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Category: Operational Policies

Subject: Consent Policy

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Introduction

Consent is the giving of permission or agreement for receipt or use of a service or personal information following a process of communication about the proposed service. Consent must be obtained before starting to provide personal or social care for a service user. This requirement is consistent with fundamental ethical principles, with good practice in communication and decision-making and the need for consent is also recognised in Irish and international law.

Scope of this policy

The need for consent, and the application of the general principles in this policy, extends to all services provided by or on behalf of the West Limerick Independent Living to service users in all locations. How the



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principles are applied, such as the amount of information provided and the degree of discussion needed to obtain valid consent, will vary with the particular situation.

In some situations, <u>permission</u>, is as matter of common courtesy and of respect for the service user, rather than <u>consent</u> may be required e.g. to enter a person's home, and should be obtained in keeping with relevant West Limerick Independent Living codes of conduct. Knowledge of the importance of obtaining consent is expected of all staff employed or contracted by West Limerick Independent Living.

Ethical issues regarding consent

The ethical rationale behind the importance of consent is the need to respect the service user's right to self-determination (or autonomy) – their right to control their own life and to decide what happens to them.

Service users are the experts in determining what 'ends' matter to them, including how they should live their everyday lives, decisions about risk-taking and preference for privacy or non-interference. With rare exceptions, the competent service user's right to refuse a service/support applies even when their decision seems unwise to the social care professional.

While respect for autonomy is very important, it is not the only ethical principle relevant to consent. Social care professionals also have a responsibility to try and maximise the well-being of, and to minimise harm to, service users and others. This means that service users cannot demand whatever they want, regardless of their effectiveness e.g. health & safety. They also have an obligation to ensure the fair and appropriate use of resources.

Health and social care decision-making

The relationship between those who provide social care and the service user should be a partnership based on openness, trust and good communication. Almost every social care intervention involves decisions made by service users and those providing their care/support.

Good decision making requires a dialogue between parties that recognises and acknowledges the service user's goals, values and preferences as well as the specialist knowledge and experience of social care professionals.

Consent in Irish law

It is a basic rule in common law that consent must be obtained; this is well established in Irish case law and ethical standards. The requirement for consent is also recognised in international and European human rights law and under the Irish Constitution.

Therefore, other than in exceptional circumstances, operating without consent is a violation of service user's legal and constitutional rights and may result in civil or criminal proceedings being taken by the service user.

No other person such as a family member, friend or carer and no organisation can give or refuse consent to a social care service on behalf of an adult service user who lacks capacity to consent unless they have specific legal authority to do so under the Assisted Decision Making (Capacity) Act 2015.



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Social care professionals have a responsibility to keep themselves informed of professional standards relevant to obtaining consent in their profession. Likewise, the employer or service provider has a responsibility to staff to provide access to legal information which may have a bearing on the service provided.

Age of consent in Irish law

The age of consent in Ireland is outlined in the following Acts:

- The Non-Fatal Offences against the Persons Act, 1997 states that persons over the age of 16 years can give consent for surgical, medical and dental procedures.
- The Child Care Act 1991, the Children Act 2001 and the Mental Health Act 2001 define a "child" as a service user under the age of 18 years, "other than a service user who is or who has been married".

What is valid and genuine consent?

Consent is the giving of permission or agreement following a process of communication about the proposed service. The process of communication begins at the initial contact and continues through to the end of the service user's involvement in the provision of social care. Seeking consent is not merely getting a consent form signed; the consent form is just one means of documenting that a process of communication has occurred.

For the consent to be valid, the service user must:

- have received sufficient information in a comprehensible manner about the nature, purpose, benefits and risks of an service.;
- not be acting under duress; and
- have the capacity to make the particular decision.

Providing information and discussing options

The exchange of information between those who provide social care and the service user is central to consent. As stated above, for consent to be valid, the service user must have received sufficient information in a manner that is comprehensible to him or her about the nature, purpose, benefits and risks of a service. The meaning of sufficient information will depend both on the individual circumstances of the service user and on the nature and extent of the service. Ensuring that information is provided in a manner that is comprehensible to the service user requires consideration of the quality of the communication between service provider and service user both in terms of the content of the information to be provided and of how that information should be provided. This will be explained in further detail below.

Importance of individual circumstances

How much information service users want and require will vary depending on their individual circumstances. Discussions with service users should as much as possible be tailored according to:

- Their needs, wishes and priorities
- Their level of knowledge about, and understanding of, their personal support service care and support needs



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- Their ability to understand the information provided/language used
- The nature of their condition.

