Support for decision-making and mental capacity

DRAFT FOR CONSULTATION

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We appreciate any comments provided to us during the consultation, all of which will be reviewed by the working group within the context and scope of the project. We ask that, where possible and relevant, you accompany any counter arguments to statements made in the document with supporting evidence e.g. a research reference.

Members of the working group should not be contacted directly, and all feedback should be made through the assigned route e.g. via survey or project manager. Feedback made through unassigned routes or after the closing date will not be accepted or responded to.

Thank you for your support with this project.

A note on the draft guidance:

The guidance is divided into five domains, each covering a series of key topics. Web links to further resources are also provided. Case examples are to be found within the text to illustrate particular points or procedures. Case Law (CL) is cited and summarised where relevant and includes a weblink for further information.

Note. The terms mental capacity and capacity are used interchangeably throughout this guidance. It is recognised that legal terminology differs across the UK home nations and includes the use of the term incapacity in Scotland.

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1. Introduction

This guidance focuses on assessing capacity and providing support for decision-making in people with speech, language and communication needs (SLCN). It considers the provisions for both practice and research in the context of the relevant legal frameworks of the UK home nations. It is targeted at the widest possible audience, including speech and language therapists, health and social care practitioners, educationalists, researchers, voluntary sector workers, persons over the age of 16 years with or without SLCN, and family members, support staff and advocates.

Note: 'mental capacity' is the term used in England and Wales (Mental Capacity Act, 2005) and N. Ireland. In Scotland the terms 'capacity' and 'incapacity' are used (Adults with Incapacity (Scotland) Act, 2000).

1.1 Purpose of guidance

This guidance on assessing capacity and supporting decision-making focuses on people who have speech, language and communication needs (SLCN). The purpose is to provide a reference point for information and practical guidance on decision-making in relation to the areas outlined below.

Legal framework

A relevant and up-to-date summary of legal provisions for mental capacity assessment and support for decision-making across the UK nations (England and Wales; Scotland; N. Ireland) with consideration of other relevant legislation as appropriate.

Policy statements and guidance

Information about and links to national and professional policies and guidance.

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Assessment of capacity

Consideration of a person's everyday ability to make a decision for themself at the time it needs to be made, taking account of SLCN.

Support for decision-making

The parts of the decision-making process that support people with SLCN to lead decision-making as much as possible.

Risk, benefits and safeguards

Considerations for stakeholders involved in decision-making processes including: people with SLCN and others who undertake different supporting roles; service providers; and speech and language therapists.

Speech and language therapy

The different roles undertaken by SLTs, including assessor, advisor, observer and facilitator, in relation to capacity assessments and guidance on decision-making processes.

Equity, diversity and belonging

Consideration of culture, beliefs, religion and first language use in mental capacity assessment and decision-making processes.

Participation

Approaches to supporting participation in decision-making processes as fully as possible through reasonable adjustments and tailored support.

Case examples

Worked example illustrating points of procedure and practice.

Links

Resources providing further information, practical tools and guidance.

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1.2 Who is this guidance for?

This guidance has been prepared for stakeholder groups who have an interest in supporting the legal and human rights of people who have speech, language and communication needs (SLCN).

Different aspects of this guidance are important to different groups, as outlined below.

People with speech, language and/or communication needs (SLCN)

- assessments of capacity that support their particular needs
- participation in making decisions that affect them and their lives
- respect for their human rights and being included.

Family members, caregivers, supporters and advocates of people with SLCN

- information and skills related to decision-making
- consideration of risks and benefits of different types of decision and potential outcomes for people with SLCN
- opportunity to support and advocate for the person with SLCN
- clear information on how and when to access speech and language therapy.

Speech and language therapists

- information and skills for contributing to capacity assessments
- information and skills to support decision-making within the relevant legal frameworks
- information and skills to support people with SLCN to participate in decision-making and capacity assessment procedures
- training and supervision resources for continuing professional development.

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Health and social care practitioners, educationalists and voluntary sector workers

- information about SLCN and how people with SLCN can be accommodated in terms of support for decision-making and the assessment of mental capacity
- information about the role of speech and language therapists training and supervision resources for continuing professional development.

1.3 Why is this guidance needed?

1.3.1 Need for support

The number of people living with SLCN is increasing. As life expectancy rises, so too does the prevalence of conditions associated with SLCN, such as dementia (Nichols et al. 2022) and stroke (King et al. 2020). Improved neonatal care and medical interventions mean that children born with conditions affecting their development and functioning are not only surviving in greater numbers, but are living longer (Getaneh et al. 2025; Smith et al. 2023). Many of these individuals also present with speech, language and communication needs (SLCN) that variously affect their abilities in language comprehension and expression as represented by different forms of communication (eg spoken, manual signs and visual symbols) (Bunning et al. 2026). Thus, the proportion of people who might require some kind of support for decision-making is on the rise.

1.3.2 Interest in decision-making

Any decision-making process involving a person with SLCN requires recognition that the person has views and that they are relevant. The legal frameworks in the UK assert the importance of providing appropriate support for a person's communication before they are judged to lack capacity.

1.3.3 Right to participate

People have the right to be involved in discussions and decision-making processes that affect them – whether it's about everyday choice-making, considerations of their health and social care, or participation in research. At the heart of the legal frameworks operating in the UK is the principle of respect for autonomy (the ability or right of an individual to make independent choices that align with their own values and interests, without being controlled by anyone

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else: adapted from Cambridge Dictionary). They formally recognise people's interest in making decisions, acting voluntarily and understanding and processing information relating to these decisions.

1.3.4 Involvement in decision-making

In everyday life, people may have capacity for some decisions and not others. The presence of SLCN, with or without cognitive impairment, may affect the process of autonomous decision-making. Depending on the person's capacity and/or the nature of their SLCN, different strategies and communication techniques may be required to support decision-making.

1.3.5 Inclusion in research

Research involving human beings is essential for developing new knowledge. However, people with SLCN are not well represented in research (Bunning et al. 2022; Jimoh et al. 2021) despite patient rights to be informed about research opportunities in the NHS (NHS constitution (https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england#nhs-values). Researchers may be reluctant to recruit such individuals as participants because of the complexity of the relevant legal, ethical and regulatory frameworks governing capacity and consent. The resulting under-representation of people with SLCN in research negatively impacts the development of relevant medical, educational and social interventions.

Note: The new draft NHS Constitution, which is currently out for consultation, goes further in stating that "the offer to be part of research should be integrated into health and care across the NHS" (https://www.gov.uk/government/consultations/nhs-constitution-10-year-review/nhs-constitution-10-year-review).

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2. Support for decision-making

Support for decision-making should be considered before guidance on the legal frameworks of decision-making, including the assessment of capacity. This is so that any reasonable adjustments and tailored support can be put in place at the start of a decision-making process. This covers both decision-making in everyday life and preparation for decision-making within an appropriate legal framework.

2.1 Concepts

2.1.1 Terms and definitions

Support for decision-making has been defined as "support practices (that) can increase opportunities for being the decision-maker" (Craigie et al. 2025; p.2). It includes any activity where a person is assisted in making their own decisions, both in everyday life and in a legal context.

You may come across different terms associated with support for decision-making and how such procedures are used. They may vary according to the purpose of the decision, usual practice in your service and the stakeholder perspective. Sometimes these terms are used interchangeably and sometimes different meanings are inferred (see below). At the heart of support for decision-making is the recognition of an individual's interest in the decision-making that affects them.

Support for decision-making has been explored with various client groups including:

- acquired cognitive impairments (Douglas & Bigby, 2020)
- aphasia after stroke (Jayes et al. 2026; 2022a; Stipinovich et al. 2023)
- autism (Wohofsky et al. 2022)
- dementia (Stokes et al. 2025)
- end of life care patients (Pujol et al. 2025)
- learning/intellectual disabilities (Devi et al. 2020; Douglas & Bigby, 2020; Harding & Tascioglu, 2018)
- mental health (Chmielowska et al. 2023; Francis et al. 2024)
- primary progressive aphasia (Cadório & Vieira, 2026).

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2.1.2 Summary of terms and definitions

Supported decision-making

Originally applied to people with cognitive difficulties (Browning et al. 2021), supported decision-making is about enabling people with all kinds of disabilities (Blanck, 2023), including SLCN, to exercise their legal capacity and to determine their own lives (Shogren et al. 2017). Craigie et al. (2025) assert the importance of increasing and enhancing the opportunities for some adults to be either a decision-maker or to participate in the process of decision-making.

NICE guidance refers to a "personalised approach" for people who may lack capacity. It recommends "support that is tailored to their own needs and circumstances. This might include help with communication or understanding information and what the different choices might mean for them, or allowing them sufficient time to consider the options. They may be given information in a range of media including 'easy read' or visual format. They may also have help from their family members, carers or advocates when they need to make a decision." (pp.8-9). (Available at: https://www.nice.org.uk/guidance/qs194/resources/decision-making-and-mental-capacity-pdf-75545781839557).

Exceptionally, the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD, 2006) promotes 'supported decision-making' as an alternative framework for legal decision-making, demanding equal recognition before the law for all persons with disabilities (Article 12). In essence, it means that there is no transfer of rights to other persons (Available at: https://inclusion-europe.eu/wp-content/uploads/2015/03/15.Position_Supported_Decision_Making_EN.pdf).

Assisted decision-making

This term is used for the "active decision-making of people with disabilities in their health and social care and all forms of decision-making support" (O'Donnell et al. 2023).

Shared decision-making

The shared decision-making procedure aims to help practitioners and patients work together around a defined decision (Amorim & Cardoso Ventura, 2023).

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NICE (2021) describes “a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care.” (p. 5).

Co-created decision-making

This emphasises interactions and relationships between the patient and relevant others (eg family members or clinicians). Stakeholder engagement in patient-centred care and the person’s own engagement in their care (sometimes referred to as ‘self-care’) and wellbeing serves to “promote a co-creation of value between people and groups, interested and interesting, that affect and are affected by the patient’s wellbeing.” (Amorim & Cardoso Ventura, 2023; p.2)

Joint shared decision-making and supported decision-making

An integrated approach that invokes both supported and shared decision-making has been proposed in end-of-life care, where people may struggle to express their views and opinions in a complex medical situation (Pujol et al. 2025). In this approach there is mutual influence between the individual’s views and opinions and the medical team’s views and opinions. The idea is that together a solution is found.

2.1.3 Benefits

Support for decision-making can bring benefits to the person with SLCN including:

- better communication with their healthcare professional, including feeling that they have 'been heard'
- being properly informed about the available options and any associated risks
- greater understanding about risks and benefits of the available options
- improved trust of their healthcare professional
- ability to participate in their own decisions in the same way as others
- the chance to voice their views and opinions and be better heard in decision-making processes that concern them
- protection for individual autonomy linked to human rights
- promotion of their own agency and mitigation against dependence on others
- improved integration in the communities where they live
- better concordance with an agreed treatment plan

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- greater satisfaction and happiness from having a say in the decision-making process
- better experience of care, including more satisfaction with the outcome.

(Sources: Mental Welfare Commission for Scotland, 2024; NICE Guideline NG197, 2021)

2.1.4 Considerations for support

Support for decision-making involves interaction between the person and their supporter and sometimes other interested parties. The 'supporter' in this context is someone who promotes the rights of the person. They make sure that optimal conditions are in place for the person to use their available skills. Browning et al. (2021) refer to this process as a dynamic interplay amongst five factors:

1. personal attributes and experiences of the person
2. the experiences and attributes of the supporter
3. the quality of their relationship
4. the decision-making environment
5. the nature and consequences of the decision.

In their pragmatic review of resources, Craigie et al. (2025) identified the environment together with communication defined as a cluster of elements for consideration:

- accessible formats for information
- communication support tactics (eg use of pictures and interpreting body language)
- involvement of persons familiar with the decision-maker
- timing of the decision.

O'Donnell and colleagues (2023) recommend a focus on two key elements when supporting decision-making: the person (which encompasses aspects of communication) and the environment. Each element includes several considerations:

Person

- understanding (processing of information around the decision; use of augmentative and alternative communication methods)
- appreciation (checking the person's situation and the possible meanings of the decision for them)
- reasoning (exploring alternatives and weighing up their relevance and implications for the person).

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Environment

- procedure (allocation of time; use of multiple media)
- space (the physical surroundings for exploring and informing about the decision)
- relationship (connections between the person and their supporters that demonstrate familiarity, trust and a commitment to support individual autonomy).

2.1.5 Barriers and facilitators

Whichever approach is selected to support decision-making with people who have SLCN (with or without cognitive impairment), it needs to be free from bias and transparent in process, and promote personal autonomy.

A structured review of the literature identified a number of barriers and facilitators related to supported decision-making.

Barriers: Obstacles or challenges that affect progress

- unequal power distribution – decision-making centred on professionals, multi-disciplinary teams, family members and paid carers (Caton et al. 2026; O'Donnell et al. 2022)
- disconnect between process and needs/experiences – dominant in health settings and noted particularly in mental health facilities for patients, family and staff (Chmielowska et al. 2023)
- lack of accessible information – limited provision of accessible information formats to people with intellectual/learning disabilities and/or caregivers to support shared decision-making (Caton et al. 2026; Sheehan et al. 2019)
- risk-averse culture – a duty of care to reduce harm can override personal choice (Francis et al. 2024; O'Donnell et al. 2022)
- knowledge and skills limitations – poor access to training for staff on implementing mental capacity legislation (Stokes et al. 2025)
- time and resource constraints – lack of time, opportunity and support materials for implementation (Francis et al. 2024)
- low confidence – knowledge gaps about implementation in context (Francis et al. 2024; Stokes et al. 2025)
- relationship problems – fear and distrust for both service users and clinicians (Francis et al. 2024)

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- organisational policies – incompatible management priorities and structure (Francis et al. 2024).

Facilitators: Conditions that support progress

- in-situ training – using case exemplars; relevant and clear organisational policies and practices; person-centred care (Francis et al. 2024; Stokes et al. 2025)
- co-design of training – based on theories of learning and coproduction (Pillen et al. 2025)
- policies in practice – embedding supported decision-making in routine, everyday practice (Francis et al. 2024)
- design of new tools to assist supported decision-making processes (Chmielowska et al. 2023; Francis et al. 2024).

2.1.6 Accessible information

Decision-making processes are dependent on the person (ie the decision-maker) understanding the choices available, any information connected to the decision including the pluses and minuses of one decision over another, and the related likely outcomes. This is why accessible information matters – so that the person is able to understand the available options and communicate their preferences.

The Disability Discrimination Act (1995) (Part III, 19 c) introduced the term 'reasonable adjustments' as a legal requirement to address physical, environmental and attitudinal barriers to people living with disabilities. Different legislation has been published since. The relevant legislation and associated disability and communication provisions are outlined below.

The Equality Act (2010)

- Provides legal protection from discrimination in the workplace and wider society.
- Disability is identified as a protected characteristic.

Health and Social Care Act (2012, s. 250)

- Correspondence between the term 'reasonable adjustment' and communication information is established.
- The Accessible Information Standard is adopted, making it legally enforceable in England.

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Accessible Information Standard (NHS England, 2015; updated - 2025)

All organisations providing NHS and/or publicly-funded adult social care services are required to follow the Accessible Information Standard (2015). The aim is to ensure that people who have a disability, impairment or sensory loss are able to:

- access and understand information about NHS and social care services
- receive essential communication support in order to access and use those services.

