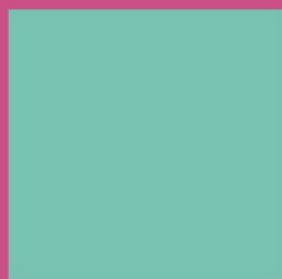




**Health  
Information  
and Quality  
Authority**

An tÚdarás Um Fhaisnéis  
agus Cáilíocht Sláinte

# Supporting people's autonomy: a guidance document





## About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is an independent Authority established to drive high quality and safe care for people using our health and social care and support services in Ireland. HIQA's role is to develop standards, inspect and review health and social care and support services, and support informed decisions on how services are delivered. HIQA's ultimate aim is to safeguard people using services and improve the quality and safety of services across its full range of functions.

HIQA's mandate to date extends across a specified range of public, private and voluntary sector services. Reporting to the Minister for Health and the Minister for Children and Youth Affairs, the Health Information and Quality Authority has statutory responsibility for:

- **Setting Standards for Health and Social Services** — Developing person-centred standards, based on evidence and best international practice, for health and social care and support services in Ireland.
- **Regulation** – Registering and inspecting designated centres.
- **Monitoring Children's Services** — Monitoring and inspecting children's social services.
- **Monitoring Healthcare Quality and Safety** — Monitoring the quality and safety of health services and investigating as necessary serious concerns about the health and welfare of people who use these services.
- **Health Technology Assessment** — Providing advice that enables the best outcome for people who use our health service and the best use of resources by evaluating the clinical effectiveness and cost-effectiveness of drugs, equipment, diagnostic techniques and health promotion and protection activities.
- **Health Information** — Advising on the efficient and secure collection and sharing of health information, setting standards, evaluating information resources and publishing information about the delivery and performance of Ireland's health and social care and support services.

## Note on this guidance

This guidance document is produced by the Health Information and Quality Authority (HIQA). It supports the commitments made by HIQA in 2013 to ensure that the rights of vulnerable services users are placed at the heart of our work, whether that be in development of standards and guidance or in our assessment of the quality and safety of services through our programmes of regulation. It is HIQA's belief that through our increased focus on rights, those providing services will become increasingly aware of their responsibilities in promoting and protecting service users.

The core human rights principles to be found in HIQA's standards and service assessments can be summarised as:

- fairness
- respect
- equality
- dignity
- autonomy

HIQA's motivation in developing and adopting a rights-based approach and in the development of associated guidance is that it can enable a move beyond questions of strict legal compliance to ensuring delivery of effective public services which respect individual rights and put the needs of individual service users at their heart.

The purpose of this guidance on autonomy is to help services to demonstrate how they show respect for human dignity, how they provide person-centred care, and how they ensure an informed consent process that values personal choice and decision-making. By ensuring that people's autonomy is respected, service providers will improve the quality of care, safety and quality of life of people who use health and social care services.

In considering and adopting this guidance, we would recommend that providers of services ensure:

1. A clear understanding of supporting autonomy within the organisation — this will require training of the executive and non-executive leadership and management within the organisation.
2. A policy review — possibly with the use of a supporting autonomy champion within the organisation.

3. Organisational reflection on strategic incorporation of a human rights based approach in the development of their corporate plan, strategic objectives and outcomes.
4. Review of the work carried out by staff and how the application of this guidance on supporting autonomy can add value to the lives of those in receipt of services

The guidance explains the meaning of autonomy, and outlines a supporting autonomy framework. A separate explanatory leaflet — entitled *My Choices: My Autonomy*, which explains the significance of this guidance to people using services — is available on [www.hiqa.ie](http://www.hiqa.ie).

## Glossary of terms used in this report

This glossary details important terms used in this guidance document and a description of their meaning in the context used.

**Accountability:** being answerable to another person or organisation for decisions, behaviours and associated consequences.

**Adverse event:** an undesired outcome that may or may not be the result of an error.<sup>□</sup>

**Autonomy:** autonomy relates to being human and worthy of respect. In a practical sense, it is the ability of an individual to direct how he or she lives on a day-to-day basis according to personal values, beliefs and preferences. In health and social care, this involves the person who uses services making informed decisions about the care, support or treatment that he or she receives. The ability to be autonomous, and make decisions, can be supported and developed.

**Capacity (legal capacity):** in practice, having legal capacity means being recognised as a person who can make decisions. It includes the capacity to be both a holder of rights and an actor under the law [the ability to exercise those rights]. Legal capacity to be a holder of rights entitles a person to full protection of his or her rights by the legal system. Legal capacity to act under the law recognises the person as an agent with the power to engage in transactions and to create, modify or end legal relationships.<sup>⊗</sup>

**Capacity (mental capacity):** the ability of a person to understand the nature and consequences of a decision to be made by him or her, in the context of the available choices at the time the decision is to be made. Essentially, individuals may require various supports to assist the decision-making process. A person should not be regarded as unable to understand information relevant to a decision if he or she is able to understand an explanation of it which is given to him or her in a way that is appropriate to his or her circumstances (whether using simple language, visual aids or any other means of communication).<sup>▽</sup>

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<sup>□</sup> Adapted from: Thomas EJ and Brennan TA. Errors and adverse events in medicine: An overview. In: Vincent C, ed. *Clinical Risk Management: Enhancing Patient Safety*. London: BMJ Publishing, 2001, pp. 31–43. *In: World Health Organization. Conceptual; Framework for the International Classification for Patient Safety*. Version 1.1. Technical Report. WHO; 2009. Available online from: [http://www.who.int/patientsafety/taxonomy/icps\\_full\\_report.pdf](http://www.who.int/patientsafety/taxonomy/icps_full_report.pdf).

<sup>⊗</sup> United Nations (UN) Convention on the Rights of Persons with Disabilities. *General comment No. 1. Article 12: Equal recognition before the law*. Committee on the Rights of Persons with Disabilities: Eleventh session; 2014.

<sup>▽</sup> Assisted Decision-Making (Capacity) Bill 2013. Dublin: Stationery Office; 2013.

**Consent:** the giving of permission or agreement for an intervention, receipt or use of a service or participation in research, following a process of communication in which a person using a service has received enough information to enable him or her to understand the nature, potential risks and benefits of the proposed intervention or service.<sup>∅</sup>

**Positive risk assessment:** positive risk-taking is weighing up the potential benefits and harms of exercising one choice of action over another. It involves identifying the potential risks involved (good risk assessment), and developing plans and actions that reflect the positive potentials and stated priorities of the service user (good risk management). It involves using available resources to achieve the desired outcomes, and to minimise harmful outcomes.<sup>Σ</sup>

**Risk:** the likelihood of an adverse event or outcome.

**Risk management:** the systematic identification, evaluation and management of risk. It is a continuous process with the aim of reducing risk to an organisation and individuals.

**Service-provider:** person, persons or organisations that provide services. This includes staff and management that are employed, self-employed, visiting, temporary, volunteers, contracted or anyone who is responsible or accountable to the organisation when providing a service. Accountability to the organisation and responsibility for care provided extends to those persons who may not be members of a regulated profession.

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<sup>∅</sup> National Consent Advisory Group. *National Consent Policy*. Dublin: Health Service Executive (HSE); 2013.

<sup>Σ</sup> Morgan, S. Positive risk-taking: a basis for good risk decision-making. *Health Care Risk Report*, March: 20-21; 2010.





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## Section A. Introduction — about the guidance

### 1. What is autonomy and why is it important?

Although there are many different definitions of autonomy, there is some general agreement about the term.<sup>(1-7)</sup> Personal autonomy, which this guidance focuses on, refers to an understanding of human beings as being worthy of respect.<sup>(2)</sup><sup>§</sup> This includes respecting a person's dignity, privacy and his or her choices. Respect for autonomy is important in the context of health and social care, as it is central to person-centred care.

In a practical sense, and in general use of the term, autonomy is about self-determination (directing how one lives).<sup>(8)</sup> Autonomy is the ability of an individual to direct how he or she lives on a day-to-day basis according to personal values, beliefs and preferences. In health and social care, this involves the person who uses services making informed decisions about the care, support or treatment that he or she receives.

Informed consent is one important practical example of the principle of autonomy. To 'give consent' to a medical treatment or a service means to give permission. The definition of consent provided by the National Consent Advisory Group's *National Consent Policy* specifies the importance of communication and information sharing in the consent process.<sup>(9)</sup> The purpose of communication is to ensure that before giving consent, people using services have sufficient information to understand the care, support, or treatment they are agreeing to, and understand the associated potential risks or benefits.

People who use health and social care services have the right to control their own lives, and the right to make informed decisions on matters that relate to them. Individuals may require different levels of assistance to exercise this control and make their own decisions, and therefore health and social care providers have a key role in this process. This involves providers taking practical steps to promote and support people's autonomy.

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<sup>§</sup> Autonomy can also be defined in a political sense, referring to the autonomy, or power, of a state or nation.

## 2. What is this guidance about and who is it for?

This guidance explains the meaning of autonomy and outlines a supporting-autonomy framework for implementing good practice in promoting people's autonomy when they are using health and social care services. The guidance is written for providers of all adult health and social care services that are regulated by HIQA. The aim of the guidance is to assist in promoting and supporting individuals' autonomy, choice and decision-making in the care setting.

Health and social care providers should champion autonomy in their services. People who use services may be vulnerable due to personal circumstances, or possible power imbalances, and may not be in a position to promote their own autonomy. A supplementary explanatory leaflet, *My Choices: My Autonomy*, explains the significance of the guidance for people receiving care, support and treatment. This shared understanding is important. The leaflet is available on [www.hiqa.ie](http://www.hiqa.ie).

Central to the guidance is the supporting autonomy framework, which outlines six steps involved in promoting autonomy. These are outlined in Section 7 of this report. The framework applies to adults in health and social care services. While autonomy may be promoted in different ways in the acute and social care setting, there are core principles that apply. The framework is a practical tool to balance service-provider responsibility and accountability with respect for autonomy and individual choice.

The guidance document includes a series of examples that explain how the various stages of the framework apply to real-life health and social care situations. These examples are based on discussions with people using services and service providers during the consultation phase. A number of published resources are included further on in this document to assist people in using the framework in their workplaces. A glossary at the front of this document explains key terms used in this guidance.

## 3. Why is this guidance important?

The law, codes of professional conduct, and regulatory standards<sup>(10-17)</sup> place increasing importance on the autonomy of the person receiving care, support or treatment. This guidance reflects a human rights approach to care delivery. The guidance aims to maximise the rights and autonomy of the person who uses health and social care services within a supportive framework.<sup>(18-21)</sup> Promoting autonomy is central to a caring service. Promoting autonomy, choice and decision-making involves more than keeping people safe and healthy. It involves respecting them, and their choices, and enhancing their quality of life.