What information should be provided about a service?

The amount of information to be provided about a service will depend on the level of care/support required, complexity, nature and level of risk associated with the service.

Choosing whether to agree or not to a major lifestyle change such as accessing a home support service often requires the service user to balance the potential risks and benefits of both approaches. In these circumstances, service users need adequate information about:

- The purpose of any proposed service and what it will involve
- The potential benefits, any risks as well as any available alternative
- If relevant, that costs will have to be paid and how and where information about these costs may be obtained.

The nature; and effect of provision of a personal support service e.g. assisted personal care in the home, are often self-evident and relatively risk-free. In these circumstances, it is usually enough for staff to seek consent to proceed after a brief description of the service.

Although service users may be provided with standardised informational material, they should be told if their particular circumstances might modify the risks or benefits as stated in such material.

Service users should be asked if they have understood the information they have been given, and whether or not they would like more information if applicable before making a decision. Questions should be answered honestly and, as far as practical, as fully as the service users wishes.

How and when information should be provided

The manner in which the social care options are discussed with a service user is as important as the information itself. The following measures are often helpful:

- Discuss options in a place and at a time when the service user is best able to understand and retain
 the information. Sensitive issues should be discussed in an appropriate location to ensure that the
 service user's privacy is protected to the greatest degree possible in the circumstances.
- · Providing adequate time and support, including, if necessary, repeating information
- Use of simple, clear and concise English and avoidance of terminology
- Supplementing written or verbal information
- Asking the service user if there is anything that would help them remember information, or make it easier to make a decision; such as bringing a relative, partner, friend, carer or advocate to meetings.

Service users should be given the time and support they need to maximise their ability to make decisions for themselves. It is particularly important to ensure this is the case for those with limited literacy skills and those who may have difficulty making decisions including those with communication difficulties, intellectual disability or cognitive impairment.



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It must not be assumed that a service user lacks capacity to make a decision solely because of communication difficulties, intellectual disability or cognitive impairment.

For those with communication difficulties, speaking to those close to the service user and to other social care staff about the best ways of communicating with the service user, taking account of confidentiality issues, may be helpful.

Additional measures may be required in specific circumstances:

Service users with limited English language proficiency

An interpreter proficient in the service user's language is required to facilitate the service user giving consent. Where practicable, this is best achieved in most cases by using a professional interpreter. The use of family (in particular of minor children) and friends should be avoided if at all possible. Additional time will always be required for discussions involving an interpreter, and this should be planned for in advance.

Deaf and hard of hearing service users

Deaf and hard of hearing service users should be asked how they would like information to be provided. Some individuals with impaired hearing can lip read, some use hearing aids and others may require sign language interpreters. Information can also be made more accessible using text and email applications. If required, a sign language interpreter should be obtained. In relation to the use of children, family and friends as interpreters see section above.

Blind and visually impaired service users

People with a visual impairment should be asked how they would like information to be provided. There are a range of formats that can be used to make written information accessible to people with visual impairments. These include large print, Braille, writing in thick black marker pen and use of audio information. Information can also be made more accessible using text and email applications.

Ensuring consent is voluntary

For consent to be valid the service user must not be acting under duress and their agreement should be given freely, in other words they must understand that they have a choice. Duress refers to pressures or threats imposed by others. Also, duress should be distinguished from providing the service user, when appropriate, with strong recommendations or pointing out the likely consequences of choices the service user may make.

Service users may also be subject to pressure from family and friends to accept or reject a particular service. Staff should take particular care in these circumstances to ensure as far as practical that the service user's decision has not been made under undue pressure and may need to meet the service user alone so that ultimately he or she makes their own decision.



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Has the service user the capacity to make the decision?

General principles

Best practice favours a 'functional' or decision-specific approach to defining decision-making capacity: that capacity is to be judged in relation to a particular decision to be made, at the time it is to be made - in other words it should be issue specific and time specific — and depends upon the ability of an individual to comprehend, reason with and express a choice with regard to information about the specific decision. The "functional" approach recognises that there is a hierarchy of complexity in decisions and also that cognitive deficits are only relevant if they actually impact on decision making.

Duty to maximise capacity

Best practice and international human rights standards favour "supported decision-making" where possible. This requires that efforts must be made to support individuals in making decisions for themselves where this is possible. A service user's ability to make decisions may depend on the nature and severity of their condition, or the difficulty or complexity of the decision. Some service users will always be able to make simple decisions, but may have difficulty if the decision is complex or involves a number of options. Other service users may be able to make decisions at certain times but not at other times, because of fluctuations in their condition or because factors such as confusion, panic, shock, fatigue, pain or medication temporarily affect their ability to understand, retain or weigh up information, or communicate their wishes.