Implementation in the home nations:

- England: Legally enforceable (s. 250 of the Health and Social Care Act, 2012)
- All Wales policy: Accessible communication and information standards in healthcare
- Scottish government: Accessible information policy; Getting it right for everyone (GIRFE) toolkit.

Six steps are identified in the requirements of the Accessible Information Standard (NHS England, 2015; updated – 2025):

1. Identify: Ask the person if they have communication or information needs and how to meet them.
2. Record: Make a record of those needs clearly in electronic or paper files.
3. Flag: Highlight the person's needs on any case notes or personal records so that this information is available to practitioners and carers.
4. Share: With the person's consent, alert other care providers to this information.
5. Meet: Provide accessible formats and communication support to meet the person's needs, including written formats (eg large print; Braille; 'easy read'; email; audio; video) and in-person communication support (eg British Sign Language interpreter; deaf-blind manual interpreter; advocate)
6. Review: Information on a person's needs must be reviewed and updated as requested by the person and those providing care and support.

(Note: These principles align with duties under the Equality Act (2010) and with policy and guidance on inclusive communication across the UK.)

There are many options for making written material more accessible to people with SLCN. Selection of approach will usually be informed by the particular needs of the audience.

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2.1.6.1 Plain or simple language

You may come across various terms connected to accessible written material, including 'plain language/English', 'simple/simplified language' and 'easy English'. Regardless of the term used, the purpose is to improve the reader's understanding of information, to ensure consideration of accessibility needs and to make services as inclusive as possible.

Plain language is a recognised international standard. It is also promoted by various government departments across the home nations:

- Department for Education: England
- NHS Inform: Scotland
- Planning terms: Plain language guide and glossary
- NHS digital services manual: How we write
- Health Research Authority

The different versions of plain language standards/guidance all have features in common. The World Health Organization standard defines a number of key features.

TRANSLATION

- Translate technical terms into language that is accessible to a non-expert audience.

FAMILIARITY

- Use words that mean something to the targeted audience.

GOOD WRITING

- Organise content so that the most important messages are highlighted.
- Create a Single Overarching Communication Outcome (SOCO) for the targeted audience.
- Break lengthy or complex information into bite size chunks for easier processing.
- Use familiar language to explain any technical terms.
- Use white space in documents to help easier reading.

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EFFECTIVE COMMUNICATION

To be effective, communication should:

- be accessible – ensure the availability of different channels of communication (eg web-based; hard copy; audio file)
- be timely – communicate at the right time
- use stories – include real-life stories as appropriate to the subject matter
- be visual – make the content visual using multiple media (eg photographs, video, infographics, charts, illustrations).

2.1.6.2 Easy Read

Written material labelled 'Easy Read' is in popular use for making information accessible. It is a way of presenting written information using short sentences, everyday words with pictures next to the text, and a clean layout (see Mencap: https://www.mencap.org/easy-read). The aim is to address difficulties with reading and understanding. A useful overview of key differences between 'plain language' and 'Easy Read' is provided by Easy Read Wales.

Based on (UKAAF), the process for developing Easy Read material can be summarised as follows: (UKAAF), the process for developing Easy Read material can be summarised as follows:

1. Coproduce: Involve people with relevant lived experience from the very start and throughout the development process.
2. Identify the key meanings: Select the key content words that communicate specific concepts, actions and instructions.
3. Write the simplified content: Use familiar concrete words in short sentences that contain 1 key idea or meaning.
4. Choose the right pictures: Select pictures that go with key words and communicate the meaning clearly.
5. Prepare your document: Design the layout and background, and organise the text using bullet points, headings and colour as appropriate.

Before working on an Easy Read document, it is important to consider:

- What information is truly useful to your audience?
- Is there a better alternative to Easy Read (eg videoclip, animation)?
- What format will be used for presenting the Easy Read information (eg paper document, PowerPoint with or without narration)?

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- How will the document be presented to the 'reader', eg as a standalone document or with 'reader' support?

Detailed guidance on developing Easy Read material is available from the following sources:

- UK Association for Accessible Formats (UKAAF)
- UK Easy Read Standards – Disability Equality Scotland
- Mencap
- Ability Net – What is Easy Read?

There are also a range of picture banks available to support the development of Easy Read material including:

- Easy on the i
- Participics
- Photosymbols
- Change

2.1.6.3 Easy Read evidence

Easy Read information is popular with service users who have intellectual or learning disabilities. It has become the subject of social enterprise across self-advocacy organisations (eg People First) who develop Easy Read documents and provide training for interested parties. However, despite its popularity with user groups and some organisations, there is limited evidence regarding the effectiveness of Easy Read health material in improving reading and understanding (Buell et al. 2019; Iacono, 2026; Wilson et al. 2026). A comparative discourse analysis of Department of Health Easy Read documents and their original source document in standard text found that the Easy Read documents used language structures that were less empowering and inclusive to the reader (Buell et al. 2024). Furthermore, a related study using an open randomised control concluded that there needs to be deliberate consideration of language content and processing demands on the 'reader' beyond more superficial manipulation of the Easy Read format (Buell et al. 2019). Iacono (2026) concluded that there is a need to research the effectiveness of Easy Read materials with people representing the range of intellectual disabilities.

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Case example of Easy Read in use showing importance of language mediation to understanding?

Research example?

Health and social care example?

2.1.6.4 Other media

Different approaches may be used to support a person with SLCN to receive and understand information and to communicate a decision. Examples include the following.

TALKING MATS

Talking Mats uses a visual form of communication, in hard or digital copy. The person reviews topics and considers options presented in pictures. Then they place their chosen options against a simple rating scale (eg good-ok-bad; yes-not sure-no) as a response.

RIX CENTRE

Based at University of East London, this inclusive research institute promotes the effective use of digital and multimedia technologies with people with intellectual/learning disabilities. RIX Wikis are easy-to-build personal websites that enable the individual to create a multimedia profiles and person-centred plan that capture their voice, skills, interests and needs.

SPEAKEASY

Speakeasy offers resources to researchers and health professionals for people with aphasia, including templates for use in research and aphasia-friendly images.

BOOKS BEYOND WORDS

A UK-based charitable publisher that creates word-free picture books designed to support people with intellectual/learning disabilities, communication difficulties, or those who find images easier to understand than text. Their books

are co-created with people with lived experience and cover topics relevant to health and social care, schools and education, home and community.

LINK TO AAC

Case scenario: Barny contributes to his decision

Barny is a 17 year old man with cerebral palsy and learning disabilities who was receiving enteral nutrition via PEG in addition to three oral meals a day.

SLT dysphagia assessment identified that Barny was showing signs of aspiration during mealtimes and referred for instrumental assessment. A Videofluoroscopy (VF) showed significant aspiration, however Barny remained in good chest health. Barny's allocated Paediatrician stopped oral feeding apart from small tastes due to concerns that aspiration might cause harm. At this time he did not assess Barny's capacity to consent to this course of action.

Barny was discharged shortly afterwards by the Paediatrician because he turned 18 years of age. Barny expressed a strong preference to continue oral feeding. The SLT took time to create a range of resources including social stories to teach Barny about the risks and benefits of continuing with oral feeding and information was shared over time.

An MCA assessment was completed using Talking Mats, specially created resources and Barny's AAC device. Barny understood a lot about the risks but struggled to understand concepts relating to the likelihood of harm occurring from aspiration so he was unable to weigh up the information to make a decision.

He thought that food would definitely go onto his lungs every time he ate but could not understand what harm this could cause.

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The SLT chaired a Best Interests meeting with the GP and a Dietitian. The decision was made to restart oral feeding with a structured EDS plan providing strategies to minimise risk with the recognition that the aspiration was not believed to be causing harm at that time. Additional information was shared with Barny's family and carers around signs that would indicate a review of the plan.

2.2 Principles and practice

2.2.1 Principles

The process of support for decision-making (SfDM) is characterised by a number of key elements:

- person-centred practice – practice that places the person at the centre and includes them in all relevant conversations
- shared information – information that is shared, readily available and accessible to the person and provides for any relevant options
- adjustments – appreciation and sensitive responding to the range of ways a person expresses themselves including methods other than spoken words
- risks – appraisal of the significance to the person of the material risks associated with the options being discussed
- respect – listening to and valuing the contributions of the person
- recognition – awareness and recognition of the person's life course values and preferences
- relationship – social connection between the person at the centre and those providing support that is based on mutual experience and familiarity.

(Sources: Amorim & Cardoso Ventura, 2023; Bigby et al. 2019; Blanck, 2023; Craigie et al. 2025; Douglas & Bigby, 2020; Royal College of Surgeons, 2016; Shogren et al. 2017)

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Case example of SfDM process with a person with SLCN

2.2.2 Requirements and considerations

Many of the open-source frameworks on support for decision-making identify a series of considerations. Whatever variations exist across these frameworks, there are some consistent elements that should be considered throughout the decision-making process. These include:

- adherence to provisions of legal statutes as appropriate
- presumption of capacity and functional assessment of capacity
- absence of undue influence and conflict of interest
- involvement of family and familiar others
- clarity around what the different supporters can achieve (correspondence to care plan may be relevant)
- clear definition of supporter role (the person, their relationship and the supports used)
- selection, acceptance and use of supports at the individual's discretion
- recognition of diversity (age, gender identity, sexual orientation, beliefs, racial origin, cultural and linguistic background and ethnicity)
- available options and alternatives
- risk-taking allowance
- record-keeping

(Derived from multiple sources, including: Bigby et al. (2019); Gillespie (2023); Mental Welfare Commission for Scotland (2024); People First Scotland; Paradigm (2023).)

2.2.3 Process

The requirements and considerations outlined above inform how support for decision-making is provided. The following steps describe the practical process of providing that support.

1. Identify a supporter

It is helpful if the supporter knows the person, understands their particular situation and appreciates the values they hold dear. This includes knowing and understanding their particular SLCN and having the support skills to facilitate communication. It is possible that the nominated supporter is not familiar with the person, in which case step 3 – relationship-building may be prioritised early on.

2. Provide training

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The person undertaking the supporter role needs to understand what is expected of them. Some organisations provide training courses to help prepare the person for undertaking the role and to safeguard a fair process.

3. Build relationships

Time should be allowed for the supporter and the person to get to know each other. Even if the supporter already knows the person, it may be helpful to build on the existing relationship in the context of the decision-making process.

4. Clarify the decision

The decision needs to be named and described, including what it comprises in terms of options, implications and potential impacts. All information about the decision should be available to both the person and the supporter. There may be more than one decision or one main decision with other associated decisions.

5. Identify support needs and resources

The support needs of the person need to be identified clearly along with any adjustments and resources that may help. Prepared communication resources might include: a range of communicative forms (eg printed words, photographs, picture symbols, objects of reference, video footage); adjusted use of language (vocabulary, semantics, social use of language); use of the person's own communication system other than speech (eg computer aided device, sign language). In addition to communication resources, psychosocial and contextual supports may be considered (eg the background noise level, lighting and privacy of the decision-making space; personal supports such as the presence of a friend, familiar other person or favourite object).

6. Note interests and preferences

The person's interests and preferences must be recognised and prioritised in the interactions about the decision. The supporter should be open to, understand and engage with the wishes and interests of the person about the decision. Importantly, they should understand that the first wish expressed may not be what the person actually wants or may reflect a lack of understanding of all the options.

7. Consider constraints and consequences

Time is needed to explore the available options carefully with consideration of possible outcomes and implications. It is important to be clear about what a particular decision may achieve for the person and to identify any constraining factors that may affect the outcome(s).

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8. Review and refine the decision

The supporter should refine the decision on the basis of a shared exploration of all the available options, their likely consequences and implications for the person. This step serves to safeguard against any quick decision-making that ignores the wider life context of the decision for the person.

9. Clarify the final decision

After inspecting the decision, considering any concomitant factors, the decision should be clarified to the satisfaction of the person and the supporter. Once the decision has been agreed and recorded, the implementation steps are articulated.

10. Action the decision

The person is supported to exercise their capacity for the particular decision. An implementation plan is enacted with the help of others who are involved in the decision.

Note: Depending on the context and nature of the decision, there may be a need for an assessment of mental capacity within the relevant legal framework before any decision is actioned.

(These steps are drawn from sources including: Bigby et al. (2019); Gillespie (2023); Mental Welfare Commission for Scotland (2024); People First Scotland; Paradigm (2023).)

PLACEHOLDER

Case example of a process followed with a particular individual with SLCN?

2.3 Participation in decision-making

2.3.1 Participation

Participation is defined as having two key elements: attendance or presence, and involvement (Imms, 2020).

Attendance ensures the visibility of the person in the decision-making process. However, involvement moves beyond simple occupation of space and time to active participation within the physical and socio-cultural environment (Simmons, 2020).

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In terms of decision-making for people with SLCN, the aim is to optimise their involvement as decision-makers in both everyday and legal decision-making.

Everyday decisions may involve interactions with the person to work out the preferred course of action, such as what clothes to wear or what activity to pursue. Legal provisions for people who lack capacity may involve proxy or substitute decision-makers, or the advice of someone who is familiar with the person (for research under the MCA, 2005 only).

2.3.2 Having a voice

Regardless of whether a decision is taken by another person on behalf of the individual or whether a decision is based on advice of other people as per the relevant legal framework, the person at the centre of the decision should have the opportunity to participate in the decision-making process as far as they are able. This means taking into consideration the person's wishes and feelings.

How we recognise and respond to the wishes and feelings of a person who lacks capacity will vary according to their life experience. For example, some individuals may have made their views and feelings very clear about a range of issues before they lost their capacity; others with lifelong conditions may have relied on familiar others to interpret their needs and responses to different options (eg people with profound intellectual/learning and multiple disabilities). In both scenarios, decision-making processes are helped by knowledge of the person and any views or responses they have expressed in the past as well as interactions with them at the time of the decision-making.

LINK TO INCLUSIVE COMMUNICATION GUIDANCE; AAC GUIDANCE

2.3.3 Working out a person's likely wishes and feelings

The process of working out the likely wishes and feelings of a person with SLCN can involve individuals' prior knowledge of the person as well as interaction with the person at the time of decision-making.

2.3.3.1 Knowledge of the person

Familiar others, close family members or carers may recall past communications by the person before the onset of capacity difficulties, where they expressed views and opinions about particular issues that are relevant to the decision.

They may draw on their wider knowledge of the person, their lifestyle and their values and preferences, and they may recall past experiences of how the person

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responded to different options using highly personalised styles of expressions that were recognised and supported.

Their wider knowledge and experience of the person over time may help to determine the person's likely wishes and feelings.

2.3.3.2 Interaction with the person

Interactions with the person need to be optimised. They should be responsive to their individual communication style, particularly when a common code of communication is not in use.

The person's way of communicating may have changed over time (eg someone with acquired capacity difficulties and associated SLCN) and it may no longer be clear what they mean.

The person may use highly personalised ways of expressing themselves that rely on familiar others and professionals to interpret the behaviours (eg someone with profound intellectual/learning and multiple disabilities). In such cases, attunement may be relevant to how a person expresses their wishes and feelings and may underpin good quality interaction (Forster & Iacono, 2014). It has been described as "being aware of, sensitive to and responsive to another person's emotional, physical or psychological state in real time." (Education Scotland: https://education.gov.scot/media/ylgmoc0u/attunement-information-note-informed-level.pdf.