Promoting autonomy can sometimes create challenges for individual health and social care providers. They may not know how best to promote autonomy, and may be concerned that respecting a person's autonomous choices could conflict with their responsibilities — as a care provider — to do no harm.<sup>(22-26)</sup> This could arise when a person's values, beliefs and preferences may be contrary to what best-evidence suggests. Service providers may sometimes not promote autonomy because of concerns for the person's safety. This can create a risk-averse culture that may inhibit personal autonomy and disregard human rights. It is important to achieve an appropriate balance between promoting autonomy and maintaining safety. This guidance aims to assist in this process.

HIQA acknowledges that promoting autonomy, and improving quality of life, may sometimes require a degree of risk. People who use health and social care services are entitled to the dignity and personal development associated with risk-taking. A positive approach to risk assessment acknowledges that risk-taking is part of a fulfilled life.<sup>(27)</sup>

Positive risk assessment considers possible harms, and focuses on individual strengths and collaborating with people to meet their individual needs.<sup>(28-31)</sup> HIQA supports positive risk assessment in appropriate settings when person-centred planning and associated necessary safeguards are in place.<sup>(32)</sup> This guidance aims to assist providers in promoting autonomy in an accountable way. The supporting autonomy framework includes a step where rights, risks and responsibilities are considered. This section of the framework explains positive risk assessment in greater detail, and provides a guide to some helpful resources.

All preferences are not necessarily facilitated in accordance with respect for autonomy. A careful process of individualised risk assessment, communication, and informed decision-making is essential. A number of factors potentially affect the extent to which a person's individual choices can be facilitated.<sup>(9)</sup> These can include:

- person's capacity (ability) to make decisions<sup>(33-35)</sup>
- respect for the autonomy of others
- specific provisions of The Mental Health Act<sup>(36)</sup>
- available resources.

It is also important to stress that the issue of inadequate resources is not an acceptable excuse for poor care.

#### 4. How was this guidance developed?

The guidance was developed in line with standard guidance procedures produced by HIQA. Core elements of the process included:

- a literature review
- consulting with an advisory group (see terms of reference in Appendix 1, and membership in Appendix 2)
- an action-learning consultation with three distinct groups in health and social care services (see locations and membership in Appendix 3)

An action-learning approach was used as it values practical experience, and is compatible with the cycle of quality improvement.<sup>(37; 38)</sup> Autonomy is a complex term that can be better understood in everyday practice.<sup>(39; 40)</sup> Meetings took place in health and social care environments, organised by the project lead, as the guidance developed. This was important to ensure the guidance was informed by and understood in the practice setting. Problems and solutions in promoting autonomy were explored from the perspective of various informed and interested parties.

HIQA inspectors were also consulted as part of the process.

#### 5. How does this guidance relate to existing HIQA standards and regulations?

This guidance document can support providers in implementing various National Standards produced by HIQA. The guidance supports these National Standards<sup>(15-17)</sup> and any associated regulations for health and social care services which promote the autonomy of adults using services.

The guidance has particular relevance in terms of the following themes in these Standards, '*Person-centred Care and Support*'<sup>(15;16)</sup> and '*Individualised Supports and Care*'.<sup>(17)</sup> However, as respect for human dignity, privacy and choice extends across various aspects of care giving, the guidance is also relevant to other themes and associated standards. This could include standards in relation to the physical care environment, intimate care, information sharing and or effective resource management.

## Section B: The guidance

### 6. Promoting autonomy in health and social care — key principles

Autonomy can be promoted in different ways depending on the person, his or her individual needs and the care setting. Promoting autonomy may involve supporting a young adult in the informed consent process prior to surgery in an acute hospital environment. In a residential service for older adults, promoting autonomy may be as simple as helping an individual to start a club in the place where they live. While in the maternity services, it may involve exploring a woman's birth plan preferences with her during the ante-natal period.<sup>~</sup> Despite these diverse settings, in all instances the personal preferences of the person are considered in a staged process.

This section lists some key principles about autonomy in health and social care. These principles are the ideas underpinning the guidance. For readers who wish to explore these ideas further, the associated legal and ethical aspects of autonomy are explained in greater detail in Appendix 4.

#### Key principles about autonomy in this guidance

- Autonomy is one of the ethical principles that health and social care providers use to guide their practice.
- Autonomy does not always involve total independence; often, decisions are made based on our relationships with others, or with the assistance of others.
- Irish and international laws support the promotion of personal autonomy in health and social care.
- Respect for autonomy is compatible with a human-rights approach to care.
- Respect for autonomy means that every adult person has a right to be involved in decisions that affect them.
- The will and preferences of the individual are central to promoting autonomy.
- Respect for autonomy means that every adult person has a right to consent to, or refuse, treatment, unless it is decided they do not have the mental capacity (ability) to do so.

<sup>~</sup> The issue of autonomy in pregnancy presents additional challenges. The foetus is afforded equal protection to that of the mother in Irish law in accordance with article 40.3.3 of the Constitution of Ireland. In this sense, the rights and autonomy of both the mother and foetus are considered. In unresolved situations of competing rights, legal advice may be required. For a further analysis of these specific issues see: Wade, K. Refusal of emergency caesarean in Ireland: A relational approach. *Medical Law Review*. 2013 22(1): pp.1-25.

- Respect for autonomy means that informed consent involves a process of communicating with people, and not merely the signing of a consent form.
- The ability of people to be autonomous and make decisions can be developed if appropriate supports are put in place.
- The ability to make a decision can change over time and is specific to the decision to be made. This is a *Functional approach* to capacity.
- Respecting autonomy involves careful balancing of the rights of people who use services, their safety and wellbeing, and the professional accountability of service providers.
- An ongoing process of engagement, and person-centred communication, with people who use services can help promote autonomy and wellbeing.
- Some individuals may wish to take less of a role in the decision-making process at some stages in their interaction with services. This should be respected.
- Respect for autonomy does not mean all choices are facilitated.

## 7. Supporting autonomy: a framework for service providers

Steps involved in promoting autonomy in health and social care services are outlined in this section.

This supporting autonomy framework is a practical tool to assist providers to promote the autonomy of people who use health and social care services (see Figure 2). It involves six steps as follows:

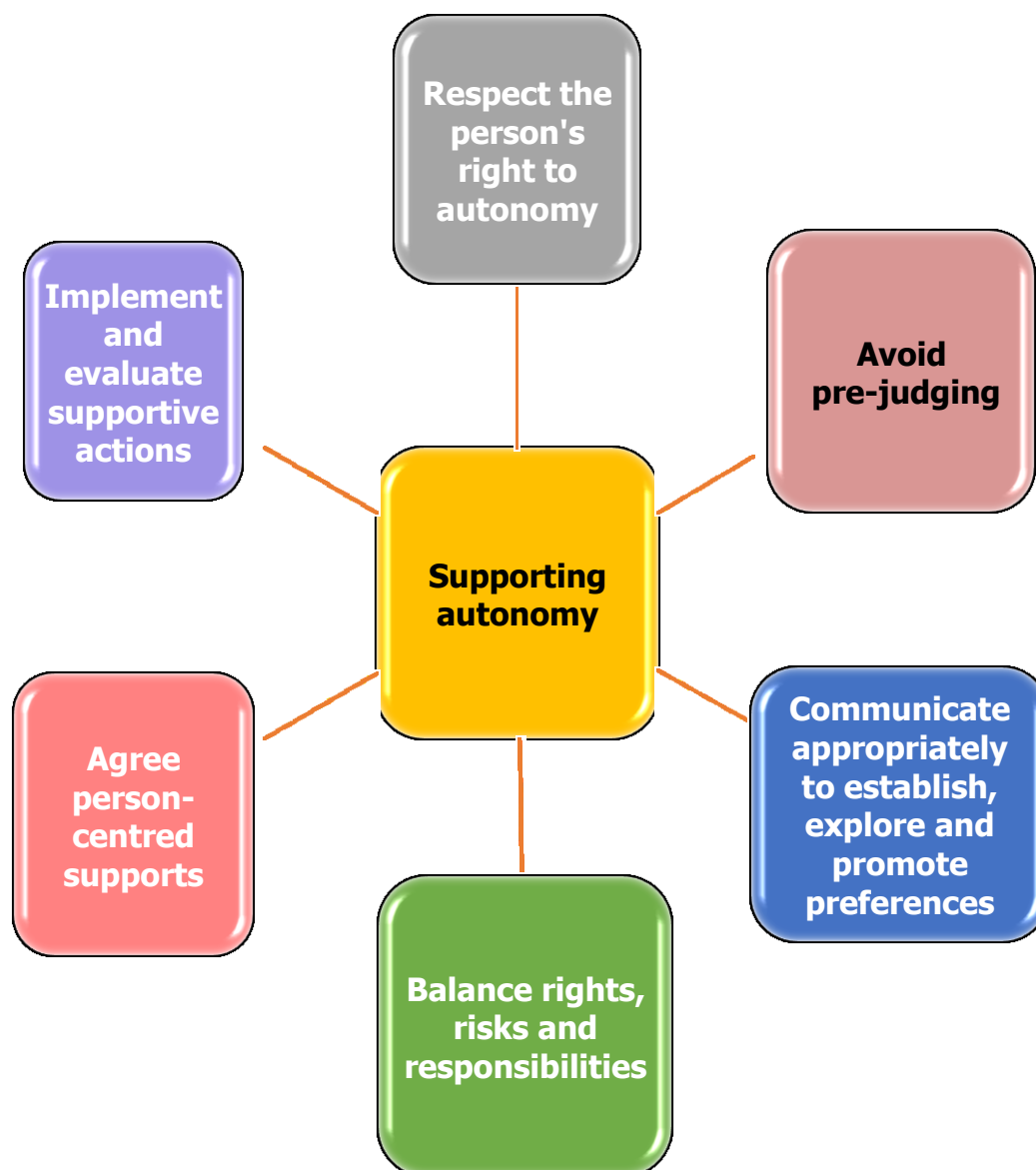
- Respect the person's right to autonomy.
- Avoid pre-judging.
- Communicate appropriately to establish, explore and promote preferences.
- Balance rights, risks and responsibilities.
- Agree person-centred supports.
- Implement and evaluate supportive actions.

The steps are not necessarily chronological, but highlight significant stages in the process.

The framework is based on experiences of autonomy in everyday life.<sup>(41-44)</sup> In this sense, autonomy is viewed as an interdependent process that involves our relationships with other people. This is referred to as relational autonomy.<sup>(45-46)</sup> The framework is compatible with a human-rights approach of supported decision-

making.<sup>(18-21)</sup> It reflects recent developments in assisted decision-making legislation in Ireland.<sup>(11)↓</sup> It also supports the rights of people who use health and social care services to make decisions about the care, support and treatment they receive.