It is important to give those who may have difficulty making decisions the time and support they need to maximise their ability to make decisions for themselves.

Approaches that may be helpful in this regard include:

- Discussing options in a place and at a time when the service user is best able to understand and retain the information
- Asking the service user if there is anything that would help them remember information, or make it easier to make a decision; such as bringing a relative, partner, friend, carer or advocate to consultations, or having written or audio information
- Speak to those close to the service user and to other health and social care staff about the best ways of communicating with the service user, taking account of confidentiality issues.

Presumption of capacity

Those who provide social care services must work on the presumption that every adult service user has the capacity to make decisions about their care, and to decide whether to agree to, or refuse, a service/care plan.

It must not be assumed that a service user lacks capacity to make a decision solely because of their age, disability, appearance, behaviour, medical condition (including intellectual disability, mental illness, dementia or scores on tests of cognitive function), their beliefs, their apparent inability to communicate, or the fact that they make a decision that seems unwise to the social care professional. Capacity should not be confused with a social care professional's assessment of the reasonableness of the service user's decision. The person who has capacity can make their own choices, however foolish, irrational or idiosyncratic others



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may consider those choices. Similarly, the fact that a service user has been found to lack capacity to make a

decision on a particular occasion does not mean that they lack capacity to make any decisions at all, or that they will not be able to make similar or other decisions in the future.

When to consider incapacity

An important implication of the presumption of capacity is that this presumption should not be challenged unless an adequate "trigger" exists. All service users may experience temporary lack of capacity due to severe illness, loss of consciousness or other similar circumstances.

The possibility of incapacity and the need to assess capacity formally should only be considered, if, having been given all appropriate help and support, a service user:

- is unable to communicate a clear and consistent choice or
- is obviously unable to understand and use the information and choices provided.

Assessing capacity to consent

Capacity to consent should be assessed if there is sufficient reason, as indicated in above, to question the presumption of capacity. This involves assessing whether:

- The service user understands in broad terms and believes the reasons for and nature of the decision to be made
- The service user has sufficient understanding of the principal benefits and risks of an service and relevant alternative options after these have been explained to them in a manner and in a language appropriate to their individual level of cognitive functioning
- The service user understands the relevance of the decision, appreciates the advantages and disadvantages in relation to the choices open to them and is able to retain this knowledge long enough to make a voluntary choice.

The fact that a person may not, in their current situation have sufficient understanding or appreciation regarding a decision should in the first instance signal a requirement for the provision of supports in order to ensure that the decision-making capacity of the individual is enhanced to the greatest degree possible, rather than an inevitable finding of incapacity to make that decision.

The social care professional should:

- Consider whether the service user's lack of capacity is temporary or permanent. In those with fluctuating cognitive impairment, it may be possible to make use of lucid periods to obtain consent
- Support and encourage service users to be involved, as far as they want to and are able, in decisions about their care/support
- Seek any evidence of the service user's previously expressed preferences, such as service user's previous wishes and beliefs
- Consider the views of anyone the service user asks you to consult
- Consider the views of people who have a close, ongoing, personal relationship with the service user such as family or friends



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• Consider involving an advocate to support the service user who lacks capacity to participate in the decision making process around consent. This may be particularly helpful in difficult situations such as when service users with no family or friends have to make a complex decision; or when there is significant disagreement regarding the best course of action.

Role of the family

No other person such as a family member, friend or carer and no organisation can give or refuse consent to a social care service on behalf of an adult service user who lacks capacity to consent unless they have specific legal authority to do so.

However, it may be helpful to include those who have a close, ongoing, personal relationship with the service user, in particular anyone chosen by the service user to be involved in decisions, in the discussion and decision-making process pertaining to social care interventions.

Their role in such situations is not to make the final decision, but rather to provide greater insight into his/her previously expressed views and preferences and to outline what they believe the individual would have wanted. In some cases, involvement of those close to the service user will facilitate the service user in reaching a decision in conjunction with social care providers.

Emergency situations involving service users who lack capacity

In emergency situations where a service user is deemed to lack capacity consent is not necessary. While it is good practice to inform those close to the service user – and they may be able to provide insight into the service user's likely preferences - nobody else can consent on behalf of the service user in this situation.