Familiar others and professionals may disagree about what a behaviour means and working out the likely wishes and feelings of the person may require a process of checking out various interpretations (Grove et al. 2020).

2.3.3.3 Communication passport

A detailed and current communication passport can support the process of deciphering a person's likely wishes and feelings. It provides a profile of the person, including their preferred communication methods, likes and dislikes, support needs and important people.

Further information about communication passports is available from the following sources:

- CALL Scotland
- SENSE
- ACE

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LINK TO AAC GUIDANCE

2.3.4 Expressing agreement or disagreement

Being able to express agreement or disagreement with a proposition is important to decision-making. It may be that the person is not the decision-maker due to lack of capacity for the particular decision at that time. However, their involvement in the process should always be encouraged and supported, whether in everyday decision-making or in legal contexts. This is reflected in the codes of practice for legislation on mental capacity/incapacity, which emphasise the importance of involving people in decisions even when they lack capacity to make those decisions themselves.

Mental Capacity Act (2005) Code of Practice (2007) – England and Wales

- "Every effort should be made to encourage and enable the person who lacks capacity to take part in making the decision." (Paragraphs 5.21–5.24; Chapter 5.13)
- "It (the Act) makes sure that researchers respect their wishes and feelings." (Chapter 11.1)

Adults with Incapacity (Scotland) Act (2000) Code of Practice (2008)

- "The person's present and past feelings and wishes must be ascertained so far as possible." (Annex 2, A guide to communicating with the person with impaired capacity)

Sibley and colleagues (2016) made a distinction between 'respecting a decision' and 'encouraging a decision'. This is useful to bear in mind when considering how to support the active involvement of people with SLCN who have been assessed to lack capacity.

Respecting a decision

This acknowledges the rights of an individual and attributes value to their involvement in decision-making. For example, agreement for person lacking capacity to participate in a research project may be in place; however, the person's expression of dissent immediately prior to data collection may override the decision by the substitute decision-maker.

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Encouraging a decision

This focuses on the learning process whereby an individual actively considers and engages with the options presented. The decision-making process actively involves the person in exploring the options around, for example, a health intervention, or whether or not they participate in a data collection exercise, with the decision-maker.

PLACEHOLDER

Case example of SfDM process with a person with SLCN

Signalling agreement and disagreement

The signalling of agreement and disagreement, sometimes referred to as assent and dissent, is relevant to decision-making in everyday life and in legal contexts (see 'Accessible information' above). Some people, unable to consider the options around a particular decision, are dependent on others to be the decision-maker. However, they may be able to indicate their agreement or disagreement with what is on offer. This is particularly the case for people with severe cognitive impairment and complex SLCN.

Note: Whilst the terms 'assent' and 'dissent' have no meaning in UK law at the time of writing, where other arrangements are made for a person who lacks capacity, they are nevertheless relevant to how a person is involved in decision-making processes.

'Assent' is defined as a positive act or expressive behaviour that conveys a person's agreement to a proposition or willingness to take part in whatever opportunity is presented.

'Dissent' is an individual's action or behavioural expression that denotes their objection or disagreement or alternative viewpoint to a proposition.

Some people with SLCN may have difficulty using a reliable 'yes' or 'no'. Others may use highly personalised gestures (facial expression or hand, body or vocal gesture) that communicate their agreement or disagreement to familiar others but are not immediately recognisable by others.

Use of assent/dissent may be considered in situations where lawful consent has been established via substituted decision-making, or consultee advice accords with participation (Tait & Carnett, 2025).

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Expression of assent/dissent can be vocal or non-vocal and a person's response types may change across time and situations.

The use of assent/dissent requires shared knowledge of the person's communication repertoire which is dependent on assessment of the individual's communication skills.

Recognising and responding to expressions of assent/dissent confers agency on the individual in a situation that affects them, even though they are not necessarily the decision-maker (Tullis & Carnett, 2025). Indeed, their use is becoming increasingly popular as part of the decision-making process, both for health treatments and research, eg people with profound and multiple learning/intellectual disabilities (Simmons, 2020; Tullis & Carnett, 2025) and older people with dementia (Black et al. 2010).

CASE SCENARIO: RAHEEM EXPRESSING ACTIVE DISSENT

Raheem has severe/profound intellectual and multiple disabilities. His mother acted as personal consultee for her son and advised on his likely preference to take part in a research project. Raheem communicates his feelings about something through facial expression, vocalisation and body language. When he likes something he claps his hands and makes repeated vocalisations of an 'ah' sound at a high pitch. When he doesn't like something he strikes himself on the side of his face.

The project was about investigating the effects of multisensory storytelling on Raheem and the familiar people in his life. Data collection involved videoing the storytelling process over six sessions to evaluate the effects on people like Raheem.

Before each session the participant was shown the video camera and the sensory storybook to be read. They were encouraged to handle the storybook and to look through the camera lens. They were also videoed for a few seconds and shown the video clip. Data collection proceeded on the basis of the participant's response.

Raheem responded positively before sessions 1-4 by clapping his hands, smiling and making his 'happy' vocalised sound, so data collection proceeded. Before session 5, Raheem's behaviour was different and he slapped the side of his face repeatedly and pushed the proffered book away, demonstrating his active dissent. On this occasion data collection did not proceed.

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[MCA, 2005: Research provisions]

2.4 Resources

- The La Trobe Support for Decision Making Practice Framework Learning Resource, Bigby et al. (2019). Area: Cognitive impairments associated with acquired brain injury and intellectual disabilities
- Supported decision-making, Bournemouth University. Area: General
- Assent Guidance: Domain – Adjustments and Supports, Bunning et al. (2024). Area: Learning/intellectual disabilities, autism, dementia, aphasia after stroke, acquired bran injury, mental health
- Consult training, Consult (Shepherd, V.). Area: Adults with impaired capacity to consent
- Capacity and Consent to Research Resources, Consult (Shepherd, V.). Area: Adults with impaired capacity to consent
- See What I Mean: Guidelines, Grove et al. (2000/under revision). Area: Severe and profound learning disabilities
- Supported decision-making, IRISS Gillespie (2023). Area: Learning/intellectual disabilities, mental health, older age and dementia
- **PLACEHOLDER**, Jayes, Volkmer & Lewer. Area: E-learning resources: Supporting people with communication disabilities
- No research about us without us, Leeds University and others. Area: Learning/intellectual disabilities
- Practical Guide to supported Decision Making, Paradigm (2023). Area: Learning/intellectual disabilities, autism, other cognitive impairments
- Supported Decision-Making: A Framework, People First Scotland. Area: Learning/intellectual disabilities
- Supported Decision-making. Citizen Space, Scottish Government. Area: General
- Mental Welfare Commission for Scotland: Supported Decision-making - Good Practice Guide, Mental Welfare Commission for Scotland. Area: Mental health, learning/intellectual disabilities, dementia and other related conditions
- Quality statement 1: Supported decision making, NICE Guidance. Area: People aged 16 and over who may lack capacity to make decisions

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- Let's Talk Dementia: Supporting communication in research partnerships involving people with dementia, University College London. Area: Dementia

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3. Legal and conceptual frameworks

3.1 Concepts and definitions

3.1.1 Capacity

Capacity/mental capacity are legal terms used to describe a person's ability to make informed decisions for themselves in relation to their health and social care and participation in research. They cover decisions of variable magnitude: from simple day-to-day decisions through to more complex and life-changing decisions.

PLACEHOLDER

Case examples of different decisions faced by people with SfDM

3.1.2 Frameworks

In the legal frameworks of the UK, it is assumed that everyone has capacity unless proven otherwise. They emphasise the importance of maximising an individual's involvement in decision-making and providing all useful support before concluding that a person is unable to make a particular decision.

'Capacity' is often defined by identifying when a person lacks the ability to make a particular decision, so that appropriate legal protections can then be provided (Ruck Keene et al. 2023).

For the purposes of the UK laws, mental capacity is decision-specific, time-specific and binary.

Decision-specific

The nature and significance of a decision may vary.

Time-specific

An individual's abilities may fluctuate or change over time, so their mental capacity should be judged at the time the decision is needed. This means that a person may be able to make a decision on one occasion and unable to make a similar decision at another time.

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A binary concept

Either a person has capacity or they do not for a specific decision at a specific time – as established through an appropriate assessment of capacity that takes account of the relevant legal framework (Heywood et al. 2019).

3.1.3 Definitions of capacity and incapacity in UK laws

Mental capacity and incapacity are variously defined in UK laws.

Mental Capacity (England and Wales) Act, 2005, Part 1, Section 2(1)

"A person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain."

Adults with Incapacity (Scotland) Act, 2000, Part 1, Section 1(6)

For the purposes of this Act, and unless the context otherwise requires … "incapable" means incapable of:

(a) acting; or
(b) making decisions; or
(c) communicating decisions; or
(d) understanding decisions; or
(e) retaining the memory of decisions,

as mentioned in any provision of this Act, by reason of mental disorder or of inability to communicate because of physical disability; but a person shall not fall within this definition by reason only of a lack or deficiency in a faculty of communication if that lack or deficiency can be made good by human or mechanical aid (whether of an interpretative nature or otherwise); and "incapacity" shall be construed accordingly.

(Note: Subject to ongoing reform. Readers should refer to current legislation and associated guidance.)

Mental Capacity (N. Ireland) Act, 2016, Part 1, Section 3(1)

"A person who is 16 or over lacks capacity in relation to a matter if, at the material time, the person is unable to make a decision for himself or herself about the matter (within the meaning given by section 4) because of an impairment of, or a disturbance in the functioning of, the mind or brain."

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(Note: Not currently passed in law with the exception of the Deprivation of Liberty Safeguards (DoLS))

A communication difficulty alone does not constitute incapacity or a lack of capacity. All reasonable steps should be taken to support communication, including the use of familiar communication partners, augmentative and alternative communication methods and assistive technology, multiple media, before concluding that a person is incapable of making a decision.

3.1.4 Capacity within the UN human rights framework

Article 12 of the Convention on the Rights of Persons with Disabilities (UN, 2006) covers equal recognition before the law. The Convention has been ratified by 192 states, including the UK, plus the European Union.

Article 12 states that parties 'shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life' and 'shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity'.

It is provided here as a point of reference as you may find it referred to in discussions about decision-making processes. However, it currently sits outside of the UK legal frameworks.

3.2 Legislation and codes of practice

3.2.1 Legal frameworks

There are a number of legal frameworks that apply to decision-making and assessment of mental capacity in the UK home nations.

England and Wales

- Mental Capacity Act (MCA, 2005)
- Mental Capacity Code of Practice (2007)

Scotland

- Adults with Incapacity (Scotland) Act (AWI, 2000) (Note: The AWI is undergoing significant changes due to be published in 2027)
- Adults with incapacity: Code of practice and associated guidance.

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Northern Ireland

- Mental Capacity Act (Northern Ireland) (MCA, 2016): Includes mental health provisions for people aged 16 and over. (Note: At the time of writing only part of the legislation is in force, primarily the DoLS framework, implemented in December 2019.)

3.2.2 Core principles

The legal frameworks contain a number of core principles.

England and Wales

- Capacity should be presumed until proven otherwise.
- Individuals must be supported to make their own decisions as far as practicable.
- Individuals have the right to make their own decision regardless of it being perceived as 'unwise' by others. (Notes: Safeguarding may be relevant if the 'unwise' decision leaves the person unprotected; a person who lacks capacity has the right to a best interests decision balancing quality of life with safeguarding them.)
- All decisions and actions must be in the best interests of the person lacking capacity.
- Decisions and actions must be less restrictive of the individual's rights and freedom.

Scotland

- Any intervention must be of benefit to the adult.
- Any intervention must be the least restrictive option.
- Take the person's past and present wishes into account.
- Take the views of other people into account.
- Encourage the person to exercise whatever skills they have. (Note: A person should not be considered incapable solely because of a communication difficulty if that difficulty can be overcome by human or mechanical aid.)

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Northern Ireland

- A person should not be treated as lacking capacity unless it has been established that they lack capacity in relation to the particular decision.
- No unjustified assumptions about a person's capacity should be made based on their condition or other characteristics.
- A person must be given all practicable help and support to make a decision before they can be considered unable to make that decision.
- A person should not be treated as lacking capacity simply because they make a decision that others consider unwise.
- Any act done or decision made on behalf of a person who lacks capacity must be in that person's best interests.

3.2.3 Mental capacity and informed consent

In order for a person to provide informed consent, they must be given information about the benefits, risks and reasonable alternatives relevant to the decision. The information should include any risk that a reasonable person in the patient's position would consider important, or that the clinician knows the individual patient would consider important.

For consent from individuals aged 16 years or above to be valid, it must be properly informed and given freely without coercion and the person must have capacity to make the required decision.

Requirements for valid consent for a child aged 15 years and below vary between the nations.

England and Wales

If the child has maturity and sufficient intelligence to appreciate fully what is proposed for a clinical treatment decision, consent may be given (Gillick competence).

Scotland

If a qualified medical/clinical practitioner attending the child states they are capable of understanding the nature and possible consequences of the procedure or treatment, consent may be given.

(Note: This reflects section 2(4): Age of Legal Capacity (Scotland) Act (1991).)

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Northern Ireland

If the child has sufficient intelligence to appreciate fully what is proposed for a clinical treatment decision, consent may be given (Gillick competence).

3.3 Decision-making in research

The consent requirements about taking part in research for adults who are not able to consent for themselves depend on the type of study and where in the UK the research is taking place.

3.3.1 Abbreviations

- CTIMP: Clinical Trial of Investigational Medical Product
- Non-CTIMP: Other research
- REC: Research Ethics Committee

3.3.2 Legislation

For clinical trials of investigational medical products (CTIMPs) in England, Wales, Scotland and Northern Ireland, the Medicines for Human Use (Clinical Trials) (Amendment) Regulations (2025) apply.

For other (non-CTIMP) research, the following statutes apply:

- England and Wales: Mental Capacity (England and Wales) Act (MCA, 2005)
- Scotland: Adults with Incapacity (Scotland) Act (AwIC, 2000)
- Northern Ireland: Mental Capacity Act (Northern Ireland) (MCA, 2016)

3.3.3 Research provisions: CTIMP

Conditions of participation

Adults who lack capacity to give informed consent may participate in clinical trials of investigational medicinal products (CTIMPs) subject to specific conditions and safeguards. These include:

- The person's rights and interests must be respected, and appropriate informed consent must be obtained.
- The potential benefits of participation must be weighed against the risks.
- Participation should involve little or no discomfort.
- The adult must not object to taking part.

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- The research must have been approved by an appropriate Research Ethics Committee.

Note: Different consent arrangements may apply in emergency research situations.

Basis for participation

A legal representative must give consent on behalf of an adult lacking capacity.

Personal legal representative

The personal legal representative must meet a number of criteria, which vary depending on where in the UK the research is taking place.

England, Wales and Northern Ireland

For studies taking place in England, Wales or Northern Ireland, the personal legal representative should be:

- not connected with the conduct of the trial
- suitable by virtue of relationship with the adult
- available and willing to do so.

Scotland

For studies taking place in Scotland, the personal legal representative should be the adult's welfare guardian, welfare power of attorney, or welfare attorney (appointed under a Power of Attorney), or if not appointed, the adult's nearest relative, named person or primary carer or other with a legitimate interest in the adult's welfare.