**Figure 2. Supporting autonomy: a framework for promoting autonomy in health and social care services**



The framework can help health and social care providers to balance respect for autonomy with professional responsibility and accountability for a quality service. It not only reflects an approach to caregiving that respects the autonomy of service users, but also appreciates the concepts of care, responsibility, accountability and

↓ At the time of publication, the Assisted Decision-Making (Capacity) Bill 2013 had not yet been enacted. All guidance should be interpreted in accordance with the prevailing law.



interdependence that are present in a professional caring relationship.<sup>(26; 44; 47-50)</sup> Effective communication with people who use services is a core aspect of the framework.

This section of the guidance explains the various steps in the framework, and what they mean for service providers. Each step in the framework incorporates some practical examples that draw on discussions in the action learning groups. Examples are not presented in order of importance. Examples include three fictitious case studies, using the first names John, Claire and Erik. The case studies are followed through in each step to explain the process that promoting autonomy involves.

## **7.1 Respect the person's right to autonomy**

Every person who uses health and social care services has the right to have his or her autonomy respected. This includes respect for their dignity, privacy and personal preferences. Autonomy can be respected in simple ways in the care setting. This could involve assisting a person to carry out their daily activities in a manner that suits their individual needs. The process of informed consent is an important practical application of respect for autonomy in health and social care.

It is important that people are supported in the decision-making process but are not subjected to undue influence. When health and social care providers share information, give advice, or assist in the decision-making process, it should be with the intention of promoting the autonomy of the person receiving care, support and or treatment. The will and preferences of the individual is central to the process. Respecting a person's autonomy includes respecting what others may consider to be unwise decisions.

It is essential that people who use services are aware of their right to an active role in deciding the care, support and treatment they receive. Service providers are required to appreciate the power imbalances that can occur within services and take the lead in promoting autonomy. Respect for autonomy does not mean every preference or choice can be facilitated. The person will require the necessary capacity to make that particular decision at that specific point in time. If proposed actions are prohibited by law, affect the autonomy of others, are clinically unsound or legitimately exceed available resources, a specific choice may not be supported.

However, the issue of insufficient resources should not be an acceptable excuse for poor care and practice in relation to promoting people's autonomy. When resource issues are a factor inhibiting autonomy, they should be reported to the relevant authority. It may be possible, in some instances, to actively manage resource challenges to find practical solutions that do not require additional funding.

### **What this means for service providers**

- Service providers design and deliver care which respects service-users' dignity, privacy, bodily integrity and personal will and preferences.
- Service providers support policy development, staff training and supervision in positive risk assessment.
- Individual health and social care providers respect autonomy in line with legislation, best-available evidence and any codes of conduct produced by professional regulators.

### **Examples of respect for autonomy can include the following:**

- organising a community homecare package to allow a person to live in their own home
- including a person in communication, regardless of cognitive ability
- committing to an informed consent process underpinned by person-centred communication
- respecting a person's right to refuse professional advice
- introducing and facilitating advance care planning
- having a residents' forum
- promoting dignity at end of life
- working in creative ways to establish the will and preferences of people who do not communicate verbally
- creating a sense of the person in the care environment, for example, pictures in their room, use of life histories
- working inter-professionally to assist in meeting the preferences of people with complex needs
- providing same-gender accommodation in acute hospital settings
- adopting an open-disclosure policy
- putting in place access to independent advocacy services
- respecting a person's information as private in accordance with the law
- maintaining privacy and confidentiality in any online and or digital communication
- creating environments which allow respect for privacy in intimate care
- involving patients, residents and other people using services in assessment, planning, delivery and evaluation of their care, support and treatment
- operating restraint-free environments wherever possible. Any restrictive practices should be person-centred, policy driven and based on individual risk assessment
- preserving human dignity and protecting vulnerable adults from abuse.

**Case study A, John: Example 1**

John is an older adult with dementia living in a community-nursing unit. John is scheduled to have a total hip replacement in hospital, following referral by his general practitioner (GP) for unresolved hip pain. In accordance with respect for John's autonomy, the team at the hospital appreciates John's right to an informed-consent process. This is evident in its efforts to communicate effectively with him to date, and seek his permission to discuss his care with family members. Staff in the hospital and the community nursing unit are committed to working with John to support his autonomy and promote his role in the decision-making process.

**Case study B, Claire: Example 1**

Claire is a young woman with an intellectual disability. She attends a vocational education centre and wants to travel to classes unaccompanied on public transport. Respect for her autonomy suggests that this is the right thing to do. Claire is 19 years old and wants some independence like the other students. However, the team in the education centre and her parents have concerns as Claire has never travelled alone and may be at risk of harm from traffic, being hassled, or could get lost in an unfamiliar environment.

Despite these legitimate concerns, the staff and Claire's parents appreciate how important this choice is to Claire. They respect her autonomy and personal preferences, and consider how best to facilitate her choices. Claire lives in a community with other people. Claire is encouraged to reflect on how this choice could affect her personal safety and how it affects her parents and care workers who are concerned about her wellbeing. Claire's request to use public transport is not facilitated immediately but a staged process of skills building is put in place for her.

**Case study C, Erik: Example 1**

Erik is a middle-aged Western-European man who has lived in Ireland for the past two years. Erik is currently being cared for by his general practitioner (GP) and the local public health nurse. Erik has Type 1 diabetes and has a diabetic leg ulcer due to the long-term vascular complications of his diabetes. The vascular team at the hospital clinic have recommended a vacuum assisted dressing to heal the wound. Erik refuses a vacuum dressing stating that he would not like to have a device like that attached to his leg when he goes to his weekly card game. The GP and public health nurse respect his right to refuse treatment, even though, based on available evidence, they consider it an unwise decision. The public health nurse and GP

respect Erik's right to autonomy, and consider how best to balance that right with their responsibility to deliver evidence-based care, and their concern for his wellbeing. Following further discussion between Eric, the public health nurse and the GP, a decision is made to continue with more standard ulcer dressings, to increase pain relief medication and arrange follow-up observation. All three agree to review the decision in a month's time.

## 7.2 Avoid pre-judging

Every person is presumed to have capacity to make his or her own decisions unless there is evidence to the contrary. Pre-conceived ideas about autonomy are not appropriate. People may differ in terms of the amount of assistance they require to make decisions. This does not mean they lack decision-making capacity. In line with a functional approach to capacity, a person may have different decision-making abilities depending on the decision to be made and the time at which the decision is required. All individuals may require assistance with decision-making at different points in their lives. While it is important not to underestimate the ability of a person to make his or her own decisions, it is also important not to overestimate the extent to which a person may be confident to make decisions on his or her own.

### **What this means for service providers**

- Service providers have systems in place to support decision-making.
- Services create a culture in which the decision-making potential of all individuals is respected.

### **Examples of avoiding pre-judging include services:**

- focusing and maximising human potential and avoiding a focus on limitations
- respecting that an unwise choice does not necessarily mean a lack of capacity
- presuming that all persons have ability to make their own decisions unless an assessment of capacity, in line with the law, indicates otherwise
- treating people in a non-discriminatory manner
- avoiding overestimating decision-making ability in some circumstances. For example, if an expectant mother may have worked as a nurse and this is known to the service, this does not mean that she requires less information or support prior to her admission to the labour ward
- appreciating that people have different life goals, needs and wants, for example, a person in a residential setting may wish to spend a lot of money on the most recent jersey from their football team.

**Case study A, John: Example 2**

John's care team in the community-nursing unit, and the hospital, do not pre-judge his ability to make decisions based on a diagnosis of dementia. Hospital policy includes reference to supporting people with cognitive impairment to be involved in decisions that affect them. The community-nursing unit has always engaged with John in a manner that encourages his role in decision-making. John has indicated that he likes his daughter to be involved in the decision-making process. She visits regularly and assists John in his communication with the community hospital staff.

**Case study B, Claire: Example 2**

Claire's decision-making ability is not pre-judged because of her intellectual disability.

**Case study C, Erik: Example 2**

Erik's refusal of treatment is not viewed as an indication of lack of capacity, despite the healthcare team's view that it is an unwise decision.

**7.3 Communicate appropriately to establish, explore and promote preferences**

Promoting autonomy requires an ongoing process of communication to address individual need. This requires truthful, open communication and an atmosphere of trust and mutual respect. Effective communication is the cornerstone of informed consent and is essential to ascertain an individual's will and preferences with regard to care, support and treatment. Effective communication can also identify any supports required in the decision-making process.

A shared dialogue about care, support and treatment will ensure that information is both given and understood. A person's preferences and requirements for assistance with decision-making may change over time. An awareness of the service-user's personal story is an important aspect to promoting autonomy. This story can only be known through real engagement with people who access services. While clinical data can assist in making appropriate assessments, information about a person, his or her life and what is important to them is required to promote autonomy in a meaningful way.<sup>(44; 51-52)</sup>

A person must be given information in a manner they can understand to assist them to make decisions. The communication process should accommodate any specific communication needs and be culturally sensitive. Communication should ideally take place at a time that people are best able to assimilate information. Plain language and easy-to-read documents will help with communication.

It is essential that communication in the consent process is a two-way process. This will enable sufficient discussion, and move beyond a mere process of authorisation.<sup>(53)</sup> If an individual has an extensive cognitive impairment or communication difficulties, his or her preferences can be identified with the assistance of family members and carers who are aware of his or her needs and wishes. Family involvement must be with the person's consent.

Should the communication process suggest an individual lacks capacity to make a specific decision, then the person's capacity should be assessed in accordance with the law. Every effort should be made to support the person to make his or her own decisions. A lack of supportive measures should not be confused with a lack of capacity. Capacity is assessed in accordance with a specific decision at a specific time. The current test for capacity in Ireland is a three-part test. It is referred to as a 'Functional Test' for capacity. Capacity to consent to, or refuse, treatment is dependent on the following criteria:

- Does the person understand and retain the information?
- Does the person believe the information?
- Does the person use the information to weigh up the risks and benefits of the situation and make a choice?<sup>Ω</sup>

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<sup>Ω</sup> This is referred to as the 'C test'. The C test is based on UK case law, *Re C - Re C* [1994] 1WLR 290. Recent case law in Ireland supports this (*Fitzpatrick & Anor v K & Anor* [2008] IEHC 104). Note that capacity should be assessed in accordance with the prevailing law. At the time of preparing this guidance, the Assisted Decision-Making (Capacity) Bill 2013 was awaiting enactment.

**What this means for service providers**

- Services communicate with people to establish their identity as a unique individual. Autonomy cannot be promoted unless the person and their preferences are known.
- Service providers recognise possible power imbalances in order to promote open communication.
- Service providers have processes in place to assess capacity in accordance with legislation and best available evidence.
- Services consult with family and friends to assist in identifying the preferences of the person receiving care, support or treatment. Services are mindful of confidentiality in this regard.

