' (September 2013) [http://www.adacas.org.au/decision-support/copy\\_of\\_SupportedDecisionMakingProjectFinalReport.pdf](http://www.adacas.org.au/decision-support/copy_of_SupportedDecisionMakingProjectFinalReport.pdf)

Advocacy for Inclusion, 'Supported Decision-making, Legal Capacity and Guardianship - Implementing Article 12 of the Convention on the Rights of Persons with Disabilities in the Australian Capital Territory' (August 2012) [http://www.advocacyforinclusion.org/publications/supported\\_decision\\_making\\_legal\\_capacity\\_and\\_guardianship2012final.pdf](http://www.advocacyforinclusion.org/publications/supported_decision_making_legal_capacity_and_guardianship2012final.pdf)

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## **Western Australia**

Western Australia Individualised Services, 'Supporting Decision-making – Principles of Supported Decision-making – Supported Decision-making Approach and Practice' (2014) <http://waindividualisedservices.org.au/wp-content/uploads/2014/11/Supported-Decision-Making-Project-Resources-Supporting-Decision-Making.pdf>

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## **Queensland**

Office of the Public Advocate – Systems Advocacy – Queensland, 'A journey towards autonomy? Supported decision-making in theory and practice. A review of literature' (February 2014) [http://www.justice.qld.gov.au/\\_data/assets/pdf\\_file/0005/249404/Decision-making-support-for-Queenslanders-with-impaired-capacity-A-review-of-literature-March-2014.pdf](http://www.justice.qld.gov.au/_data/assets/pdf_file/0005/249404/Decision-making-support-for-Queenslanders-with-impaired-capacity-A-review-of-literature-March-2014.pdf)

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University of New South Wales, 'Decisions of the Disabled and Supported Decision-making' Australian Human Rights Centre (audio of discussion and debate) <http://www.ahrcentre.org/news/2015/08/11/732>

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## Canada

Reach Canada, 'Report on Supported Decision-making' (January 2009)

<https://www.reach.ca/?action=site.show&lid=139&desc=Background>

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## Ontario

Law Commission of Ontario, 'Legal Capacity, Decision-Making and Guardianship: Interim Report' (October 2015) <http://lco-cdo.org/en/capacity-guardianship-interim-report>

Krista James & Laura Watts, Commissioned by the Law Commission of Ontario, 'Understanding the Lived Experiences of Supported Decision-Making in Canada – Legal Capacity, Decision-Making and Guardianship' March 2014

<http://www.lco-cdo.org/capacity-guardianship-commissioned-paper-ccel.pdf>

Bonnie Lashewicz et al, Commissioned by the Law Commission of Ontario, 'Understanding and addressing voices of adults with disabilities within their family caregiving contexts: Implications for capacity, decision-making and guardianship' (January 2014)

<http://www.lco-cdo.org/capacity-guardianship-commissioned-paper-lashewicz.pdf>

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Gerard Quinn, 'All power to the people – why change on disability policy is so slow in Ireland – Lessons for the next generation of researchers' Disability Studies Association of Ireland (9 October 2015)

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[www.mwscot.org.uk](http://www.mwscot.org.uk)