Professional legal representative

In all the UK home nations, if a personal legal representative is not available, a professional legal representative may be appointed. The professional legal representative should be either an independent person who is responsible for the medical treatment of the adult, or a person nominated by the healthcare provider.

Further provision is made for emergency situations.

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Role of the legal representative

The legal representative:

- can be asked to give consent on behalf of the incapacitated adult
- is free to decide whether they wish to make this decision or not
- can be asked to consider what the adult would want and to set aside their own personal views when making this decision
- must receive sufficient information, in an understandable form, about the trial to ensure an informed decision.

The participant

The participant themselves must also receive information suited to and according to their capacity for understanding about the trial and its risks and benefits.

3.3.4 Research provisions: Non-CTIMP (other research)

Definitions

Non-CTIMPs are defined in England, Wales and Northern Ireland as 'other intrusive research'. In Scotland, non-CTIMPs are 'other medical, surgical, nursing, dental and psychological research'.

Conditions of participation

Adults who lack capacity to give informed consent may participate in non-CTIMP research subject to specific conditions and safeguards. These include:

- The research will further knowledge.
- The research will benefit the adult or others in a similar condition.
- Participation should entail little or no discomfort.
- The adult does not object to taking part.
- The research has been approved by an appropriate Research Ethics Committee.

Note: Different consent arrangements may apply in emergency research situations.

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Basis of participation

The basis of participation depends on where in the UK the research is taking place.

England, Wales and Northern Ireland

For research taking place in England, Wales or Northern Ireland, advice must be sought from a consultee on the likely wishes and feelings of the adult lacking capacity about their participation in the research study or otherwise. The consultee does not give consent on behalf of the adult.

The consultee may be either a personal consultee or a nominated consultee.

- A personal consultee is a person who cares for the adult lacking capacity or is interested in that person's welfare, but is not doing so for remuneration or acting in a professional capacity.
- A nominated consultee is a professional who is independent of the study and can provide advice where a personal consultee is not available or willing.

The consultee:

- can be asked to advise on the views and feelings of the adult lacking capacity about participation
- is free to decide whether they wish to provide this advice or not
- should receive study information to ensure that the advice given is informed.

Scotland

In Scotland, a legal representative can be asked to give consent on behalf of an adult who lacks capacity to do so themselves. This might be:

- the adult's welfare guardian or welfare power of attorney, or welfare attorney (appointed under a Power of Attorney) or attorney, if not appointed
- the adult's nearest relative.

The legal representative:

- can be asked to contribute to decisions affecting an adult with incapacity

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- is free to decide whether they wish to make this decision or not within the scope of their legal authority
- should take account of the adult's wishes and preferences and set aside their own personal views when making this decision
- should receive sufficient information to ensure an informed decision.

Recording

For research taking place in England, Wales or Northern Ireland, consultee advice is recorded on a consultee declaration form.

For research taking place in Scotland, consent is recorded on either a welfare guardian/welfare attorney/nearest relative consent form or a recovered capacity participant information sheet and consent form.

The participant

The participant themselves must also receive information, suited to and according to their capacity of understanding about the research and its risks and benefits.

For research taking place in Scotland, if the participant expresses a view that they do not wish to take part in the study, this view must be acted upon.

3.3.5 Regaining capacity

Participants who lack capacity at the start of a research study may regain capacity during the course of the study. Researchers therefore need to consider how this possibility will be addressed, particularly in relation to ongoing consent and the participant's involvement in decision-making.

The information below applies to England, Wales, Scotland and Northern Ireland. It is taken from Policies, Standards and Legislation, NHS Health Research Authority.

Research plan

If it is likely adult participants might regain capacity during the course of your study, their involvement in the ongoing consent process needs to be in the research plan/protocol.

In most cases it is appropriate to ask them to give their own consent when and if they are able.

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Regained capacity: CTIMP

If a participant regains capacity during a CTIMP, you should inform the legal representative (Clinical Trials of Investigational Medicinal Products: CTIMPs).

Regained capacity: non-CTIMP

If a participant regains capacity during non-CTIMP research, you should:

- inform the personal or nominal consultee (relevant to non-CTIMP/other intrusive research) at the outset
- prepare an appropriate participant information sheet and consent form that explains what has happened so far and what you are seeking their consent for
- plan how you will handle a participant withdrawing consent at each stage of your study and tell them what they can expect.

3.3.6 Losing capacity

The guidance below is taken from Policies, Standards and Legislation, NHS Health Research Authority.

Planning

Where there is a significant risk of participants losing capacity during a study, consider discussing ongoing options with them during the original consent and include information in the participant information sheet.

Validity of prior consent

CTIMPs

For CTIMPs, consent to participate in a study is presumed to remain legally valid after loss of capacity (provided your protocol does not change significantly).

NON-CTIMPS IN ENGLAND, WALES AND NORTHERN IRELAND

For other intrusive research in England, Wales or Northern Ireland:

- There are a very limited set of circumstances in which earlier consent covers a loss of capacity.
- Plan ahead the steps you would take in the event of capacity loss during a study and whether you would withdraw the participant from the study or

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keep them in. Note that as required by protocol, remaining in the study requires approval by the appropriate REC and advice from a consultee.

- Note that you have a legal obligation to consider a request by the participant's representative for them to withdraw from the study after loss of capacity. This should take consideration of the current situation (eg possible benefits and harms associated with continued participation).
- Where potential for losing capacity formed part of the original consent, review how best to proceed if the participant does subsequently lose capacity. The original consent given by participants should not automatically be considered absolute.

NON-CTIMPS IN SCOTLAND

For other medical, surgical, nursing, dental and psychological research (non-CTIMPs) in Scotland, legally there is no specific provision for adults who lose capacity. RECs might expect the original consent should be respected in most circumstances.

Any request by a legal representative to withdraw a person from a study after capacity loss should be considered carefully to ensure that it reflects the person's wishes before they lost capacity. You should also consider their current situation fully (eg possible benefits and harms associated with continued participation).

Consult with carers

In all cases, you should consult with carers and take note of any signs of objection or distress from the participant.

Considerations

For research taking place in England, Wales or Northen Ireland, you must consider withdrawing a participant if they raise any objections.

For research taking place in Scotland, you should withdraw a participant if they raise objections. Additionally, the legal representative may decide to withdraw an incapable participant. It is important that they make this decision having considered the wishes of a participant before loss of capacity and in light of current circumstances.

Protocol change

For research taking place in England, Wales or Northern Ireland, if your protocol changes during your study or you plan to obtain further consent from participants during your study, you must ask the legal representative for their consent or the consultee for advice on behalf of any adults who have lost capacity.

For research taking place in Scotland, if your protocol changes during your study or you plan to obtain further consent from participants during your study, you must ask the legal representative for their consent.

3.4 People with speech, language and communication needs (SLCN)

3.4.1 Abilities

People with different types of developmental and acquired SLCN, with/without cognitive impairment, may experience challenges with decision-making. The following conditions may be associated with communication and/or cognitive differences that may impact on decision-making abilities:

- acquired brain injury
- autism
- intellectual/learning disabilities
- progressive neurological conditions, including dementia
- stroke
- mental health conditions

(Note: When someone is compulsorily detained under the Mental Health Act (MHA, 1983) there are circumstances in which they can be given treatment without their consent.)

Some temporary conditions include:

- delirium and the effects of acute illness on the function of the brain
- effects of substance misuse
- effects of medication
- post-traumatic amnesia characterised by confusion, disorientation and short-term memory loss associated with a head injury, illness or fluctuating mental health.

In addition to the person's SLCN, the nature of the decision requires examination. There are particular factors that may affect how the person with SLCN is able to make a decision or participate in a decision-making process.

A person's ability to make decisions may be affected by factors that define the decision:

- context: the background for a decision, including any time limits, available options and any constraints that may apply
- complexity: the number of variables, the cognitive effort required to process choices and any uncertainty of outcomes
- magnitude: the overall importance to the person of the decision and the potential outcomes.

Depending on decision complexity, magnitude and context, a person may be able to make some decisions and not others.

Before embarking on any decision-making process, a first step is to ensure that all necessary support is in place for the person to use their own skills as far as possible. This is important for people with SLCN because decision-making depends upon a range of communication abilities, including the ability to understand information and communicate a choice or preference. With all necessary support in place, their capacity should be presumed before triggering an assessment of capacity as appropriate.

Many people with SLCN also have cognitive difficulties due to the nature of an underlying health or developmental condition that causes their communication difficulties. These cognitive difficulties may also impact their decision-making abilities, for example the ability to retain information about decisions and consider the advantages and disadvantages of different decision options. Each person's unique pattern of communicative and cognitive strengths and needs will affect their decision-making abilities differently.

PLACEHOLDER

Case examples showing how cognitive difficulties may affect capacity for decision-making

3.4.2 Risks and support needs

Lawful decision-making means acting within the relevant legal framework. It is about following the principles laid down in the statutes, using power in a way that is in accordance with the law and acting with fairness. Organisations do have such an obligation, particularly in care settings (see 'An Introduction To Public Law by The Public Law Project).

In all lawful decision-making processes, there may be risk. The presence of SLCN may affect how:

- a person is able to exercise optimal capacity for decision-making and maintain their personal autonomy (capacity to make free informed choices and direct their own life according to their personal values)
- others recognise and respond to the person's exercise of capacity
- a person who lacks capacity is involved in decision-making processes, whether through use of best interests, consultee advice or substituted decision-making.

People providing support may also face risks, particularly when making decisions on behalf of someone who lacks capacity. Such decisions must comply with the relevant legal requirements, including the principles of best interests under the Mental Capacity Act 2005 and benefit and least restriction under the Adults with Incapacity (Scotland) Act 2000. Different types of risk will require different management strategies.

Types of risks include: masking; under- or over-estimation; unnecessary mental capacity assessments; and under-representation in research.

Masking

The presence of SLCN can make it harder to recognise a person's true ability to make decisions; their capacity for decision-making is masked. This can make assessing their mental capacity more challenging. It is important that professionals, care staff and others involved in carrying out a mental capacity assessment have the knowledge and practical skills to organise or provide relevant support for decision-making and to help with advance decisions.

Under-/over-estimation

A failure to recognise and understand an individual's SLCN may lead to their capacity for decision-making being under-estimated or over-estimated.

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If it is under-estimated, there is the risk of disempowerment and exclusion from their role as decision-maker. There may also be a risk to the person's ability to retain independent control over different aspects of their lives (Lamont et al, 2013).

If it is over-estimated, there is the risk of the person making 'uninformed decisions' simply because they do not understand the information as presented. This increases their vulnerability and may further bring a safeguarding risk. Alternately, it may be the case that appropriate supports for the person's SLCN have not been put in place to allow the person to use their own abilities. In either case, the person may require a mental capacity assessment involving input from an SLT.

Unnecessary mental capacity assessments

Professionals without specialist knowledge or experience of working with people with SLCN may make assumptions about an individual's decision-making abilities based on initial perceptions of their communication skills. This may lead to professionals carrying out mental capacity assessments for people with SLCN who do not require them.

Under-representation in research

People with SLCN are vulnerable to being excluded from research that is relevant to their care and treatment. Their non-participation means that health and social care interventions may have unassured value to such individuals when they have not been included in trials.

Studies have found that adults with capacity and/or communication difficulties were often excluded from research in England and Wales (Jimoh et al. 2021) and were not catered for within set inclusion criteria (Bunning et al. 2022).

3.5 Role of the SLT

3.5.1 Contribution of the SLT

The SLT brings some specialist knowledge, skills and experience to the context of decision-making for people with SLCN.

Acting within the law

Everyone involved in lawful decision-making, professionals, those acting in supportive or advocacy roles, substitute decision-makers and legal advisors all

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need to have a good understanding of the legal framework that applies in their jurisdiction. There may be insecurities around enacting the legal provisions in context and anxiety to comply with the legal provisions, which makes training and support essential.

Culture

The person's cultural background and beliefs may affect the way they approach decision-making. UK mental capacity legislation and approaches to advance decision-making emphasise the concepts of autonomy and self-determination. In some cultures, there is more focus on decisions being made collectively by people's families and members of their community, rather than on an individual basis. Sometimes, people may prefer healthcare professionals to take the lead on healthcare decisions rather than make a decision for themselves. People may not want to consider certain healthcare decision options because they are not compatible with their religious beliefs. It is important not to make any assumptions or judgements about people's attitudes towards decision-making or the decision options they choose.

Inclusive communication

Skills in inclusive communication approaches will provide effective support for people with SLCN at the start of a decision-making process where there is the presumption of capacity. This will not only support their involvement in the process, but in some cases, enable them to demonstrate their mental capacity in the context of a particular decision.

LINK TO: INCLUSIVE COMMUNICATION

Multidisciplinary approach

The contribution made by different multidisciplinary team (MDT) members to these processes should be recognised; the SLT does not work in isolation. By understanding the expertise of others in the MDT, the skills of the SLT can be put to good use for more effective practice with service users, families, carers and colleagues.

Options

The assessor(s) need(s) to be clear about the decision options available to an individual and the potential consequences of choosing each option or of not

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choosing any option (Department of Constitutional Affairs, 2007; NICE guidance). The assessor(s) should also be able to provide the specific support an individual needs in order to maximise their decision-making ability (The Scottish Government, 2008).

Resources

The types of support for decision-making and the materials used should be compatible with and sensitive to the person at the centre of the decision-making with consideration of their:

- individual preferences or familiarity with particular types of support and materials (eg symbols set preference)
- cultural and linguistic background and arrangements for translators/interpreters as appropriate
- own communicative repertoire (skills, style and preferences) including any highly individual modes of expression.

SLTs can help identify the most appropriate types of support and materials, ensuring that these are tailored to the person's individual communication needs, abilities and preferences.

Skilful communication

Appropriate knowledge and skills are needed for the effective identification and support of individual needs to optimise the person's decision-making abilities. If professionals do not have the necessary knowledge and skills, they need to recruit specialist support from others – whether SLTs or other professionals, family members, carers and other people who know the individual and can provide guidance.

3.5.2 Shared knowledge and understanding

All parties involved in the decision-making process (eg family member, caregiver, SLT, other members of the MDT) need to have shared knowledge and understanding of the decision a service user is being asked to make. This includes information about any related options and their likely consequences, risks and benefits.

It is important for the SLT to consider the relevant place of their expertise in relation to the knowledge and skills of other members of the MDT. Depending on the nature of the decision, the SLT may lead a capacity assessment, support

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another colleague who leads the assessment, or carry out the assessment jointly.

3.5.3 Roles, processes and risks

For people involved in lawful decision-making with the person who has SLCN (eg health and social care professionals, family members, paid support staff, carers and advocates) and for those undertaking particular roles (eg substitute decision-maker, advisor), there are particular processes, risks and support needs.

Substitute decision-maker

People who have the responsibility for making decisions on behalf of others may not know how to support individuals with SLCN to express their wishes and preferences about decision options. For example, family members who are nominated attorneys or court-appointed deputies, or professionals and family members/carers involved in best interests decision-making may not know how to support people with SLCN to communicate what they would like to happen in a specific situation. Best interests

Family members who are nominated attorneys or court-appointed deputies, or professionals and family members/carers involved in best interests' decision-making, may not know how to support people with SLCN to communicate what they would like to happen in a specific situation. In addition, there is the potential for bias, suggestibility or coercion in the decision-making process where other agendas may be present.