**Examples of effective communication to establish, explore and promote preferences include:**

- basing person-centred communication on individual needs assessment
- using plain language, and or easy-to-read documents as required (refer to the resources section for some examples)
- communicating to explore choices that may cause harm. For example, discussion with a woman in labour, who is refusing a clinically indicated caesarean section, may reveal inaccurate concerns which can be corrected
- assessing understanding at the time of giving information. Asking questions that avoid yes and no answers, for example, asking: "What is your understanding of this treatment plan?"
- establishing the circumstances that support effective communication. For example, a comfortable, quiet, unrushed environment
- speaking with people in a respectful and approachable way
- working creatively with people who are unable to speak to establish processes of communication, for example, use of communication aids such as pictorial systems, picking up non-verbal cues, use of eye contact, use of assistive technologies
- sharing patient and or service-user information in a variety of mediums to support written text, such as pictures, DVDs, online
- recognising the significance of non-verbal cues. This can include interpreting behaviour that challenges as being responsive behaviour and an indication of possible need. As an example, a person who continuously throws cushions on the floor may be indicating a wish to sit on the floor in comfort with use of a bean bag
- using interpreters or technology to communicate with people who do not speak English

- finding out what matters to the person in relation to their care, support or treatment
- using communication and or hospital passports to explain a person's needs and wants when they are in unfamiliar environments<sup>¶</sup> (see the resources section of this guidance report for examples of passport documents)
- promoting end-of-life discussions and advance care planning to enable evidence of expressed will and preferences in future care situations (see the resources section for some examples of advance care planning tools).

### Case study A, John: Example 3

With his permission, John's daughter attends the hospital pre-assessment clinic with him. John's cognitive ability fluctuates. He can communicate verbally but sometimes requires assistance to take in and understand information. He is very sensitive to background noise and finds large-group conversations difficult. John's daughter is able to share this detail with the team at the hospital.

John also brings his hospital passport with him from the community-nursing unit. John's passport explains John's specific communication needs in addition to other information about his needs, wants and his life story. It outlines that John was a school principal and loved fishing during his retirement. John had also completed an advance care-planning document in accordance with the policy of the community-nursing unit.

All staff in the pre-admission clinic appreciate that John communicates best in a quiet environment. Any non-essential staff are asked to leave the consulting room on this occasion. Through a process of communication, using clear language, at a slow pace, the surgeon establishes that John has the capacity to consent to surgery. John indicates that he understands the purpose of the surgery, the risks involved, and is able to retain and weigh up those risks to give his permission to proceed at this time. John sometimes refers to his daughter for assistance during the decision-making process. However, staff communicate directly with John. The consent process is documented in his hospital notes by the surgeon.

The nurse and physiotherapist spend some time with John after the consultation, to explain in detail what the post-surgical period will be like, and establish any specific post-operative needs. Additional written information is given, using plain language statements about surgery and explanatory pictures. John is provided with a follow-up contact number to raise any future queries. John and his daughter are also introduced

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<sup>¶</sup> Communication, or hospital, passports provide a brief outline of the specific needs of individuals who may not be able to communicate in an unfamiliar environment. They are predominantly in use in dementia care and intellectual disability settings, but can be useful for any person with a cognitive impairment.



to the medical social worker and her role is explained. As John will be returning to the community-nursing unit, discharge planning is arranged by the medical social worker and or nursing staff in association with the nursing staff in the unit.

### **Case study B, Claire: Example 3**

Claire can communicate very effectively. The education centre staff, her family and staff in the residential centre have always supported Claire to express her preferences and engage in conversation. Claire requires information in an easy-to-read format in order to take it in. Claire's social care worker asks another student in the centre to talk to Claire about how he developed skills in using public transport independently over a period of time. Issues about choices, and balancing safety and choice, are discussed in the house group meeting. The social care worker, Claire and others who live in the house contribute to this discussion. Claire writes about this choice, and how to progress it, in a decision-making diary.<sup>6</sup>

### **Case study C, Erik: Example 3**

Erik is currently distressed about the chronic nature of his diabetes diagnosis, the onset of complications and planned management strategies. The public health nurse explains to her line manager that she needs to spend some extra time with Erik to explore his decision to refuse the vacuum-assisted dressing. In the course of discussions with Erik, he reveals that he feels the management of his diabetes is taking over his life and that it is causing him great distress. The public health nurse listens to his concerns and discusses how he can accommodate treatment measures within his daily life.

This may include pre-planning meals out with friends in advance to adhere to dietary recommendations. It could also involve, where possible, reorganising the time of vacuum-dressing changes to suit Erik's lifestyle. Erik seems open to negotiation regarding the vacuum dressing once he realises the nurse is willing to work with his specific quality-of-life needs, in addition to more general clinical needs. Erik retains the right to refuse the treatment proposed but agrees to consider the points raised.

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<sup>6</sup> The use of a decision-making diary has been noted as a useful step in supported decision-making, by the Office of the Public Advocate in South Australia in an evaluation of its processes. For further information, see: Wallace M. *Evaluation of the Supported Decision Making Project*. Office of the Public Advocate (Government of South Australia); November 2012. Available online from: [http://www.opa.sa.gov.au/resources/supported\\_decision\\_making](http://www.opa.sa.gov.au/resources/supported_decision_making). (See: Participant Experiences {Johnny} p.17).

## 7.4 Balance rights, risks and responsibilities

Health and social care providers are responsible and accountable for the extent to which they promote autonomy, deliver quality care and maintain the safety of people who use health and social care services. Codes of professional conduct, contracts of employment and the rule of law underpin this accountability. People who use health and social care services are responsible for the decisions they make when those decisions are informed, voluntary and made with sufficient capacity.<sup>€</sup>

While personal limitations and or vulnerability should not prevent individuals from being autonomous or making decisions about their care, support and treatment, it is important to consider a person's vulnerabilities when exploring their choices with them. Taking the time to consider any limitations, and how they can be addressed, will prevent the abandonment of service-users under the guise of promoting autonomy. In this way, autonomy can be promoted while also protecting people who use services. Allowing a compromised person do as they wish, without appropriate assessment and support, is not respecting or promoting autonomy.

Appropriate risk assessment is essential to ensure that autonomy is promoted in a safe, supportive environment. Risk assessment should incorporate best available evidence. Positive risk assessment acknowledges the role of risk in human development, and prevents a risk-averse culture from developing, which may impede autonomy, human rights and human flourishing. A risk-averse culture may result in restrictive practices that are unnecessary.

Some additional resources for health and social care providers around positive risk assessment are included in the resource section of this document. Self-reflection can be used by health and social care professionals to enable them to consider the extent to which they balance the competing ethical principles of 'autonomy' and 'do no harm'. This can help promote autonomy and safety. See Appendix 5 for a self-reflection checklist.

Following a risk assessment, and discussion about these risks, both parties may come to a negotiated position. Alternatively, the individual may choose to ignore professional advice and engage in behaviours that constitute a significant degree of risk to their health and wellbeing. The engagement with people using services is central to professional accountability. Meaningful interaction about rights, risks and responsibilities is required. While the decisions of individuals must be respected, respect for autonomy can never be used to avoid engagement and discussion. It is essential that all decisions are fully informed as part of a thorough consent process.

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<sup>€</sup> The concept of shared patient and or service-user responsibility, and subsequent contributory negligence, cannot be assumed in the Irish courts. Irish case law has recognised the relationship between patient and specialist as a 'dependent' one, and outlines the duties of healthcare professionals in this regard. For further detail, see *Philp v Bon Secours Hospital* [2004] IEHC 121.

It is also important to document the consent process and discussions regarding risk. Refusal of treatment is to be respected unless the person lacks the capacity to make that specific decision. Any refusal of treatment is also documented. Documentation should be completed by the health or social care professional who has been engaged in the discussion with the person.

### **What this means for service providers**

- Service providers balance the person's right to autonomy with the service's responsibility to deliver safe, evidence-based care.
- The ethos of service providers is to promote autonomy in order to avoid a risk-averse culture.
- Service providers appreciate the importance of safeguarding when facilitating the person's autonomy and choices.

### **Examples of balancing, rights, risks and responsibilities include:**

- carrying out evidence-based, person-centred risk assessments to establish the magnitude and likelihood of risk
- considering the person's strengths in the risk assessment process
- engaging in personal reflection to identify over-protective behaviours (see the checklist in Appendix 5)
- engaging in effective communication as outlined in the step above to establish factors that may be influencing decisions
- explaining the risks associated with personal preferences. For example, the midwife caring for a woman who refuses to discontinue smoking during pregnancy will continue to engage with the woman during her ante-natal care, in a non-judgmental manner, to ensure she understands the associated risks
- balancing a person's preferences with a professional obligation to give safe, evidenced-based care. In the example above, the midwife informs the woman of smoking cessation and stress reduction programmes and/or strategies. She continues to care for the woman and monitor the pregnancy for any deviations from the norm. All care and education is documented
- negotiating with people to balance their wishes with safe, health-promoting behaviours where possible. For example, a person who wants to eat unhealthy fast-foods five times a week may agree to eat this type of food only at the weekend in order to improve their overall health and wellbeing.

### **Case study A, John: Example 4**

John's surgeon explains the risks associated with surgery during the consent process in a manner John can understand. John may wish to have his daughter present to support him. Knowledge of these risks is an important factor to facilitate John to give an informed consent. An opportunity is given to ask questions. If John refuses the surgery, the risks associated with not having the operation will be explained. These include the likely persistence of his osteoarthritis pain, and the need for ongoing pain relief medication.

John's capacity to refuse treatment is assessed in exactly the same way as his capacity to consent to treatment (see example 3). John retains a right to refuse treatment, once it is established he has the capacity to do so. Refusal of treatment should not be interpreted as a lack of capacity without appropriate communication and assessment.

### **Case study B, Claire: Example 4**

A thorough discussion takes place with Claire to explain, in a way she can understand, how dangerous the town centre can be in times of peak traffic without proper use of the rules of the road. The steps involved in travelling to the centre independently are listed and any risks are identified. The positive aspects of taking this risk are also listed. A compromise occurs where Claire agrees to be assessed weekly on another aspect of travelling safely to the centre, until she is eventually allowed to travel unaccompanied. This involves Claire demonstrating that she applies the rules of the road. It also includes Claire accepting responsibility for not wearing head phones when walking.

Claire discusses this support plan with her parents who are happy with the level of support in place. However, a social worker (Kate) who is working with Claire in the vocational education centre is concerned about her accountability if Claire is harmed during her journey to and from the centre. The process of communication with Claire and the safeguarding measures in place to develop her competency in using public transport show that autonomy is promoted in a responsible way.