Note. Involvement in substitute and best interests decision-making could be stressful for family members and other decision-makers causing them to feel a sense of guilt or burden (Murphy & Oliver, 2013).

Independent mental capacity advocate (IMCA)

Under the MCA (2005), an IMCA is a trained specialist to support people who lack capacity to make important decisions where there is no family member or friend available for consultation. The person with SLCN may be unable to instruct the IMCA about their wishes, bringing similar risks to those present in best interests decision-making (as above).

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Consultee advice (research only: England, Wales and Northern Ireland)

People who have responsibility for advising on the likely wishes and feelings of the person may neither have insight into the person's views and opinions about a particular proposition, or knowledge of how to involve them in the decision-making process. It may also be hard to separate their own views from those assumed to be the case for the person being supported (Heywood et al. 2019).

Provider organisations

Provider organisations are required to comply with the legal frameworks governing mental capacity and supported decision-making. Service users and their families or advocates may make legal challenges to the findings of mental capacity judgements if they perceive assessment processes to be inaccurate or inadequate. This could affect the provider's standing in the community and its business. For example, regulatory bodies (eg the Care Quality Commission) examine the quality of mental capacity assessment processes during their inspections.

MDT

The SLT's expert knowledge and skills in communication assessment and facilitation may not be recognised or understood (Jayes et al. 2020; 2021; McCormick et al, 2017) or indeed identified as a service priority compared to swallowing disorders (Jayes et al. 2016; 2021). This would be to the detriment of the person requiring support and the SLT professional role in the multidisciplinary team. It is important to promote the SLT role in mental capacity assessments and in support for decision-making processes for people with SLCN. Access to training and supervisory support are essential to ensure competence in mental capacity assessments and decision-making procedures.

3.5.4 Optimising conditions

In order that people with SLCN have the chance to express their views and opinions and to use their capacity for decision-making, specialist input from an SLT may be needed.

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SLTs have different roles with regard to support for decision-making, advance care planning, mental capacity assessment, best interests decision-making (MCA, 2005 – England and Wales) and decision-making on behalf of the person if least restrictive option and of benefit to the person (AwIA, Scotland, 2000). The role may vary according to the clinical context, service user group and host organisation. SLTs working with people with mental health conditions and dementia in England have proposed key roles that SLTs can play in capacity assessment (Borrett & Gould, 2020; Devereux et al, 2016).

SLTs can support in decision-making by:

- assessing SLCN
- assessing capacity
- being involved in lawful decision-making processes
- providing expert support and advice

SLCN assessment

SLTs can carry out an in-depth assessment of a person's communication skills. This might include the person's ability to communicate at the current time and also in the future with reference to their ability to understand, retain and recall information, to weigh up different options and their implications, and to express a decision.

Capacity assessment

Capacity assessment refers to a process that determines whether an individual has the ability or mental capacity to make a specific, informed decision at the time it is needed. The laws covering mental capacity assessment in each UK nation are slightly different but include similar principles and tests of capacity.

SLTs either lead assessments or contribute to MDT assessments of people with SLCN. The UK legal frameworks for mental capacity apply to all professionals; anyone can carry out an assessment of capacity. However, guidance is provided as to who should be the primary decision-maker responsible for the assessment. NICE clinical guidelines identify SLTs as a profession who can provide specialist input during the mental capacity assessment (NICE: 1.1.27,2018).

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Involvement in lawful decision-making processes

The information below is adapted from Devereux and Psychiatry of Old Age Clinical Excellence Network, RCSLT 2016.

ADVANCE CARE PLANNING

Sometimes known as an 'Advance Decision to Refuse Treatment' (ADRT) or 'living will', advance care planning is a decision that can be taken now to refuse a specific type of treatment at some time in the future. Whilst not legally binding in the same way, a person with SLCN can be supported to record their preferences about future care and treatment. SLTs can support and facilitate communication with service users who have SLCN and/or swallowing disorders in decision-making processes. A further role might be in confirming that an individual with SLCN has capacity to make an ADRT, which is a legal requirement for validity.

BEST INTERESTS

Best interests is a process that involves the person at the centre of the decision-making and others connected to them. Best interests is followed after a mental capacity assessment has demonstrated that the person lacks capacity to make the decision for themselves. SLTs can enact different roles according to the nature and circumstances of the decision including advocacy for service users in certain circumstances or communication coordinator between professionals and service users.

Expert support

SLTs can provide tailored support to enable people with SLCN to either demonstrate their capacity for decision-making or express their wishes and preferences when they lack capacity for decision-making.

Expert advice

SLTs can also provide advice and training on how to support someone with SLCN so they can exercise their own capacity or participate in a decision-making process.

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Case scenario: Harriet contributes to best interests

Harriet is a young woman with severe learning disability who uses AAC. She had been placed in supported living following college and the placement broke down. Her social worker was looking for a new placement and wanted Harriet's views but Harriet had stopped communicating with people. The social worker had already carried out a capacity assessment and determined that Harriet did not have capacity.

Harriet had previously used Talking Mats successfully to give her opinion. The SLT worked with Harriet's previous teacher to prepare and then complete a couple of Talking Mats with Harriet to get her opinions. This fed into the best interest decision about where Harriet would be placed next.

[MCA, 2005; Code of Practice, 2007]

3.5.5 Roles in decision-making

There are typically a number of people involved in a decision-making process.

Decision-maker

The decision-maker is the person who ultimately works out what is in the individual's best interests and should be the person who will carry out any actions arising from the best interests decision. Sometimes, the decision will relate directly to a communication or eating, drinking and swallowing (EDS) difficulty or a speech & language therapy intervention.

- The decision may involve selecting the most appropriate option for an alternative communication method to be used by a person who is unable to use speech. The SLT may be the person who is most knowledgeable about the available options and their match to the abilities and needs of the person. Formal assessment by a multi-disciplinary team of the person's specific cognitive, motor, vision and hearing abilities, and psycho-social needs in context informs best interests decision-making. the service user is encouraged and supported to contribute to the decision-making process.
- For EDS, the key decision-maker will vary between the medical consultant with responsibility for the overall health of the person and the SLT with support of the MDT depending on the level of risk of physical harm and rationale for accepting risk. Please see revised guidance on complex dysphagia decision making (previously EDAR guidance).

[Add link to complex dysphagia management guidance]

- The decision maker documents the decision to be made and the underpinning process. They should always work collaboratively with other members of the multidisciplinary team during mental capacity assessment and best interests' decision-making processes.

Advocate

If a mental capacity assessment finds that a person with SLCN lacks capacity to make a decision, an SLT could be an advocate, or alternately support a mental capacity advocate when a decision is made in their best interests.

Being an advocate involves the SLT eliciting the person's preferences and views about different decision options using a range of inclusive communication strategies and techniques. This information can then be shared with people making the best interests decision (eg professionals, family members, carers, attorneys, deputies or guardians).

Educator or trainer

SLTs may educate professionals, service users and their families and carers about the types of support people with SLCN may require to make decisions and demonstrate their mental capacity.

SLTs can also use their specialist skills to train other people to use inclusive communication approaches to support people with SLCN when they make everyday decisions or during mental capacity assessments.

They may help multidisciplinary colleagues to improve the quality of their capacity assessments.

They may also train attorneys, deputies and guardians to use the same approaches with people who no longer have capacity to make specific decisions but who need support to express their preferences and wishes about decisions.

Communication expert

SLTs may use knowledge and skills to carry out accurate assessments of service users' communication skills. It is especially important to collect information about the reliability of an individual's:

- yes and no responses

- preferred modes of expression including any highly personalised styles of communication
- level of understanding
- preferred supports and adjustments.

This will enable identification of communication supports required by service users to support decision-making. By drawing on expert knowledge and skills, valid judgements about a service user's different decision-making abilities (eg the ability to understand information related to a decision) may inform a judgement about their mental capacity.

In Scotland, there is a requirement that anyone who is assessed as needing a communication support, low or high tech device, or voice banking has a legal right to this (amendment to the Health (Tobacco, Nicotine etc. and Care) (Scotland) Act (2016) Part 4).

PLACEHOLDER

Case examples of SLT enacting different roles with people who have SLCN

3.6 Resources

- The Law & Ethics (MCA, 2005- England & Wales; research provisions), ASSENT Guidance (Bunning et al. 2022)
- Consult training, Consult (Shepherd, V.)
- Capacity and Consent to Research Resources, Consult (Shepherd, V.)
- Mental Capacity (England and Wales) Act Code of Practice, Dept. for Constitutional Affairs (2007)
- Decision: An ethical decision-making Framework for Allied Health Professions in Northern Ireland, Dept. of Health (N. Ireland) (2025)
- Mental Capacity (England and Wales) Act 2005, Dept. of Health (2005)
- Making decisions: the Mental Capacity Advocate service, Dept. of Health and Social Care (update 26 June 2025)
- Mental Capacity Resource Centre, Essex Chambers
- Decision-making and Mental Capacity (2018), National Institute for Clinical Excellence (NICE)
- Mental Capacity (Northern Ireland) Act 2016, Northern Ireland Government

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- Mental Capacity Act (Northern Ireland) 2016: Codes of Practice, Northern Ireland Government (2016-19)
- Adults with Incapacity (Scotland) Act 2000, Scottish Government (2000)
- Adults with Incapacity (Scotland) Act (2000) Codes of Practice, Scottish Government (2011)
- Mental Capacity Act (2005) at a glance, Social Care institute for Excellence
- Convention on the Rights of Persons with Disabilities, United Nations (2006)

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4. Assessment of capacity

4.1 Principles of assessment

4.1.1 Preparation

If SLCN are identified, it is important to plan how to provide support during a capacity assessment. Support should be tailored to meet individual needs. It is beneficial to plan how to do this in collaboration with relevant colleagues (eg occupational therapist, psychologist or mental health professional) and people who know the person being assessed well (eg a family member or carer).

People with SLCN are likely to need communication support from SLTs during capacity assessments. This will usually involve SLTs carrying out a communication assessment in order to establish what types of support are likely to be most effective, acceptable and easy for the person to use (see Borrett & Gould, 2021).

Inclusive communication approaches can be used during capacity assessments to help the person being assessed to access decision information and express her/his thoughts and choices more easily and effectively.

Some tools and resources have been developed to support more consistent practice and improved legal compliance in mental capacity assessments for people with SLCN with/without cognitive impairment.

Mental capacity assessment support tool (MCAST)

The MCAST was developed as a toolkit to support the needs of individuals with aphasia after stroke or those with chronic cognitive impairment during mental capacity assessments (Jayes, 2017; Jayes et al. 2022). It is designed to facilitate practice that complies with legal frameworks in England and Wales whilst optimising 'patient autonomy, safety and well-being'. It has proven validity, reliability and fidelity for use with stroke survivors (Jayes et al. 2026).

Web-based mental capacity assessment tool (MCA WAT)

The MCA WAT was developed for people with learning disabilities (Dodd et al. 2023) in England. The purpose was to introduce contemporaneous recording capacity assessments whilst helping to improve staff knowledge and confidence in this area. The tool was found to be largely effective, although the selection and use of communication aids was variable.

Web-based ASSENT guidance

The web-based ASSENT guidance focuses on adults who may lack capacity and have communication difficulties in the context of the research provisions of the MCA (2005) for England and Wales. Evidence-based and supported by coproduction processes, the guidance contains specific domains on 'capacity and decision-making' and 'adjustments and supports' (Bunning et al. 2022).

Supporting adults with communication impairment

The 'Supporting adults with communication impairment' pack is designed for use supporting adults with communication impairment and facilitating decisions, particularly in health settings. The pack can be used to conduct a capacity assessment under the Mental Capacity Act (2005).

4.1.2 Common principles

Different legislation governs how mental capacity is addressed in England and Wales (Mental Capacity Act, 2005), Scotland (Adults with Incapacity (Scotland) Act 2000), and Northern Ireland (Mental Capacity Act (Northern Ireland) 2016). However, some common principles exist that serve to guide practice when assessing mental capacity.

16 years and over

The legislation applies to people aged 16 and above.

Assumption of capacity

A person is assumed to have mental capacity unless proven otherwise through carrying out a prescribed test.

Decision and time-specific

The assessment is for a particular decision at a particular time and a person's capacity may vary from decision to decision and over time.

Prescribed test

The test of capacity focuses on the ability to: understand all relevant information about a decision; remember this information; weigh up and use this information; communicate the decision.

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All practicable support

All practicable support is given to help the person optimise their communicative and cognitive abilities, emotional wellbeing and mental health functioning.

Outcome

The outcome of the assessment is categorical – either a person has capacity or they do not.

Based on assessment outcomes only

Any judgement about a person's capacity is based on the assessment findings. It is not based on their appearance, behaviour, diagnosis or the decision option they wish to choose.

4.1.3 Criteria for assessing capacity

The legal criteria for assessing a person's capacity to make a particular decision vary across the UK nations, as outlined below. In all cases, capacity is presumed unless there is evidence to establish otherwise, and the responsibility for establishing a lack of capacity rests with the assessor.

Understanding for the decision (all UK)

The person must understand information that is most relevant to the decision: Case Law: Heart of England NHS Foundation Trust and JB 2014) *"A broad general understanding of the kind that is expected from the population at large"*. This includes the reasonably foreseeable consequences of deciding one way or another or failing to make the decision.

"Remembering information

ENGLAND, WALES AND NORTHERN IRELAND

The person must retain the information for as long as it takes to make the decision (this may only be for a short period).

SCOTLAND

The person must retain the information relevant to the decision long enough to be able to make the decision and act on it.

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Using the information to make a decision

ENGLAND AND WALES

The person must use and weigh the information in order to make a decision.

SCOTLAND

The person must use or weigh the information in order to make a decision and act on it.

NORTHERN IRELAND

The person must use and weigh the information and appreciate its relevance to their own situation.

Expressing the decision (all UK)

The person must communicate a decision using any means.

4.1.4 Types of decision

Capacity legislation applies to a wide range of decisions (eg which treatment to consider, where to live, what sort of care to receive at home, whether to take part in research or not).

The significance or meaning of a decision and its implications will vary from person to person and over time.

There are occasions where SLTs may be asked to consider a person's capacity outside of the local legal framework (eg capacity to consent to marriage/sexual relations and testamentary capacity). In these cases, SLTs should always seek clarification from the professional asking them to complete a capacity assessment or the multidisciplinary team about the specific legal test to be used and any associated case law.

4.1.5 Assessment of capacity to consent/refuse

The legal criteria for assessing a person's capacity to consent to or refuse treatment vary across the UK nations, as outlined below.

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England and Wales

The assessment is specific to the decision being made and considers whether the person is able to:

- understand the information relevant to the decision
- retain that information
- use and weigh the relevant information as part of the decision-making process
- communicate their decision.

Where the person is unable to do one or more of the above, the functional inability must be because of an impairment or disturbance in the functioning of their mind or brain. The causal link between the impairment or disturbance and the person's inability to make the decision should be recorded.

Scotland

The assessment is specific to the decision being made and considers whether a person is capable of:

- acting
- making decisions
- communicating decisions
- understanding decisions
- retaining the memory of decisions

A person must not be considered incapable solely because of a communication difficulty if that difficulty can be overcome by communication support or augmentative and alternative communication (AAC) methods.)

An amendment to the Health (Tobacco, Nicotine etc. and Care) (Scotland) Act (2016) Part 4 entitles people with SLCN to be provided with communication equipment and support.

Northern Ireland

For treatment decisions governed by common law, the assessment is specific to the decision and time it is made.

The assessment considers whether person has an impairment or disturbance of mental functioning and, if so, whether this impairment or disturbance interferes with their ability to:

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- comprehend and retain the material information, especially the likely consequences of having or not having the treatment in question
- use the information and weigh it in the balance as part of the process of arriving at the decision
- communicate that decision.

4.2 Assessment considerations

The process of capacity assessment can be broken down into three stages: functional test; diagnostic test; and causative nexus.

4.2.1 Stage 1 – functional test

To prove lack of capacity, each legal framework of the four nations requires the assessor to demonstrate that a person is incapable of making the specific decision in question at that given time due to a condition that affects the functioning of their mind or brain. This corresponds to stage 1 – functional test.

All the legal frameworks require the assessor to assess the person's ability to:

- understand information relevant to the decision
- retain that information
- use and/or weigh that information to make a decision
- communicate their decision or preferred option.

If the person cannot do one or more of these things, the assessor must conclude that they are unable to make an informed decision. Note that it is not the responsibility of the person being assessed to prove that they have capacity to make a decision; it is the assessor's responsibility to provide evidence that the person lacks capacity to make the decision.

Assessors need to ensure the person being assessed is given the support and education they need to optimise their decision-making abilities. This could mean support to:

- enhance cognitive and communicative (including sensory) abilities
- address emotional and mental health needs
- address their understanding about a particular decision, course of action and any possible risks and consequences.

It is important that any support requirements are identified before the capacity assessment takes place. This could be achieved by:

- an SLT carrying out an assessment of the person's functional speech, language and communication skills (both comprehension and expression)
- seeking information from the person's care record
- reviewing a communication passport
- talking to multidisciplinary colleagues or the person's family or carers.

Different factors may affect a person's mental capacity. For example, it can vary over time due to changes including physical and psychological health, medication, energy/fatigue levels and personal circumstances. If you suspect that a person's capacity may fluctuate, it is important to plan to carry out the functional test at a time when the person's decision-making abilities are likely to be at their best.

This may not be possible, for example if a decision needs to be taken immediately. In this situation, it might be beneficial to reassess the person's mental capacity. In this situation, you should take the minimum action necessary and avoid any irreversible decisions if possible and then reassess mental capacity at a later time.

Temporary health conditions

When it is thought that a person may recover from a temporary health condition, the capacity assessment should be delayed, if possible, until a time when the person's condition has improved. This is to give the person the best chance of demonstrating their mental capacity.

Sometimes a capacity assessment cannot be delayed because a decision needs to be made immediately. However, if a decision is not required urgently, assessment can be revisited at a later date when the person's condition has improved. This is because the assessment may have a different outcome at a different time.

4.2.2 Stage 2 – diagnostic test

As highlighted in the previous section, there are some differences in the way the diagnostic test (stage 2) operates across the legal provisions of England and Wales, Scotland and Northern Ireland.

In all cases, the assessor needs to identify that the person has a health condition that affects the way their mind or brain works. This condition can be temporary

or chronic/permanent and can include conditions that affect communication skills.

Note: There does not necessarily need to be an established diagnosis; a reasonable belief that there is an impairment or disturbance is sufficient.

Examples of temporary conditions include changes in functioning due to substance use disorder, medication, delirium, post-traumatic amnesia or changes in mental health. Examples of chronic conditions include learning or intellectual disability, mental health conditions, stroke, brain injury and progressive neurological conditions such as dementia.

4.2.3 Stage 3 – causative nexus

The phrase 'causative nexus' refers to the direct, logical link proving that a person's inability to make a particular decision is caused by an impairment or disturbance of the mind or brain. It links the outcomes from stage 1 to stage 2.

Simply identifying that a person has a particular condition such as Alzheimer's disease or autistic spectrum disorder is not sufficient to establish whether they have capacity or not.

Case Law Example: PC & NC v City of York Council [2013] EWCA Civ 478.

This case clarified the causative nexus requirement under section 2(1) on the MCA (2005). It established that an inability to make a decision must result from a mental impairment rather than merely relating to it. **Essex Chambers (2014): https://www.39essex.com/our-thinking/cases/ncc-v-pb-tb/**

4.2.4 Recording outcomes

It's very important that assessments are recorded comprehensively and clearly. The documentation doesn't need to be typed but it should be completed at the time, be legible and be signed.

Check the code of practice for the mental capacity law that operates in the nation where you work for full guidance on how to record assessments. You should also follow local guidance and policy about what to include.

The NICE guideline NG108 in England provides specific guidance on documents relevant to the assessment of mental capacity and the list below gives some suggestion of items you might wish to record, although separate provisions for research may be used.

Possible items to record

Person present: Who was present during the assessment and what were their roles?

- The decision: What was the decision the person was asked to make?
- Support: What support was provided to help the person understand the information about the decision? If appropriate support was identified but was not practical or appropriate to provide, what was the reason?
- Information: What information about the decision was provided to the person?
- Functional: How were the person's abilities underpinning their decision-making capacity assessed?
- Evidence: What evidence was collected relating to the person's ability to understand, retain and weigh information about the decision and communicate their decision?
- Diagnosis: What evidence was gathered relating to the presence/absence of an impairment or disturbance of the mind or brain and, if present, whether it was temporary or permanent?
- Causative Nexus: What evidence was there that the person's functional ability was explained by an impairment or disturbance of the brain or mind?
- Response: How did the person communicate during the assessment in order to demonstrate their decision-making abilities and decision choice (eg by using words or gestures or by pointing to written words or images)?
- Outcomes: What were the outcomes of the assessment? Where the person lacked one or more decision-making abilities, how did they relate to an impairment or disturbance of the mind or brain?
- Conclusion: What was the assessor's conclusion about the person's capacity?
- Capacity: If the person was judged to have capacity, what decision did s/he make?
- Lack of Capacity: If the person was judged to lack capacity, were they able to indicate a preference for a particular decision option?
- Management plan: Based on the outcomes and conclusion and the legal provisions detailed, what was the recommended procedure (eg best

interests process; refer to an advanced decision; consult a nominated attorney; deputy or guardian to review capacity at a later date)?

Evidence suggests that mental capacity assessors find it helpful to use appropriate documentation tools to record their assessments. The organisation you work for may have developed its own resource that you could use based on the legal framework for your nation.

Further information on the assessment of capacity is available in 'Assessing and Determining Mental Capacity' from Essex Chambers.

4.2.5 Challenges and facilitators

Challenges

Carrying out assessments of capacity within the relevant law has been described as multi-faceted and invariably complex (Stokes et al. 2025). Some of the challenges of the mental capacity assessment process are outlined below.

COMPLEXITY

The complexity of assessing a person's capacity has been acknowledged (Cliff & McGraw, 2016; Jayes et al. 2021; 2022a & b). Particular settings and situations may add to process complexity. For example, Cliff & McGraw (2016) identified the need to manage external influences around family involvement in a home care setting. The effects of ethical, emotional, relational and contextual factors were an identified consideration for research decision-making in palliative care (Barry et al. 2026).

INSECURE UNDERSTANDING

Variable knowledge and understanding about the legal basis of decision-making, whether for the purposes of research or health and social care, has been reported amongst people (eg family members, carers, health and social care professionals including SLTs, researchers, research ethics committee members) involved in capacity assessments and decision-making processes (Borrett & Gould, 2021; Dodd et al. 2023; Killett et al. 2024; McKay & McCusker, 2024; Redley et al. 2025; Shepherd et al. 2018). The problem of monitoring staff knowledge of legal frameworks was viewed as impacting implementation negatively (Stokes et al. 2025).

VARIABLE PRACTICE

Support for SLCN is highly variable (Lislerud et al. 2013) with some practice incompatible with legal requirements (Jayes & Palmer, 2017; Sorinmade et al. 2011). Webb et al (2020) found that the four components of the functional mental capacity assessment were not usually identified by respondents when reviewing mental capacity assessment procedures. Further comment suggests that some sub-sections of the population are held to a higher standard regarding mental capacity than the generally population (see Judged to a higher standard – Changing Our Lives).

ACCESS TO TRAINING

Perceived lack of knowledge, skills and access to training – on implementing decision-making according to the law have been reported (Jayes et al. 2022b; Jayes et al. 2021; Stokes et al. 2025).

TIME AND RESOURCES

A lack of time and limited range of material resources for presenting decision-relevant information have also been identified (Borrett & Gould, 2021; Bunning et al. 2022; Jayes et al. 2021; 2023; Jayes & Palmer 2017; Stokes et al. 2025).

CONFLICTING VIEWPOINTS

Disagreements sometimes occur between individuals involved in a decision-making process with opposing views on an individual's capacity (Borrett & Gould, 2021; Cliff & McGraw, 2016).

SLT EXPERTISE

Expert knowledge of SLCN and the communication process underscores the relevance of speech and language therapy to both the assessment of capacity and the decision-making process itself. SLTs may occupy a variety of roles, eg supporter, advocate or decision-maker, although their role is often not recognised or deployed (McCormick et al. 2017). That said, a lack of knowledge and confidence in SLTs has also been observed (Borrett & Gould, 2021). Further factors affecting the involvement of SLTs are access to speech and language therapy (Jayes et al. 2022) and the need for training on capacity assessment within the relevant legal frameworks (Stokes et al. 2025).

Facilitators and recommendations

For people with SLCN (with/without cognitive impairment) the aim is to ensure the provision of fair, equitable and suitably-adjusted opportunities. This is so they can use whatever capacity and communicative abilities they possess for decision-making. To this end, the following facilitators are identified as evidence-based recommendations.

TRAINING

- service development through staff training on all aspects of the functional test (Shepherd et al. 2018; Webb et al. 2020)
- in-person training using real-life examples (Stokes at al. 2025), information sharing, skills modelling and reflection (Pillen et al. 2025)
- training alongside ongoing support to achieve a balance between substitute decision-making and personal values and emotional burden (Barry et al. 2026)
- training in legal and conceptual aspects of mental capacity (Borrett & Gould, 2021).

SUPPORT AND RESOURCES

- support and practical resources available to staff working closely with people with SLCN (Jayes & Palmer, 2017; Jayes et al. 2021)
- availability and use of a toolkit to aid assessment of capacity (Dodd et al. 2023; Jayes et al, 2022b)
- development and use of structured, evidence-based guidance for navigating the legal framework (Ryan et al. 2021)
- clear and accessible information about safeguarding for staff and carers of people living with dementia (Dixon et al. 2022)
- timely advice to carers and people with dementia around everyday decision-making – cognisant to change in abilities over time (Kritika & Manthorpe, 2013)
- strategic adaptations and accommodations during the research recruitment process, which may serve to support the inclusion of people with SLCN (Jimoh et al. 2022).

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PERSON-CENTRED CARE

- respect for person-centred care that maintains the person at the centre of the process (Stokes at al. 2025).

BEST PRACTICE

- a regionally-agreed approach to best interests decision-making processes in Northern Ireland (McIlroy et al. 2026)
- organisational policies and processes in care settings that address any gaps in practice (Stokes at al. 2025; Webb et al. 2020)
- capture of what constitutes best practice in implementation of mental capacity legislation in care settings (Stokes et al. 2025).

MULTIDISCIPLINARY APPROACH

- close collaborative teams where speech and language therapy is valued (Borrett & Gould, 2021)
- different disciplines working together as a team (Cliff & McGraw, 2016).

RELATIONSHIP DEVELOPMENT

- development of a trusting relationship with the person and relevant family member(s) (Boahen, 2015; Borrett & Gould, 2021; Dixon et al. 2022)
- managing and utilising the influence of the family (Cliff & McGraw, 2016).

4.2.6 Complex capacity

Some people present particular challenges to the process of capacity assessment, which may be associated with conditions of executive dysfunction, fluctuating capacity and limited engagement in assessment. Below are descriptive summaries of conditions, challenges and risks along with recommended approaches to carrying out mental capacity assessment in such cases.

Executive dysfunction

Executive dysfunction is cognitive impairment that affects processing necessary for initiating, planning, sequencing, inhibiting responses, managing impulses, adapting to changing circumstances and online awareness (CoPBA 2026).

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It is also referred to as frontal lobe paradox/knowing-doing dissociation and is typically caused by frontal/pre-frontal cortical involvement.

It affects the ability to think about behaviour in real time and to pause and reflect before acting on impulse (Owen et al. 2017).

Note: Impulsiveness and a lack of insight do not equal incapacity but their impact on decision-making needs to be considered (Curtice & Moltu, 2026; Whiting et al., 2020; CL: *Warrington Borough Council v Y & Ors 2023).*

Timely recognition of difficulties may be a problem due to masking that occurs in some environments where there is a high level of support or controlled conditions (eg clinical setting) (Marram, 2026).

There is also a risk of overestimation of capacity (see Moore et al., 2019) as language and verbal reasoning skills are frequently superior to adaptive functioning and insight (George & Gilbert, 2018).

Assessment should incorporate collateral information and behavioural evidence into judgments of how the person 'uses' the information as part of the process of making a decision under the MCA 2005 and MCA(NI) 2016 and 'acts on' their decision under the AWIA (2000).

The 3D Capacity Assessment Model captures a holistic, multi-dimensional framework used in clinical and legal settings to gather this evidence through three complementary methods: conversations with the person, conversations with familiar others, and real-world observation.

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CONVERSATIONS WITH THE PERSON

Conversations with the person can be used to explore the person's awareness of and explanation for the difference between what they say they will do and what they actually do (knowing-doing dissociation).

CONVERSATIONS WITH FAMILIAR OTHERS

Conversations with familiar others can provide evidence of mismatch between the person's self-report and other people's reports and cross-referencing.

See example; [CL: DY, Re (Capacity, 2024] EWCOP 4; DY, Re (Capacity) [2024] EWCOP 4 (30 January 2024).

REAL-WORLD OBSERVATION

Real-world observation can provide evidence of how a person functions within real-world environments and situations in which actions did not match what they said they could do or would do. Observation may need to be repeated over an extended period of time to collect sufficient evidence (Essex Chambers, 2025; NMCF webinar link 2023).

Fluctuating capacity

Fluctuating capacity (or changing capacity in a decision-making process) is associated with variations in cognitive or mental state during the day, or between days and weeks.

It can occur in many conditions and contexts including dementia, bipolar disorder, substance use disorder, anxiety, emotionally unstable personality disorder and autistic spectrum disorders.

Failure to recognise fluctuating capacity can have serious consequences. For example, a person may be wrongly assessed as having or lacking capacity to refuse a proposed treatment and then experience serious harm or die, or they may receive treatment to which they did not consent, which breaches their human rights, thereby placing the professional at risk of liability (39 Essex Chambers, 2025).

There is no one approach that is best. Options include:

- one-off decisions
- macro decisions
- anticipatory declarations
- contemporaneous assessment.

Recommended practice depends on the person's presentation and how their decision-making manifests. **Case Law Example: *LA v PG & Ors 2023***; A Local Authority v PG & Ors [2023] EWCOP 9 (10 March 2023)] No one approach is best, rather it depends on the presentation of the person and how their decision-making manifests. All approaches require documentation to contain a detailed explanation of how the professional reached their view about capacity.

All approaches require documentation to contain a detailed explanation of how the professional reached their view about capacity.