Kate can explain that both Claire's autonomy and safety are considered in the plan of action. Kate has documentary evidence of this. The process of capacity building, support and skills development, outlined above, allows Kate to be accountable for her practice. (Further discussion of the associated legal and ethical principles is contained in Appendix 4 of this report.↔)

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↔ Should an adverse event occur, any claim for negligence will be considered on the basis of the facts of the individual case. Documentary evidence is important in this regard.

**Case study C, Erik: Example 4**

Erik retains the right to refuse the vacuum assisted dressing for his leg ulcer. However, the public health nurse and GP are obligated to care for Erik in the best possible way, and to ensure his decision is informed and that he is aware of possible risks arising from his decision. The public health nurse and GP need to ensure, in so far as is possible, that his refusal is not influenced by wider factors that could have been addressed in the care planning process. All discussions about rights and risks are documented.

**7.5 Agree person-centred supports**

In this stage of the framework, the person is supported to be more autonomous, or self-directing, in their care, support or treatment. The level of support that will be required to enable a person to be autonomous can vary depending on the issues involved. Supporting a person to be autonomous is sometimes referred to as capacity building. This means that the support assists the person to have greater ability to make their own decisions and live more independently. This type of support is relevant in health and social care settings, even though the specific nature of support may vary.

In social care, support may involve skills teaching about relationships and boundary setting for a young adult with an intellectual disability. This will allow the person to be more autonomous in interacting with their peers. In an acute care setting, supportive measures may involve using a language interpreter to assist a non-English speaking person to understand the treatment the medical team is proposing. This will facilitate an informed-consent process. More long-term supportive measures in the healthcare setting may involve education and skills development to promote independence in the management of chronic illness. Access to service providers is an important element of support for people with long-term conditions.

Supportive measures are consistent with the Assisted Decision-Making (Capacity) Bill 2013. The bill outlines procedures for decision-making assistance agreements, where somebody is appointed by a person to assist, or support, them in the decision-making process.<sup>~</sup> Supports are also an important part of balancing safeguarding with promoting autonomy. Supported decision-making has been positively evaluated. It has been shown to increase the confidence of people who have been supported, increase the extent to which they feel in control of their lives and improve their decision-making ability.<sup>(54)</sup> Ongoing support is also recognised as an important feature of promoting autonomy and independence in the management of long-term

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<sup>~</sup> This is only one provision of the bill. The bill also outlines other supportive measures, which are detailed further in Appendix 4. This bill has not yet been passed and not currently law in Ireland.

conditions. Supported mechanisms are identified on the basis of individual assessment and evaluated to decide their effectiveness. The resource section of this document highlights a number of helpful documents and websites to assist you in supporting the decision-making of people who access your services.

### **What this means for service providers**

- Service providers identify and provide individualised supports to promote autonomy, choice, decision-making and independent living.

### **Examples of person-centred support include:**

- including other people in the decision-making process, with the service-user's consent, in line with the law
- promoting informed decision-making by providing person-centred communication
- providing home care plans to promote independent living
- building skills in the use of public transport to promote autonomy in community living
- providing education and ongoing support for people with long-term care needs, for example, individuals receiving home dialysis therapies
- developing decision-making ability through the use of decision-making diaries
- scheduling first or last hospital appointment times for people with specific communication needs to promote their decision-making capacity.

### **Case study A, John: Example 5**

John is supported in decision-making by ensuring an informed-consent process that meets his individual needs. The team at the hospital pre-assessment clinic also considers how John can be supported to make decisions, and have his autonomy respected during his time as an inpatient. The team makes specific reference to John's hospital passport as a useful tool in his admission notes. With his permission, the involvement of John's daughter is also another form of support.

### **Case study B, Claire: Example 5**

Claire's will and preferences to travel independently by bus is respected in the example above. Her decision and autonomy are supported. Claire receives support in the form of information she can understand about the risks involved in using public transport in the town centre. The step-by-step programme to build her ability and confidence in applying the rules of the road, and using public transport safely, is a vital aspect of support in this example. The sense of autonomy in community could be enhanced if the local bus

company is informed that some passengers may require more assistance in buying tickets and locating their stop. Some bus companies are willing to work with services in this regard. The involvement of the wider community in supporting people with decision-making and independent living is an important factor.

### **Case study C, Erik: Example 5**

Erik is supported by appropriate communication to allow him an opportunity to express his difficulties adjusting to his illness at this point in time. Further support is offered in the form of additional education about his diabetes, and practical measures to accommodate his treatment regime in his everyday life. The public health nurse working with Erik, arranges, in so far as is possible, dressing changes to accommodate his personal needs.

## **7.6 Implement and evaluate supportive actions**

In this step, health and social care providers implement supportive actions and facilitate their choices where possible with regard to care, support and treatment. Ongoing evaluation of supportive mechanisms is required. People's ability to make autonomous decisions, carry out their autonomous wishes and the level of support they require to do so can vary over time. The supportive systems put in place may result in increasing a person's independence and ability to make future decisions.

Alternatively, changes in the person's health or general life circumstances may mean that a greater level of support is required in future situations. This can only be known through ongoing engagement with the person and assessment and identification of their changing needs.

### **What this means for service providers**

- Service providers appreciate that a person's ability to be autonomous can change over time.
- Service providers evaluate supportive measures in place to decide if they remain effective for the person's needs.

### **Examples of implementing and evaluating supportive actions include:**

- implementing supportive measures with agreement by the person and multidisciplinary team
- constantly evaluating all supportive mechanisms to decide their effectiveness and any changes required.

### **Case study A, John: Example 6**

John's cognitive abilities may have deteriorated when he is admitted to hospital for surgery. This may alter his decision-making ability for this hospital stay. Additional supports may need to be put in place to maintain his role in the decision-making process. His capacity may need to be assessed in relation to each decision to be made.

Under existing legislation, if John is considered to lack capacity, he may then become a Ward of Court, and decisions regarding his care will either be made by the High Court, or by a Committee of the Ward appointed by the Court. This would likely be John's daughter in this case study, but not necessarily so. While family members may be consulted about an adult's care and treatment (with permission from the adult) they do not have the legal right to consent to, or refuse treatment, on the person's behalf unless formally appointed in law to do so.

The Assisted Decision-Making (Capacity) Bill 2013, which is currently awaiting enactment, provides for a series of measures to support decision-making, including decision-making assistance agreements. This law, once enacted, would allow John, as one option, to assign his daughter, or another individual, as his designated healthcare representative in an advance healthcare directive. John would do this while he had the necessary capacity. Once this legislation is enacted, codes of practice will be developed to outline the process of decision-making for individuals who require support.<sup>6</sup>

Even when deemed to lack the capacity to make his own decisions, John's autonomy can be promoted by ensuring his care, support and treatment reflects any previously expressed will and preferences. Advance care planning documentation, a life-story book, John's communication or hospital passport or communication with John's family and friends could assist in providing this evidence.

### **Case study B, Claire: Example 6**

Claire makes great progress and enjoys travelling to the education centre independently. The exposure to, and appropriate management of, risk has greatly increased her self-confidence. The staff at the centre and her parents may be less apprehensive regarding Claire's future choices and preferences.

<sup>6</sup> For current information on the status of the Assisted Decision-Making (Capacity) Bill 2013, see the Houses of the Oireachtas' website: <http://www.oireachtas.ie/viewdoc.asp?DocID=24147&&CatID=59>.



**Case study C, Erik: Example 6**

Erik agreed to the vacuum-assisted dressing for a while but later changed his mind and refused to give consent, despite ongoing interaction from the public health nurse and GP. The discussion that took place and Erik's refusal of treatment is documented by the professionals involved. An alternative dressing is now in place. It is not working as effectively. The public health nurse and GP continue to work with Erik.

**8. Barriers to autonomy**

Sometimes barriers can exist which inhibit the ability of people who use health and social care services to be autonomous. Some individuals may lack the ability to communicate, or facilitate, their own will and preferences. Person-centred communication, individualised supports, communication with significant others and advance care planning may assist in this process. Organisational barriers to autonomy include:

- an organisational culture that does not respect service-user autonomy
- a risk averse, overprotective approach to care
- staff who do not implement actions or supports to promote autonomy.

This framework presented within this guidance document can assist service-providers to promote autonomy and support organisational change.

Insufficient funding and resources to neither meet personal will and preferences nor provide sufficient supports are another significant barrier. When a lack of resources prevents measures to promote autonomy, this should be made known to the appropriate authorities. A lack of resources does not mean that poor standards of care are acceptable. Prudent management of resources is essential.

In some instances, practical solutions may be found that do not require additional funding. Resource decisions should take account of the needs of people and the levels of demand on the service. Staff who make decisions on the use of resources are accountable for the decisions made, and should ensure these decisions are well informed.<sup>(17)</sup>

## **9. Conclusion**

Promoting the autonomy of people who use health and social care services is a central aspect of person-centred care. Promoting autonomy involves service providers engaging with people who use services to respect their dignity, privacy and personal preferences. This includes assisting an individual, as required, to make informed decisions about the care, support and treatment that he or she receives.

The supporting autonomy framework outlined within this document provides a practical tool to assist providers in promoting autonomy in their services.

It is important to engage with people to balance any safety concerns with promoting autonomy. This will help avoid a risk-averse service developing. It is also important to view the informed consent process as an ongoing process of dialogue with the person receiving care, support or treatment. This guidance should be interpreted in parallel with the law and contemporary national health and social care policies.

In the development of this guidance, many comments were received from those engaged with. Specifically, one service provider outlined:

“This is an extremely interesting and welcome document and when put in place will further empower the individuals accessing, or already in our services. The inclusion of service users in a meaningful way is long overdue but can be challenging to put in place. The document is informative and thought provoking for staff and hopefully will encourage us to examine our own attitudes, take account of our own communication skills and encourages us to treat others with respect.”

The reflective checklist provided in Appendix 5 will help you to decide the extent to which you promote autonomy in your place of work.

## Resources

This section lists a series of published resources that directly support the individual steps in the framework. A list of wider reading related to the guidance is included in the reference list that follows.

This list is not exhaustive. It does not include all the resources that may be relevant to service providers. It is up to service providers to identify the best available, and most current, evidence relevant to their activities.

All online resources and references were accessed when preparing this guidance document.

### Respect the person's right to autonomy

Anthony, S. *Consent to Medical Treatment in Ireland*. London: Medical Protection Society; 2015. Available online from:  
<http://www.medicalprotection.org/docs/default-source/pdfs/Booklet-PDFs/ireland-booklets/consent-to-medical-treatment-in-ireland---an-mps-guide-for-clinicians.pdf?sfvrsn=0>.