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Advice should be sought from local Mental Capacity leads where they exist (eg in England and Wales) regarding the most appropriate approach, particularly where there is significant risk involved with the outcome of any capacity assessment.

ONE-OFF DECISIONS

- If the decision can wait until the person's decision-making ability has improved, then capacity assessment should be delayed.
- If it is not possible to delay the decision due to clinical urgency, the person should be assessed with optimum support to give them the best chance of being able to make the decision.
- If the person is assessed to have capacity to make the decision, the assessor should record clearly why they thought this in case it is challenged in the future. They should also ask the person what they would want to happen in the event that they lost capacity in the future for making similar decisions.
- If the person is assessed to lack capacity, the decision-maker should take the minimum necessary steps, avoiding any irreversible decisions where possible, and revisit the capacity assessment when their presentation improves.

Essex Chambers (2025). Available at: https://www.39essex.com/our-thinking/mental-capacity-resource-centre/

MACRO DECISIONS OR THE LONGITUDINAL VIEW

Some situations involve repeated smaller decisions that form part of one overall 'macro' decision. These decisions take place not at any one singular point in time but over a longer time period and may take into account unforeseen demands. Examples include managing financial affairs or a health condition such as diabetes, or dysphagia management, which involves multiple choices in a day such as what food and drink to choose, how to prepare it, whether to accept recommended support or environmental adaptations, what eating behaviours to engage in and whether to take other aspiration-reducing measures.

This approach involves determining the frequency of capacity fluctuations in relation to the decision. If the person only presents with having capacity for limited times of the day or week it can be appropriate to conclude that they lack

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capacity to make the decision overall, especially if there is risk of significant harm. The situation should be reviewed regularly.

CASE LAW EXAMPLE: CHESHIRE WEST & CHESTER COUNCIL V PWK 2019; EWCOP 57

In this case, PWK had been assessed as having fluctuating capacity around his finances secondary to anxiety. The judge ruled that because managing his finances was a continual decision, the anxiety was unpredictable and its impact was very serious, he could be said to lack capacity to manage finances.

CASE LAW EXAMPLE: ROYAL BOROUGH OF GREENWICH V CDM (REV 1) [2019] EWCOP 32 (20 FEBRUARY 2019)

P had been assessed as having fluctuating capacity around diabetes management secondary to emotional dysregulation from her personality disorder. The judge ruled that because managing diabetes involves repeated micro-decisions that make up an overall macro-decision, even if she could at times makes certain micro-decisions she still lacked capacity to make the macro-decision.

CASE LAW EXAMPLE: CALDERDALE METROPOLITAN BOROUGH COUNCIL V LS & ANOR [2025] EWCOP 10 (T3)

LS had been assessed as having fluctuating capacity in multiple areas secondary to mild intellectual disability. The judge ruled that because she would face continuous unpredictable demands on her decision-making and would become easily overwhelmed by her decision-making impairments, it was appropriate to take a longitudinal view and declare her to lack capacity for residence and care. He noted that it should be routinely considered whether she may regain capacity to make these decisions.

ANTICIPATORY DECLARATIONS

With regular loss of capacity that is very likely to occur in defined circumstances, the court can make an anticipatory declaration that a person loses capacity in these circumstances and determine which actions would be in their best interests in that case.

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CASE LAW EXAMPLE: GUYS AND ST THOMAS NHS FOUNDATION TRUST (GSTT) & ANOR V R [2020] EWCOP 4 (29 JANUARY 2020)

R experienced psychotic episodes associated with bipolar affective disorder and was heavily pregnant. She currently had capacity to make decisions about her obstetric care but there was a substantial and likely risk that she would lose capacity during labour and require a caesarean section. The judge ruled that in the event that she lost capacity during labour, it would be in her best interests for the care plan put before the court to be delivered to her.

CASE LAW EXAMPLE: OLDHAM METROPOLITAN BOROUGH COUNCIL V KZ & ORS [2024] EWCOP 72 (T3)

KZ was assessed as having fluctuating capacity in multiple areas secondary to frequent dysregulation in the context of language deprivation. The judge ruled that because the evidence demonstrated that staff could clearly determine the periods when he was dysregulated and therefore had lost capacity, it was appropriate to make anticipatory declarations about a care plan for steps to take to protect him during these periods, rather than a longitudinal declaration that would treat him as never being able to make these decisions for himself.

CONTEMPORANEOUS ASSESSMENT

Where loss of capacity is not guaranteed to occur under sufficiently predictable conditions, anticipatory declarations may not be appropriate.

In this case, assessment should be at the point in time that the care and treatment is needed and the professional should act according to their reasonable belief about the person's capacity in that moment.

Protection from liability depends on evidencing the professional's reasonable belief that the person lacked capacity at that point in time and their reasonable belief that it was in the person's best interests to take the actions they did.

Collaboration with the person is needed to record their advance wishes about what they would like to happen in instances where they lose the required capacity. This gives professionals additional reassurance that they are making best interests decisions with the person's wishes at the centre.

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CASE LAW EXAMPLE: LEICESTERSHIRE COUNTY COUNCIL V P & ANOR (CAPACITY: ANTICIPATORY DECLARATION) - FIND CASE LAW - THE NATIONAL ARCHIVES [2024] EWCOP 53

P was assessed as having fluctuating capacity around care and contact, secondary to dissociative episodes. The judge ruled that anticipatory declarations were not appropriate because the loss of capacity happened relatively infrequently and because there was considerable uncertainty about how to establish that she had dissociated to the extent that she would lose capacity. Instead, carers should complete a contemporaneous assessment that could include up-to-date information about her wishes. P was able to make clear that she wished to be protected from risk, so her care team were able to make a care plan with her agreement about what she wished to happen to protect her when she lost capacity.

CASE LAW EXAMPLE: DARLINGTON BOROUGH COUNCIL V AW & ORS [2025] EWCOP 33 (T3) (01 AUGUST 2025)

AW was assessed as having fluctuating capacity in multiple areas secondary to post traumatic stress disorder and autistic spectrum disorder. The judge ruled that because the evidence was not able to clearly set out the circumstances in which AW would lose capacity and best interests decisions would be needed, it was not appropriate to make anticipatory declarations. Instead, the team should make contemporaneous assessments of capacity.

Refusal of assessment

When a person refuses to take part in a capacity assessment, professionals should consider whether the refusal is attributable to personal choice or other factors. These may include:

- personal denial that there is any reason for their capacity to be assessed
- general refusal to engage with professionals, such as not attending appointments or allowing professionals over the threshold into their home
- lack of engagement because an impairment is preventing the person from understanding the need to engage in assessment
- lack of engagement due to influence of another person's actions, ie coercive control.

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If a person refuses to take part in a capacity assessment, there are a number of considerations and possible approaches.

Is the person unwilling to engage?

A person may be unwilling because they are reluctant to answer certain questions, do not have a trusting relationship with staff, or are embarrassed.

- Consider whether they can be given more choice to help them feel more in control, such as by offering to have a person of their choice present.
- Explain why you want to assess the person's decision-making and why it is important to do so.

Note that threats or attempts to force the person to engage are not acceptable and nobody can be forced to undergo an assessment of capacity. Legal advice is needed in both of these situations, not just where the person was unable to engage due to incapacity.

Does the person not understand the need to engage?

Sufficient evidence is needed from collateral sources and observations that the person's incapacity is what is preventing them from understanding the need to engage in assessment. In such cases, the assessment can proceed in the person's best interests with relevant supports in place.

If the person objects clearly and there is considerable distress, an assessment should not continue. In such cases, seek advice from your local Mental Capacity Assessment team as legal advice may be required to consider an application to the Court of Protection to determine whether the person lacks capacity to make the required decision.

Is the person unable to engage because of the influence of another person?

If there is a concern about someone else's influence, advice should be sought via the local safeguarding pathways and mental capacity lead.

Appropriate legal routes such as adult protection support orders in Wales, orders from the Court of Protection to allow access to the person, or the inherent jurisdiction of the High Courts should be considered.

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Mental Health Act (MHA) and Mental Capacity Act (MCA) interface

How the Mental Health Act (MHA, 1983) applies for people with supported communication needs is beyond the scope of the current guidance. However, situations may arise that require specific consideration of how mental capacity legislation interacts with the MHA (1983).

TREATMENT WITHOUT CONSENT

Under the powers of the MHA (1983), a patient can be given care and treatment for a mental disorder without their consent whilst detained under Section 2 or Section 3. The decision to provide this treatment with or without the detained patient's consent cannot be overruled by a lasting power of attorney or advance decision to refuse treatment. This includes treatment "the purpose of which is to alleviate, or prevent worsening of, the disorder or one or more of its symptoms or manifestations" (MHA, 2003 – amendment, 2007) and therefore can include the provision of certain speech and language therapy interventions.

ONGOING PHYSICAL NEEDS WHILST UNDER DETENTION

Co-occurring physical health needs should be managed under the MCA (2005). People can sometimes be given physical health treatment under Section 63 of the MHA if the symptoms being treated are a direct manifestation of the mental disorder. Decisions about Section 63 must be made by the Psychiatrist who is the Responsible Clinician, and advice should be sought from local Mental Health Act teams if needed.

4.3 Lack of capacity and lawful procedure

4.3.1 Lack of capacity

For people with an assessed lack of capacity, other decision-making procedures may be used depending on the home nation's legal framework. It is important to be familiar with the requirements of the law that applies in your country and the guidance of the relevant code of practice. Whilst there are some common principles shared by the home nations regarding best interests, separate provisions also apply.

4.3.2 Best interests (England and Wales only)

Best interests is a process under the MCA (England and Wales) (2005). It is defined in a code of practice that recognises the rights and freedoms of the

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person at the centre of the decision-making process (see 'Assessing and Determining Best Interests' May 2025, Essex Chambers).

Note: Unlike the Mental Capacity Act 2005, the Adults with Incapacity (Scotland) Act 2000 does not use the term 'best interests'. Instead, decisions are guided by statutory principles including benefit to the adult, the least restrictive alternative, taking account of the person's wishes and consulting relevant others.

Principles

Those involved in the best interests procedure should:

- encourage and facilitate the active involvement of the person who lacks capacity in the decision-making process as much as possible
- consider the present and past wishes and feelings of the person when making a best interests decision
- involve relevant people in the decision-making process: the person's nearest relatives, carers, any attorneys, deputies and guardians or an independent medical capacity advocate (IMCA) (if appropriate) and anyone else concerned with the person's welfare
- choose a decision option that benefits the person and is least restrictive of their rights and freedom
- demonstrate respect for confidentiality issues
- record the decision and give clear reasons.

Exceptions: England, Wales and Northern Ireland

There are a number of exceptions to the best interests process in England, Wales and Northern Ireland:

- For patients aged 16 or over, where there is reasonable belief that the patient lacks the capacity to consent to the proposed treatment/procedure and reasonable belief that the actions taken are in the patient's best interests, treatment may usually proceed. Certain serious medical treatment cases may require an application to the Court of Protection.
- Some decisions are excluded from the best interests framework. For example, in England and Wales, the Mental Capacity Act (2005) covers a vast range of financial decisions but some decisions are specifically excluded, such as decisions about family relationships (including sexual relations); voting; unlawful killing or assisted suicide; organ donation;

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fertility treatment. In these cases, capacity should be assessed for the decisions but a best interest decision can only be made by a court of law, not by professionals.

- Where a patient aged 16 or 17 has capacity to consent but refuses to do so, the High Court may authorise the treatment in some circumstances.
- For patients aged under 16, consent may be provided by a person with parental responsibility, provided the decision falls within the scope of parental responsibility.
- Medical treatment for mental disorder may be given to patients of any age without consent under the compulsory treatment provisions of Part IV of the Mental Health Act 1983, where the relevant legal requirements are met. This can include certain treatments ancillary to the treatment of mental disorder, such as anaesthesia ancillary to electroconvulsive therapy.

Exceptions: Scotland

Exceptions to the best interests process in Scotland are as follows:

- For patients aged 16 and over, a medical practitioner may authorise treatment where they certify in the prescribed form that the adult is incapable of providing consent to the medical treatment in question. Note: Section 47 of the Adults with Incapacity (Scotland) Act 2000 only authorises treatment. It does not authorise deprivation of liberty and cannot be used where Part 16 of the Mental Health (Care and Treatment) (Scotland) Act 2003 applies. It also cannot authorise placing an adult in hospital for treatment of mental disorder against their will, or actions inconsistent with decision by a competent court. Force or detention may only be used where immediately necessary and only for as long as necessary.
- Certain serious procedures, such as neurosurgery, drug treatment to reduce sex drive, ECT, abortion or therapeutic procedures resulting in sterilisation, require independent medical authorisation. Other procedures, including non-therapeutic sterilisation and implantation of hormones to reduce sex drive, require approval from the Court of Session.
- For patients aged under 16 who are not sufficiently mature to make the decision on their own behalf, consent may be provided by a person with

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parental rights and responsibilities (s.2 Children (Scotland) Act 1995, s2 AOLCA).

- In an emergency, where consent from a person with parental rights and responsibilities is not available and the child lacks capacity, a person who has care or control of the child but does not have parental responsibility or rights in relation to that child, can consent to treatment under section 5 of the Children (Scotland) Act 1995. Note that this excludes teachers and others who have control of a child in school.
- Patients of any age may receive medical treatment for mental disorder under the compulsory treatment provisions of Part 16 of the Mental Health (Care and Treatment) (Scotland) Act 2003 (MHCTA), where the relevant legal requirements are met.
- Emergency treatment may also be provided under common law where a patient is unable to give or refuse consent.

4.3.3 Consultee advice (England, Wales and N. Ireland)

This applies to research provisions of the Mental Capacity (England and Wales) Act 2005.

Principles

Those undertaking the role of consultee should:

- remember that no-one can legally give consent on behalf of an adult lacking capacity to participate in research
- be kept informed about the person's research participation and lend support as appropriate
- give advice to the researcher on what the likely wishes and feelings about the person's participation would be if they were able to consent for themselves.

Scotland

There is no direct equivalent to the consultee role in Scotland. Research involving adults with incapacity is governed by the Adults with Incapacity (Scotland) Act (2000) and requires consent from an appropriately authorised representative in accordance with the Act.

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4.3.4 Deprivation of Liberty Safeguards (DoLS) (England and Wales only)

The Deprivation of Liberty Safeguards (DoLS) Code of Practice comes under the legal framework of the Mental Capacity Act (2005). Originally designed for professionals and organisations responsible for the care and treatment of people who lack capacity to consent to their care arrangements, the code aimed to support decision-makers in ensuring that any deprivation of liberty is lawful, proportionate and in the person's best interests.

Principles

Firmly rooted within the MCA (2005), DoLS:

- is about safeguarding the rights of people who are under high levels of care and supervision
- applies to people in care homes, hospitals, supported accommodation, Shared Lives accommodation and their own homes.

It needs to be authorised in advance where possible by a responsible body, which includes health authorities.

Current situation

On 2 June 2026, the UK Supreme Court issued a landmark judgement that overturned the P v Cheshire West and Chester Council (2014) test for a deprivation of liberty. The key changes from this ruling are identified as:

- Continuous supervision and control and 'not free to leave' is no longer the sole legal baseline.
- Instead of relying on a single 'acid test', a multi-factorial assessment is needed that includes examination of the specific individual situation (eg type, duration, effects and manner of restrictions).
- If the person who lacks full capacity can understand their environment and express that they accept it, they can give valid consent to their arrangements.
- If there is a lack of expressed objection by the person or general contentment with their care and there is unlikely to be coercion, it may be difficult to conclude that they are deprived of liberty.

The current situation is that organisations need to begin aligning their practice with the new legal position on DoLS by:

- sharing the ruling with all people involved in their organisation

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- upskilling the workforce on what deprivation of liberty means in line with this ruling.

(Taken from guidance from the Department of Health & Social Care: UK Supreme Court 2026 judgment on what constitutes a deprivation of liberty.)

Scotland only

Scotland does not have an equivalent system to the Deprivation of Liberty Safeguards (DoLS). Restrictions on liberty are governed through the Adults with Incapacity (Scotland) Act 2000, the Mental Health (Care and Treatment) (Scotland) Act 2003 and relevant human rights law. Any intervention must comply with the statutory principles of the Adults with Incapacity (Scotland) Act 2000, including benefit to the adult and the least restrictive option.

4.4 Resources

Capacity & Decision-making (MCA, 2005- England & Wales; research provisions), ASSENT Guidance (Bunning et al. 2022)

- Mental Capacity Toolkit, Bournemouth University
- Consult training, Consult (Shepherd, V.)
- Capacity and Consent to Research Resources, Consult (Shepherd, V.)
- Decision: An ethical decision-making Framework for Allied Health Professions in Northern Ireland, Dept. of Health (N. Ireland) (2025)
- Mental Capacity Web-based Assessment Tool, Dodd et al. (2023)
- Carrying out and Recording Capacity Assessments, Essex Chambers (2021)
- Mental Capacity Assessment Support Toolkit (MCAST), Jayes (2017)
- Communicating Capacity, Jayes **PLACEHOLDER**
- Essex Autonomy project, National Mental Capacity Forum
- Decision-making and Mental Capacity (2018), National Institute for Clinical Excellence (NICE)
- Mental Capacity Act (2005) at a glance, Social Care institute for Excellence

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5. Evidence, research priorities and future directions

5.1 Structured review of evidence

This guidance was developed with reference to a scoping literature review methodology (see Pollock et al. 2024). A broad subject matter, the aim was to map out and define the concepts, procedures and reported outcomes associated with two main topics: assessment of mental capacity; and support for decision-making. Exploratory questions were formulated to guide the background search for evidence, with reference to the PICO framework (population-intervention-comparison-outcome). In addition, literature on legislation, policy and practice-focused advice and guidance were also searched.

Scope

This is a very broad subject that covers legislation and codes of practice across all of the home nations. The legislation itself also has separate provisions for different types of decision affected by mental capacity (eg research, treatment, welfare, finance). Within these provisions, capacity is treated in different ways and this varies across the home nations. In compiling the current guidance, the review of evidence was centred around the particular requirements of adults with SLCN. Thus, the guidance views the legislation through a specific lens that falls short of a comprehensive review.

Currently, there are differences in the available evidence sourced by the individual home nations. The state of the codes of practice accompanying the legislation also varies. In particular, Northern Ireland's development of legislation and code of practice, at the time of writing, has been subject to delays associated with power-sharing in its government.

The guidance focuses exclusively on adults – defined as 16 years and over and/or where there is proven Gillick competence. This is because decision-making for children falls under parental responsibility; however, the involvement of children in decisions affecting them is readily acknowledged and supported (Scottish Government: https://www.gov.scot/publications/decision-making-children-and-young-peoples-participation/pages/guidance/; Coyne et al. 2015; Davey et al. 2010). . This begs the question of how to involve the child with speech, language and communication needs in the decision-making process, which implicates opportunities for the expression of assent and dissent.

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Topic 1: Assessment of capacity

The first two review questions focused on the assessment of capacity.

PICO: Population: adults with SLCNs; Intervention: mental capacity assessment; Comparison: different approaches to mental capacity assessment; Outcomes: recorded difficulties, capacities, accommodations.

1.1 What difficulties are identified with regard to assessing the mental capacity of adults with speech, language and communication needs for the purposes of: a. research and b. treatment?
1.2 How are speech, language and communication needs accommodated in mental capacity assessment procedures for the purposes of: a. research and b. treatment?

Topic 2: Support for decision-making

The second pair of review questions focused on supported/shared decision-making. The hyphen between the I-C served to recognise the absence of a dominant intervention and the need to draw comparisons between the different approaches.

PI-CO: Population: adults with SLCNs; Intervention: supported/shared decision-making; Comparison: different approaches to support provision; Outcomes: definitions, accommodations.

2.1 How are support for decision-making procedures conceptualised for use with people who have speech, language and communication needs for the purposes of: a. research and b. treatment?
2.2 How are speech, language and communication needs accommodated in supported/shared decision-making procedures for the purposes of: a. research and b. treatment?

Review

The review included published, peer-reviewed articles: perspective pieces, primary research and literature reviews (systematic, scoping, umbrella). In addition, searches of relevant government department websites across the home nations were conducted, as well as broader searches for policy documents and published guidance (documentary and web-based).

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Key findings

The key findings correspond to the research questions. They are located in the relevant section.

Support for decision-making (RQ 1 and 2)

The findings are summarised in section 2.15.

INSERT LINK

ASsessment of capacity (RQ 3 and 4)

The findings are summarised in section 4.2.5

INSERT LINK

5.2 Research priorities

The research priorities below are viewed through the lens of people with SLCN.

Support for decision-making

- Support for decision-making interventions relevant to people with SLCN: process and outcomes
- Core outcome measures for people with SLCN associated with a range of conditions.
- Decision-making in the lives of people with SLCN: perspectives and experiences of people with SLCN and other stakeholder groups. Knowledge and skills required for SLTs.
- Participation in decision-making processes for people who are assessed to lack capacity.
- The role of assent and dissent in decision-making with people who lack capacity.
- Easy Read documentation: development processes including coproduction, role of mediation, impacts on understanding.
- Use of multiple media in decision-making procedures and their effectiveness.

Assessment of capacity

- Reliability and validity of capacity assessments for people with SLCN
- Characteristics of assessment approaches for people with SLCN including reasonable adjustments and tailored communication supports in use.

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- Impact of speech and language therapy on assessment processes and outcomes
- Implementation of legal frameworks across UK jurisdictions – barriers and facilitators.
- Assessment tools and procedures: development and evaluation.

5.3 Future directions

Decision-making for people with SLCN is far from straightforward. Showing that they have capacity may be challenged by the presence of SLCN. Communication runs as a central thread through all decision-making processes which presents a risk for people with SLCN. Successful navigation of a decision-making procedure, including assessment of capacity as appropriate, may need to go beyond more general reasonable adjustments.

Deliberate address of individual SLCN in all types of decision-making, in everyday life and legal contexts, is about knowledge of:

- the person at the centre of the decision, their culture, values, views and opinions.
- the optimal communication conditions for the individual to demonstrate their capacity for decision-making; the person's SLCN
- how an individual's SLCN affects their understanding of information, their ability to remember information and consider what it means for them personally, and their expressive communication skills.

Selecting communication resources that will work for the individual and enable to make decisions or to participate in decision-making processes.
Learning how the person processes information and expresses themself
Interacting with the person through repeated opportunities and over time to understand and respond to their particular way of communicating. This necessitates input from SLT.

At the heart of future directions in practice and research lies the clear recognition of speech, language and communication within decision-making in everyday life and in legal contexts.

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Annex 1. Glossary

Advance care plan

Not a legal term, it is a statement prepared with a person who has intact capacity about what types of arrangements they would like to be made for their care and treatment at a time when they lack mental capacity.

Applies to England, Wales, Scotland and N. Ireland.

Advance Decision to Refuse Treatment

A legally binding decision made by somebody with intact mental capacity to refuse a specific treatment or medical intervention at a time in the future when they lack capacity to consent to or refuse the treatment.

Applies to England and Wales.

Advance Statement

A written record made by somebody with intact capacity about how they would like to be treated and cared for at a time in the future when they are no longer able to make such decisions for themselves.

Applies to England, Wales, Scotland and N. Ireland.

Advocate

Independent of family and other agencies involved in supporting the person. An advocate may help the person express their needs, views, choices and /or feelings.

Assent/dissent

Term used in decision-making by people who are assessed to lack capacity for the purposes of research participation. It captures expression of agreement or approval to a proposition/disagreement or refusal to a proposition.

Attorney

A person appointed to act for someone else in legal or financial matters. They manage the person's affairs when they no longer have mental capacity.

Applies to England, Wales, Scotland and N. Ireland.

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Best interests

A legal standard that covers a process of decision-making by others on behalf of a person after a mental capacity assessment has demonstrated that the person lacks capacity to make the decision for themself.

Applies to England, Wales and N. Ireland.

Scotland: actions are framed around whether a benefit is delivered rather than 'best interests'

Code of Practice

Authoritative written guidance that outlines practical standards and procedures in line with a particular statute.

Applies to England, Wales, Scotland and N. Ireland.

Combined Powers of Attorney

Merges financial/property powers and health/welfare powers into a single legal document that allows management of personal affairs in the event of loss of capacity.

Applies to England, Wales, Scotland and N. Ireland.

In addition: 'Combined Lasting Power of Attorney' in England & Wales (https://jordansllp.co.uk/services/lasting-power-of-attorney/combined-lpa/) and 'Combined Continuing and Welfare Power of Attorney' in Scotland.

Consultee

- Personal consultee: a person who cares for the adult lacking capacity or is interested in that person's welfare, but is not doing so for remuneration or acting in a professional capacity;
- Nominated consultee: a professional who is independent of the study, can do so where a nominated consultee is not available or willing.

Applies to England and Wales: Research provisions of MCA (2005)

Continuing Power of Attorney

A legal document used to appoint a trusted person to manage someone else's financial and property affairs.

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Applies in Scotland. Termed 'Property and Financial Affairs Lasting Power of Attorney' in England, Wales and N. Ireland.

Court Appointed Deputy

Someone who is a family member or friend rather than a professional, chosen by the Court of Protection to make decisions on behalf of person who lacks capacity.

Applies to England, Wales and N. Ireland. Termed a 'Financial or Welfare Guardian' in Scotland.

Court of Protection

A court of law that specialises in hearing cases relating to how decisions should be made on behalf of people who lack mental capacity. It makes decisions or appoints helpers called deputies for people who lack mental capacity.

Applies to England and Wales only. N. Ireland: Office

Deprivation of liberty safeguards (DoLS)

A legal framework that protects vulnerable adults in care homes or hospitals that lack the mental capacity to consent to their care arrangements.

Applies to England and Wales.

Enduring Power of Attorney

Applies to finance and property only – made and signed before October 2007. However, this situation will change to one like the system in England and Wales when the Mental Capacity Act (Northern Ireland) 2016 is implemented.

Applies to N. Ireland.

Health and Welfare Attorney

A trusted person who is appointed to make health and care decisions. When someone (called the 'donor') makes a lasting power of attorney (LPA), they pick people to make decisions for them in case they lose mental capacity.

Operates via a Health and Welfare Power of Attorney OR a legal professional who specialises in welfare benefits and social care law under the MCA (2005) in England and Wales.

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Operates via a Welfare Power of Attorney under the AwIA (Scotland) (2000) in Scotland.

Governed under the MCA (N. Ireland) (2016 in N. Ireland.

Guardian

A person appointed by a court to manage the personal welfare of someone who lacks capacity.

Applies in Scotland.

Independent Mental Capacity Advocate (IMCA)

A statutory legal safeguard under the MCA (2005), the IMCA oversees the best interests' decision-making process for people aged 16 and over who lack mental capacity to make vital decisions, such as essential medical treatments or long-term accommodation changes. It is used in situations when a person's family and friends are not available, or cannot or do not want to be involved in the process.

Applies to England and Wales.

Lasting Power of Attorney (LPA)

This is a domestic legal document. There are two types of lasting power of attorney. People may nominate someone to be their attorney for either property and financial decisions, OR health and welfare decisions, or both.

Applies in England and Wales. Enduring Power of Attorney is used in N. Ireland.

Local Sheriff Court

Term used in Scotland (similar to court of protection in England and Wales). It handles applications for adults with incapacity.

Applies in Scotland.

Nearest relative

Includes: spouse; child; father or mother; brother or sister; grandparent; grandchild; uncle or aunt; nephew or niece.

Applies in Scotland.

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Office of the Public Guardian

A government agency that registers powers of attorney and deputyships / guardianships. It oversees the work of deputies and guardians and investigates any concerns about the conduct of attorneys, deputies and guardians.

Applies in England and Wales, Scotland.

Professional deputy

Court appointed deputy who is an expert (eg solicitor, accountant) rather than a lay person, authorised to manage the property, financial or personal welfare decisions of someone who lacks capacity.

Applies in England, Wales and N. Ireland.

Property and Financial Affairs Deputy

Appointed by the Court of Protection, the role may be undertaken by a close relative or friend (18 years and over) and legal professionals (eg solicitors and accountants) for the management of property and finances only.

Applies in England, Wales and N. Ireland.

Supported decision-making

Decision-making by individuals who are assisted by others to understand, think about and communicate about decisions. Other related terms in use are: assisted decision-making; shared decision-making; co-created decision-making; combined shared and supported decision-making.

Welfare deputy

Decisions about personal care and welfare – appointed by the court of Protection – to make ongoing personal, medical and social care decisions on behalf of the person who lacks capacity.

Applies in England and Wales.

Welfare guardian

Court-appointed – makes personal, medical and lifestyle decisions for an adults who lacks capacity.

Applies in Scotland.

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Annex 2. UK legislation and policy

- Standards Plain Language, England & Wales: Dept. for Education
- Mental Capacity (England and Wales) Act Code of Practice, England & Wales: Dept. for Constitutional Affairs (2007)
- Mental Capacity (England and Wales) Act 2005, England & Wales: Dept. of Health (2005)
- Making decisions: the Mental Capacity Advocate service, England & Wales: Dept. of Health and Social Care (update 26 June 2025)
- Mental Capacity (Northern Ireland) Act 2016, Northern Ireland: Government
- Mental Capacity Act (Northern Ireland) 2016: Codes of Practice, Northern Ireland: Government (2016-19)
- Decision: An ethical decision-making Framework for Allied Health Professions in Northern Ireland, Northern Ireland: Dept. of Health (2025)
- Adults with Incapacity (Scotland) Act 2000, Scotland: Government (2000)
- Adults with Incapacity (Scotland) Act (2000) Codes of Practice, Scotland: Government (2011)
- Health (Tobacco, Nicotine etc. and Care) (Scotland) Act, 2016; Amendment to Part 4: entitles people with communication difficulties to be provided with communication equipment and support. Referred to as Augmentative and Alternative Communication (AAC), Scotland: Government (2016)
- Getting it right for everyone (GIRFE) toolkit, Scotland: Accessible information policy
- Plain language guidance, Scotland: NHS Inform
- Supported Decision-making – Good Practice Guide, Scotland: Mental Welfare Commission
- Amends to Mental Health Act (1983), UK: Mental Health Act 2025 (2025 c.33)
- How we write, UK: NHS digital services manual

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- Plain language summaries of research findings, UK: Health Research Authority
- Planning and improving research policies, UK: Health Research Authority
- The Equality Act (2010), UK: Public General Acts
- All Wales policy: Accessible communication and information standards in healthcare, Wales: Government
- Planning terms: Plain language guide and glossary, Wales: Government

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