Assisted Decision-Making (Capacity) Bill 2013. Dublin: Stationery Office; 2013. Available online from:  
<http://www.oireachtas.ie/viewdoc.asp?DocID=24147&&CatID=59>.

Department of Health. *Towards a Restraint Free Environment in Nursing Homes*. Dublin: Department of Health; 2011. Available online from:  
<http://health.gov.ie/blog/publications/towards-a-restraint-free-environment-in-nursing-homes/>.

Health Service Executive (Social Care Division). *Safeguarding Vulnerable Persons at Risk of Abuse: National Policy & Procedures*. Dublin: Health Service Executive; 2014. Available online from:  
<http://www.hse.ie/eng/services/publications/corporate/personsatriskofabuse.pdf>.

Letts, P (General Ed). *Assessment of mental capacity: A practical guide for doctors and lawyers*. 3<sup>rd</sup> Edition. London: British Medical Association and the Law Society; 2009.

National Consent Advisory Group. *Consent: A guide for health and social care professionals*. Dublin: Health Service Executive; 2013. Available online from:  
[http://www.hse.ie/eng/about/Who/qualityandpatientsafety/National\\_Consent\\_Policy/Consentguidehealthsocialcareprofessionals240414.pdf](http://www.hse.ie/eng/about/Who/qualityandpatientsafety/National_Consent_Policy/Consentguidehealthsocialcareprofessionals240414.pdf).

Tysall, A and Duffy, A. *Open Disclosure: National Guidelines*. Dublin: Health Service Executive and State Claims Agency; 2013. Available online from:  
[http://www.hse.ie/eng/about/Who/qualityandpatientsafety/nau/Open\\_Disclosure/opendiscFiles/opdiscnationalguidelines2013.pdf](http://www.hse.ie/eng/about/Who/qualityandpatientsafety/nau/Open_Disclosure/opendiscFiles/opdiscnationalguidelines2013.pdf).

The Irish Hospice Foundation. *Ethical Framework for End of Life Care. Module 4: Patient Autonomy in Law and Practice*. Available online from:  
<http://hospicefoundation.ie/wp-content/uploads/2013/10/Module-4-Patient-Autonomy-in-Law-and-Practice.pdf>.

### **Avoid pre-judging**

Assisted Decision-Making (Capacity) Bill 2013. Dublin: Stationery Office; 2013. Available online from:  
<http://www.oireachtas.ie/viewdoc.asp?DocID=24147&&CatID=59>.

### **Communicate appropriately to establish, explore and promote preferences**

Accessible Information Working Group. *Make it Easy: A guide to preparing Easy to Read Information*. Accessible Information Working Group; 2011. Available online from: <http://info.iaslt.ie/wp-content/uploads/2013/07/Make-it-Easy-December-2011.pdf>.

Alzheimer's Society (UK) and Royal College of Nursing. *This is me — tool for people with dementia receiving professional care*. Available online from:  
[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1290](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1290).

Anthony, S. *Consent to Medical Treatment in Ireland*. London: Medical Protection Society; 2015. Available online from:  
<http://www.medicalprotection.org/docs/default-source/pdfs/Booklet-PDFs/ireland-booklets/consent-to-medical-treatment-in-ireland---an-mps-guide-for-clinicians.pdf?sfvrsn=0>.

Assisted Decision-Making (Capacity) Bill 2013. Dublin: Stationery Office; 2013. Available online from:  
<http://www.oireachtas.ie/viewdoc.asp?DocID=24147&&CatID=59>.

Citizen's Information Board. *Accessible Information for All*. Citizen's Information Board; 2009. Available online from:  
[http://www.citizensinformationboard.ie/publications/social/downloads/Accessible\\_Information\\_For\\_All.pdf](http://www.citizensinformationboard.ie/publications/social/downloads/Accessible_Information_For_All.pdf).

Letts, P (General Ed). *Assessment of mental capacity: A practical guide for doctors and lawyers. 3<sup>rd</sup> Edition*. London: British Medical Association and the Law Society; 2009.

Molly, W. *Let me decide*. Health and Personal Care Directive; 2012. Available online from: <http://www.letmedecide.ie/index.php/home>.

National Adult Literacy Agency. *Literacy Audit for Healthcare Settings*. Dublin: National Adult Literacy Agency; 2009. Available online from: [https://www.nala.ie/sites/default/files/publications/literacy\\_audit\\_for\\_healthcare\\_settings.pdf](https://www.nala.ie/sites/default/files/publications/literacy_audit_for_healthcare_settings.pdf).

National Consent Advisory Group. *Consent: A guide for health and social care professionals*. Dublin: Health Service Executive; 2013. Available online from: [http://www.hse.ie/eng/about/Who/qualityandpatientsafety/National\\_Consent\\_Policy/Consentguidehealthsocialcareprofessionals240414.pdf](http://www.hse.ie/eng/about/Who/qualityandpatientsafety/National_Consent_Policy/Consentguidehealthsocialcareprofessionals240414.pdf).

Public Health England: Reasonable adjustments database. *My Hospital Passport*. (Hospital passport for people with communication difficulties developed by West Sussex Access to Healthcare Group, Brighton Learning Disability Liaison Team and Sussex Partnership NHS Foundation Trust. Inspired by previous hospital passports developed by Gloucestershire Partnership NHS Trust and St. George's Healthcare Trust.) Available online from: <https://www.improvinghealthandlives.org.uk/adjustments/?adjustment=21>

The Alzheimer Society of Ireland and The Irish Hospice Foundation. *I have dementia: How do I plan for the future?* Dublin: The Alzheimer Society of Ireland; 2015. Available online from: [http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Alzheimers\\_PlanForFuture-Brochure\\_web1-%281%29.pdf?ext=.pdf](http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/publications/Alzheimers_PlanForFuture-Brochure_web1-%281%29.pdf?ext=.pdf).

The Irish Hospice Foundation. *Think Ahead: a guide for members of the public in discussing and recording their preferences in the event of emergency, serious illness or death*. Dublin: The Irish Hospice Foundation; 2015. Available online from: [www.thinkahead.ie](http://www.thinkahead.ie).

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## Balance rights, risks and responsibilities

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## Appendices

### Appendix 1 — Terms of Reference: Autonomy Guidance Advisory Group

1. To advise the Authority during the development of guidance on promoting service user autonomy in health and social care services.
2. To advise on a guidance document that will:
  - Support existing standards from the authority, and associated regulation, with regard to promoting autonomy and person-centred care.
  - Reflect recent evidence, relevant legislation and national policy documents of reference to autonomy/decision-making in health and social care.
  - Explain what autonomy means for services providers and people who use those services.
  - Outline a model of communication/interaction to support the promotion and facilitation of autonomy in health and social care services.
  - Be fit for purpose as practical guidance for health and social care professionals, individuals who access those services, regulators and local ethics committees.
  - Provide a means to reconcile respect for autonomy and individual choice with service-provider responsibility and accountability.
3. To advise on the final guidance document in preparation for approval by the Executive Management Team of the Health Information and Quality Authority.

## Appendix 2 — Members of the Autonomy Guidance Advisory Group convened by the Health Information and Quality Authority

Name	Affiliation
Dr Anna-Marie Greaney, Chairperson and Project Lead	Institute of Technology, Tralee
Paul Alford	Inclusion Ireland
Bernie Austin	Health Service Executive
Emer Begley	The Alzheimer Society of Ireland
Ann Bridge	World Health Organization Alliance, Patients for Patient Safety <sup>◇</sup>
Michael Corbett	Disability Federation of Ireland
Eilionóir Flynn	Centre for Disability Law and Policy, NUIG
Tony Foley	General Practitioner
James Forbes	ChildVision: National Education Centre for Blind Children
Mary Godfrey	State Claims Agency
Mary-Rose Gough	Member of Relatives' Panel, Health Information and Quality Authority
Joan Heffernan	Health Information and Quality Authority <sup>*</sup>
Paul Ivory	Bioethics Unit, Department Of Health
Marie Kehoe-O'Sullivan, Director, Safety & Quality Improvement and Project Sponsor	Health Information and Quality Authority
John Kubiak	National Institute for Intellectual Disability, Trinity College Dublin

<sup>◇</sup> Until April 2015.

<sup>\*</sup> Until February 2015.

Name	Affiliation
Miriam McCarthy	Health Service Executive <sup>o</sup>
Sinead McEvoy	Health Information and Quality Authority <sup>‡</sup>
Josephine Mcloughlin	St John of Gods
Regina McQuillan	Beaumont Hospital / St Francis Hospice
Fiona Martin	Cherry Orchard Hospital
Danielle Monahan	SAGE, Support & Advocacy Service for Older People
Linda Moore	Health Information and Quality Authority <sup>‡</sup>
Aine Ní Aileagain	Inclusion Ireland
Brid-Ann O'Connor	Kerry Parents and Friends Association
Patricia O'Sullivan	Service-user
Margaret Philbin	Irish Association of Directors of Nursing and Midwifery
Iryna Pokhilo	Cairde: Challenging ethnic minority health inequalities
Kathy Ryan	Irish Dementia Working Group
Lorraine Ryan	Social Care Ireland
Asim A. Sheikh	Barrister at Law / University College Dublin
David Smith	Royal College of Surgeons in Ireland
Gregory Swanwick	Health Service Executive

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<sup>o</sup> Until May 2015.

<sup>‡</sup> Until May 2015.

<sup>‡</sup> Until July 2015.

## **Appendix 3 — Location and membership of the three action-learning groups<sup>×</sup>**

### **ChildVision, National Education Centre for Blind Children, Grace Park Road, Drumcondra, Dublin 9**

(Incorporating residential and vocational education services for young adults with an intellectual disability)

Mary Burke, Staff Nurse, Intellectual Disability

Mary-Theresa Cahill-Kennedy, External Advocate

James Forbes, Head of Care (Action-learning Site Lead)

Tracy Hale, Vocational Education Coordinator

Marion Hayes, Family Member

Michael Hayes, Service-user

Ger Hopkins, Social Care Worker — Residential Services, Orientation and Mobility Instructor

Orlaith Jackson, Service-user

Roisin Winters, Social Care Worker — Residential Services.

### **Croom Orthopaedic Hospital, Croom, Co. Limerick**

Patricia Fitzgerald, Staff Nurse

Miriam McCarthy, Patient Advocacy Liaison Services Manager (Action-learning Site Lead until May 2015)

Mary Neenan, Service-user (previous inpatient)

Eileen O'Sullivan, Service-user (outpatient)

Bonita Page, Medical Social Worker

Geraldine Ringrose, Family Member

Raymond Sheehy, Healthcare Assistant

Rosalie Stack, Physiotherapist (Action-learning Site Lead from May 2015).

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<sup>×</sup> The names of services and individuals are listed here with their permission.

**St Brendan's Community Nursing Unit, Lake Road, Loughrea, Co. Galway**

Bernie Austin, Director of Nursing (Action-learning Site Lead)

Sabina Fahy, Consultant Psychiatrist of Old Age

Jimmy Kennedy, Service-user

Trish Martyn, SAGE, Support and Advocacy Services for Older People

Callum McGougan, Occupational Therapist

Brian O'Brien, Family member

Patsy-Ann Quinn, Occupational Therapist

Edel Shiel, Clinical Nurse Manager.

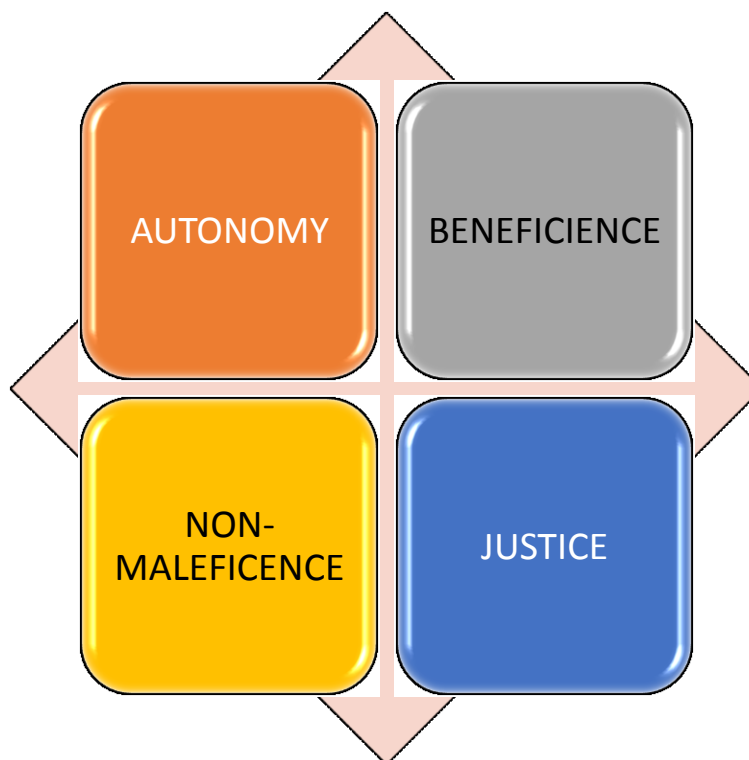


## Appendix 4 – Understanding autonomy in health and social care

### 1. Autonomy and ethical principles

While autonomy is supported by the law, it is also important in another system of rules and principles known as ethics. Ethics is about the rightness and wrongness of actions. Sometimes, the terms ethics and morality are used to mean the same thing. Actions may be determined as unethical (immoral) even if they are permissible in law. Ethics gives us another way to view the world or judge how appropriate actions may be. There are a number of ethical principles which can be considered when deciding what the right course of action is. Autonomy is one of these principles, along with beneficence (to do good), non-maleficence (to do no harm) and justice (to treat people fairly).<sup>1</sup> See Figure 1.

**Figure 1. Principles of bio-medical ethics (Beauchamp and Childress 2013)**



Sometimes, principles can conflict with one another. For example, from time to time, a person's choices (respecting the principle of autonomy) could result in harm to themselves or others (contrary to the principles of beneficence and non-maleficence). This is an ethical dilemma, as outlined in the example which follows. The guidance in this document can support ethical decision-making in dilemmas involving personal autonomy. An ethical decision-making framework, of which a number exist, can also assist in this process. These frameworks adopt a problem-

solving approach to ethical decision-making and help with the thought processes necessary to make ethical decisions.<sup>28</sup>

### **Example of an ethical dilemma where other ethical principles conflict with autonomy**

Magda is a young woman with a diagnosis of type 1 diabetes. Magda has recently refused to take her insulin medication. Her refusal continues despite being told by her diabetes team about the risks of hyperglycemia (high blood glucose levels) as a result of not taking it.

Magda's expressed preference, her choice, is to discontinue her insulin (the principle of autonomy) but the healthcare team is aware of the risks this poses to her health and life (the principles of beneficence and non-maleficence).

This is a typical situation that health and social care professionals may find themselves in, when promoting a person's autonomy conflicts with their professional responsibilities to deliver evidence-based care. It is important to note that respect for autonomy, and measures to promote autonomy, do not abdicate professional responsibility for the standard of care delivered. It is essential to reconcile professional accountability with respect for the autonomy of people who use health and social care services. Magda's choices will require discussion and exploration.

There may be specific issues in Magda's life that are resulting in her refusal to take her medication at this time. For example, she may have had a bereavement, be stressed because of exams, or may have concerns about side effects. There may be other treatment options, though less effective, to explore. If Magda continues to refuse insulin therapy, and is assessed to have the capacity to do so, this choice must be respected. The law supports the right of a person to make what may be considered an unwise decision if they are deemed to have the necessary capacity. This is also supported by the Assisted Decision-Making (Capacity) Bill 2013. The supporting autonomy framework outlined in this guidance document provides a pathway to reconcile the principles of autonomy, beneficence and non-maleficence in a staged process.

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<sup>28</sup> The Irish Hospice Foundation provides a series of online modules as part of the Ethical Framework for End-of-Life Care to support ethical decision-making at end of life. These modules, developed in association with University College Cork and Royal College of Surgeons in Ireland provide further material of relevance on autonomy, ethics and the law. This is available online from: <http://hospicefoundation.ie/healthcare-programmes/hospice-friendly-hospitals/initiatives-staff-development/ethical-decision-making/>[sic].

## 2. Autonomy and community — relational autonomy

Philosophers have varied ideas about the extent to which autonomy involves absolute control over personal preferences and isolated decision-making. Research has shown that in the real world of practice, autonomy can be experienced as an independent process.<sup>3</sup> This guidance builds on a relational understanding of autonomy, or autonomy in a community. In this sense, autonomy does not involve isolated decision-making. Rather, it involves our interdependent relationships with other people.<sup>4</sup> People often consult with, or consider, others when making decisions and may invite others to assist in the decision-making process.

In the same way, autonomous decisions in health and social care sometimes necessitate assistance from service-providers, and involve considering factors beyond a person's personal preferences. Respecting the autonomy of others (in certain situations), and living within the laws of the state, may limit the extent of people's personal preferences. This does not mean that autonomy is less important. Making decisions involves considering how those decisions affect others. This involves meaningful communication and may on occasion require negotiation and compromise.

### Example of autonomy in a community

Stephen lives in a designated residential centre for adults with an intellectual disability. He enjoys listening to late-night radio on high volume. This is an expression of his autonomy (his personal will and preferences). However, respect for the autonomy of the people he lives with (and their right to a good night's sleep) requires consideration.

In discussion with his link worker, and the other residents at the house meeting, Stephen agrees to use headphones, or listen to his music in another part of the house where others will be undisturbed. Stephen's preferences remain important but his final actions incorporate a concern for others.

In a wider sense, the role of community is important in promoting autonomy. Recent initiatives such as dementia-friendly communities can contribute to the independence and quality of life of people living with dementia.<sup>5</sup> The supporting autonomy framework in this document helps develop such initiatives to promote the autonomy of people who use health and social care services.

### 3. Autonomy and the law <sup>△</sup>

The right to autonomy is protected in Ireland in accordance with Article 40.3.1 of the Constitution of Ireland.<sup>6</sup> The right to autonomy is not specifically mentioned, but is interpreted by the courts as an aspect of the constitutional right to privacy. The right to autonomy is understood in healthcare law to include the right to consent to, or refuse, medical treatment.<sup>7</sup> Autonomy is also indirectly protected in line with Article 8 of The European Convention on Human Rights, as an associated right to respect for privacy, family life and the home.<sup>8</sup>

The 2006 United Nations (UN) Convention on the Rights of Persons with Disabilities, which came into force in 2008, refers specifically to the autonomy of people with disabilities.<sup>9</sup> The convention obliges Member States to provide people with disabilities with access to the necessary supports to make their own decisions. The Convention represents a significant change in how people with disabilities are supported to make their decisions.<sup>Φ</sup>

In line with the Convention, many countries are moving from a protective legal focus on the best interests of the individual to one that respects and promotes autonomy. This means that what is in somebody's best interests, according to health and social care professionals, while important, is no longer the overriding factor in the decision-making process. In line with the UN Convention, an individual's personal will and preferences is central to promoting their autonomy.

In Ireland, the Assisted Decision-Making (Capacity) Bill 2013 reflects this change in many respects.<sup>10</sup> The bill provides for a reform of the law in individuals who require, or may require, future assistance to make decisions (exercise their legal capacity). The reform includes removal of the existing ward-of-court system and providing a series of measures to support decision-making. Supportive measures in the bill include provision for:

- decision-making assistance agreements
- the appointment of co-decision-makers
- nominating an attorney under an enduring power of attorney
- the appointment of a designated healthcare representative in line with an advance healthcare directive.

The principles of the bill include a presumption of mental capacity and the right of a person to make what may be deemed to be an unwise decision.

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<sup>△</sup> All guidance should be interpreted in accordance with existing legislation

<sup>Φ</sup> At the time of publication, Ireland has signed up to, but not ratified this treaty. Ratification is pending following enactment of the Assisted Decision-Making (Capacity) Bill 2013.

The bill outlines a functional assessment of mental capacity (the ability to make a decision is decided on during a specific decision at a specific time). This is instead of a status approach to capacity (an individual's decision-making ability is decided by their diagnosis).<sup>Σ</sup> The level of support required to enable a person to make their own decisions may vary considerably. In some cases, simply providing a person with the opportunity to make decisions is enough. For others, support in the form of appropriate communication may be required to help with decision-making. Ongoing support may be required to enable individuals to enact their personal choices. The supporting autonomy framework in this guidance provides a pathway to enable assistance with decision-making.

Autonomy underpins the legal principle of informed consent. The National Consent Advisory Group's National Consent Policy<sup>11</sup> specifies the importance of communication and information sharing in the consent process. In order for a person to make an informed consent, the common law states that he or she requires the necessary capacity to make that decision. The courts currently assess capacity in line with a functional approach, as outlined above. This means that a person is deemed to have capacity to consent to a service, or refuse a treatment or service, if they meet certain criteria.

### **Capacity to consent to treatment as interpreted in the Irish courts**

Capacity to consent to or refuse treatment is dependent on the following criteria:

- Does the person understand and retain the information?
- Does the person believe the information?
- Does the person use the information to weigh up the risks and benefits of the situation and make a choice?<sup>Ω</sup>

It is also essential that an individual give their consent freely. Health and social care providers can educate and advise but not coerce people to make decisions. In essence, informed consent has three core elements: full disclosure, capacity and voluntariness. Adherence with the criminal law and certain provisions of the Mental Health Act 2001<sup>12</sup> mean that all personal will and preferences may not be respected.

<sup>Σ</sup> The UN Committee has expressed concern that a functional approach to capacity, as in the functional test, may place too onerous an obligation of proof on the person. There is also concern from a human rights perspective, that a lack of mental capacity, when assessed in this way, is then used to deny legal capacity. For further detail see: Committee on the Rights of Persons with Disabilities, *General Comment No. 1 – Article 12: Equal Recognition Before the Law*, Paragraph 12-15, UN Doc. No. CRPD/C/GC/1, adopted at the 11<sup>th</sup> Session (April 2014).

<sup>Ω</sup> This is referred to as the 'C test'. The C test is based on UK case law, *Re C - Re C* [1994] 1WLR 290. Recent case law in Ireland supports this (*Fitzpatrick & Anor v K & Anor* [2008] IEHC 104).

#### **4. Respecting autonomy and professional accountability — towards a solution**

Health and social care providers are required to consider the concept of autonomy in association with the law, contracts of employment, regulatory requirements, organisational policies and professional codes of conduct. Therefore, they may have concerns that respecting autonomy conflicts with professional responsibility and accountability to deliver safe, quality and evidence-based care. This is when an individual's autonomous decision (the principle of autonomy) may conflict with a professional's obligation to do no harm and promote the wellbeing of those in their care (the principles of beneficence and non-maleficence).<sup>13</sup>

Respecting autonomy does not mean that these issues are unimportant. It means that professionals communicate with service users to ensure that decisions are informed, and undertake appropriate risk assessments in light of the person's wishes. Positive risk assessment will focus on the value of risk as well as the possible hazards.<sup>14</sup> The relevance of positive risk assessment may vary depending on the issue and the specific health and social care setting. It is important that health and social care professionals document discussion about risks, and any service-user decisions to disregard the advice given about their care, support or treatment.<sup>9</sup>

A process of engagement and person-centred communication is essential to balance respect for autonomy with a professional concern to care 'in the best way'. The framework presented in this guidance draws on an understanding of autonomy in a community as outlined above, and builds on theoretical accounts of respect for autonomy within a caring, accountable and professional relationship.

#### **5. Autonomy as context-dependent and optional**

An individual may require greater help with autonomy at different points in their lives. In addition, an individual may require health and social care professionals to take a greater role in the decision-making process at certain points in their care, support or treatment. Research has shown that sometimes people who use services like to place trust in their healthcare professionals to make the right decisions for them.<sup>15</sup> While research has shown that people like their healthcare providers to respect their autonomy,<sup>16</sup> studies have also shown that when receiving care, people sometimes prefer a more shared approach to decision-making.<sup>17</sup> Research also suggests that decision-making can create distress for some people.<sup>18</sup>

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<sup>9</sup> Should a person experience an adverse event when using health and social care services, any legal action will be judged on its own merit, to determine if negligence has occurred. The courts in Ireland have outlined the relationship between patient and specialist as a 'dependent' one and extend particular duties to healthcare providers. As an example see *Philip v Bon Secours Hospital* [2004] IEHC 121. Patient responsibility cannot be assumed if this is not properly informed and supported.

There is some concern that an overemphasis on informed consent and a rights-based culture may minimise the trust that is important in a therapeutic and caring relationship.<sup>19</sup> When informed consent is interpreted only as the signing of a consent form, it does not promote autonomy effectively. Respect for autonomy also involves respecting a person's wish not to engage in every decision-making opportunity. Mandatory autonomy is not appropriate. It can impede autonomy, as it disregards personal will and preference, and could result in undue stress.<sup>20</sup>

## **6. Autonomy, advance care planning and advance care directives**

Advance care planning is recognised as an important aspect of promoting the autonomy of people who use health and social care services. Advance care planning enables people to highlight their will and preferences about their care, support and treatment in future care situations when they may not be in a position to communicate their wishes. Legislation to support advance care planning in Ireland is pending as part of the Assisted Decision-Making (Capacity) Bill 2013. The bill provides a legislative framework for advance care directives.

The provisions in the bill will enable a person to prepare an advance care directive, detailing the care they would like to receive, or not receive, in future healthcare situations. The bill also provides for the appointment of a designated healthcare representative. A list of resources to assist in advance care planning is provided in the resources section of this HIQA guidance document. These resources can be used in the absence of specific legislation. However, once the legislation is enacted, it will provide greater clarity for service providers and service users on using advance care planning instruments and their legal status.

## Notes to Appendix 4

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<sup>1</sup> Beauchamp, T and Childress, J. *Principles of biomedical ethics*. 7<sup>th</sup> Edition. New York: Oxford University Press; 2013.

<sup>2</sup> Benjamin M and Curtis, J. *Ethics in nursing: Cases, principles and reasoning*. 4<sup>th</sup> Edition. New York: Oxford University Press; 2010.

<sup>3</sup> See:

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<sup>4</sup> Meyers, D. *Self, society and personal choice*. New York: Columbia University Press; 1989.

<sup>5</sup> The Alzheimer's Society of Ireland. *Defining and Delivering on Dementia Friendly Communities*. Dublin: The Alzheimer's Society of Ireland; 2011.

<sup>6</sup> *Constitution of Ireland*. Dublin: The Stationery Office; 1937 (2012 edition).

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<sup>7</sup> Madden, D. *Medical Law in Ireland*. Kluwer Law International, The Netherlands; 2011.

<sup>8</sup> Council of Europe, Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights, as Amended) (ECHR) Article 8. Geneva: Council of Europe: 1950.

<sup>9</sup> UN General Assembly, *Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly, 24 January 2007, A/RES/61/106*.

Available online at: <http://www.un-documents.net/a61r106.htm>.

<sup>10</sup> Assisted Decision-Making (Capacity) Bill 2013. Dublin: Stationery Office; 2013.



<sup>11</sup> National Consent Advisory Group. *National Consent Policy*. Dublin: Health Service Executive; 2013.

<sup>12</sup> Mental Health Act 2001. Dublin: Stationery Office; 2001.

<sup>13</sup> See:

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- b. Kukla, R. Conscientious autonomy: displacing decisions in health care. *Hastings Centre Report*. 2005 35(2): pp.34-44.
- c. Tauber, AI. *Patient autonomy and the ethics of responsibility*. Cambridge: MIT Press; 2005.
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- e. Mol, AM. *The logic of care: Health and the problem of patient choice*. London: Routledge; 2008.

<sup>14</sup> See:

- a. Morgan, S. Positive risk-taking: a basis for good risk decision-making. *Health Care Risk Report*. March 2010: pp.20-21. Available online at: <http://static1.1.sqspcdn.com/static/f/586382/9502389/1290262470707/HCCR+16-4morgan.pdf?token=k3j3ciVukfDiJTwp7EqJBbspc%3D>.
- b. Department of Health (UK). *Independence, choice and risk: a guide to best practice in supported decision-making*. London: Policy Management Unit; 2006. Available online from: [http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh\\_074773](http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_074773).

<sup>15</sup> Schildmann J, Ritter P, Salloch S, Uhl W and Vollmann J. 'One also needs a bit of trust in the doctor...' a qualitative interview study with pancreatic cancer patients about their perceptions and views on information and treatment decision-making. *Annals of Oncology*. 2013 24: pp.2444-2449.

<sup>16</sup> See:

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- b. Oliveira VC, Refshauge KM, Ferreira ML, Pinto RZ, Beckenkamp PR, Negrao Filho RF and Ferreira PH. Communication that values patient autonomy is associated with satisfaction with care: a systematic review. *Journal of Physiotherapy*. 2012 58(4): pp.215-229.

<sup>17</sup> Hamann J, Neuner B, Kasper J, Vodermaier A, Loh A, Deinzer A, Heesen C, Kissling W, Busch R, Schmieder MD, Spies C, Casparis C and Harter M. Participation preferences of patients with acute and chronic conditions. *Health Expectations*. 2007 10: pp.358-363.

<sup>18</sup> Myron R, Gillespie S, Swift P and Williamson T. Whose decision? Preparation for and implementation of the Mental Capacity Act in statutory and non-statutory services in England and Wales. London: Mental Health Foundation; 2008.

<sup>19</sup> Turillazzi, E and Neri, M. Informed consent and Italian physicians: change course or abandon ship — from formal authorisation to a culture of sharing. *Medicine, Healthcare and Philosophy*. 2015 18: 449-453.

<sup>20</sup> Davies, M and Elwyn, G. Advocating mandatory patient 'autonomy' in healthcare; adverse reactions and side effects. *Health Care Analysis*. 2008. 16(4), pp. 315-328.

## Appendix 5 — Self-reflection checklist for health and social care providers: Am I respecting and promoting autonomy?<sup>∅</sup>

Use the 20-item checklist below to assist you to reflect on the extent to which you promote autonomy.

### Respect the person's right to autonomy

1. Do I value the service-user's right to privacy and dignity?
2. Do I respect the service-user's knowledge, preferences and choices?
3. Do I appreciate the person's right to make decisions that I may consider unwise?

### Avoid pre-judging

4. Do I avoid making assumptions about decision-making ability?
5. Do I understand that a lack of ability to make some decisions does not mean an inability to make any decisions?
6. Do I rush to capacity assessment if the person does not agree with what the service suggests?

### Communicate appropriately to establish, explore and promote preferences

7. Do I communicate with people in a manner they can understand?
8. Do I make an effort to know the person and what is important to them?
9. Do I take the time to ensure that a person's decisions are informed?
10. If I am unable to support a person's choices, do I explain this and give the reasons why?
11. Do I make every effort to communicate in a manner that builds decision-making capacity?
12. If an assessment of capacity is required, do I carry this out in accordance with the law?

<sup>∅</sup> This checklist was inspired by the work of Chiovitti (2011) who encourages self-reflection as a means to balance safety and personal choice in professional caring relationships. For further information see: Chiovitti, R.F. 2011. Theory of protective empowering for balancing patient safety and choice. *Nursing Ethics*. 2011 18(1): pp.88-101.

### Balance rights, risks, and responsibilities

- 13. Am I overprotective?
- 14. Do I carry out risk assessments that balance the positive and negative aspects of risk taking?
- 15. Are risk assessments based on best available evidence?

### Agree person-centred supports

- 16. Do I consider how personal choices can be facilitated when limitations exist?
- 17. Do I consult with service users and colleagues to identify supports that may be required to promote autonomy?
- 18. Do I retain a commitment to supporting autonomy even when this may be challenging?

### Implement and evaluate supportive actions

- 19. Do I appreciate that autonomy and decision-making ability fluctuate?
- 20. Do I evaluate supports, to decide if additional, or less, support is required?





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