Non-emergency situations involving service users who lack capacity

In non-emergency situations, a distinction can be made between those service users who, depending on the nature of their incapacity, may or may not be able to express an opinion regarding the proposed service/care plan. Even in the presence of incapacity, the expressed view of the service user carries great weight:

- Cannot express opinion: This includes service users who have severe dementia or have sufficient
 clouding of consciousness to impair effective communication. Decisions should be made in the best
 interests of the service user, bearing in mind the principles outlined above. It is good practice to
 inform those close to the service user of planned service and to seek their agreement if possible.
 However, it is important to remember that the primary duty of the social care professional is to the
 service user.
- Can express opinion: Many service users who lack capacity to make a decision will nevertheless be
 able to express a preference to receive or forgo a service. Such preferences should in general be
 respected. Most social care decisions regarding those who lack capacity arise in the community, and,
 except in emergencies, it may often be impractical or undesirable to try to impose care on someone
 who refuses it.



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Is it always necessary to seek service user consent?

The general principles of consent apply to all decisions about social care/support, however, while the agreement of the service user should always be sought, there are a number of situations where the amount of information provided about a service may legitimately be abbreviated. These include:

Where the service user declines information

Some service users do not want to know in detail about their service or the care plan. While this should be respected if possible, it is important that some basic information be provided about personal and intimate care procedures in order that consent can be obtained and the service user has been advised of what is involved. If a service user refuses to receive detailed information about their care plan, this should be documented.

The fact that a service user might be upset or refuse services as a result of receiving information as part of the consent process is not a valid reason for withholding information that they need or are entitled to know.

Specific Issues relating to consent

Scope of consent

The need for consent, and the application of the general principles in this policy, extends to all services conducted by or on behalf of the West Limerick Independent Living to all service users in all locations. Thus, it includes social care services and applies to those receiving care/support in the community and in other care settings. How the principles are applied, such as the amount of information provided and the degree of discussion needed to obtain valid consent, will vary with the particular situation. In some situations, permission, as matter of common courtesy and of respect for the service user, rather than consent may be required e.g. to enter a person's home, and should be obtained in keeping with relevant West Limerick Independent Living codes of conduct.

A useful approach to consent in this context is to consider what a reasonable person in the service user's situation would consider appropriate.

Thus, for example, it might be judged that someone facing washing intimate body parts would more likely prefer to focus on the issues of dignity, privacy and respect than on the much smaller concerns associated with hair care. However, individual preferences remain important in these circumstances: if service users have a strong preference for detailed information and for involvement in all aspects of decision-making, this should be respected as far as possible.

Who should seek consent from a service user?

The person who is providing a particular social care service is ultimately responsible for ensuring that the service user is consenting to what is being done. The task of providing information and seeking consent may be delegated to another professional, as long as that professional is suitably trained and qualified.

In particular, they must have sufficient knowledge of the proposed service and of the benefits and risks in order to be able to provide the information the service user requires. Inappropriate delegation (for example



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where the seeking of consent is assigned to a social care professional with inadequate knowledge of the service) may mean that the "consent" obtained is not valid.

If different aspects of care/support are to be provided by different professional disciplines, each should usually obtain consent for their particular intervention.

When should consent be sought?

The provision of information and the seeking and giving of consent should involve a continuing process of keeping service users up to date with any changes in their care plan and the changes proposed. It should not be an once-off, sometimes 'eleventh hour' event, exemplified by getting a hurried signature on a consent form.

While there are no legal provisions relating to the duration of consent, it is good practice where possible to seek the service user's consent to the proposed service changes well in advance, when there is time to respond to the service user's questions and provide adequate information.

Types of consent

The validity of consent does not depend on the form in which it is given. Service users may indicate consent orally, in writing or in certain limited circumstances by implication (such as where a service user nods their head or blinks their eyes). In all situations, common courtesy and respect for the service user is required.

Before accepting a service user's consent, those who provide social care services must consider whether the service user has been given the information they want or need, and how well they understand what is proposed.

How should consent be documented?

It is essential for those who provide social care to document clearly both the service users' agreement to the service/care plan and the discussions that led up to that agreement if:

- the service/care plan involve significant risks;
- there may be consequences for the service user's social or personal life;
- or in any other situation that the service provider considers appropriate.

This may be done either through the use of a consent form or through documenting in the service user's notes that they have given verbal consent.

If a consent form is used and the service user is unable to write, a mark on the form to indicate consent is sufficient. It is good practice for the mark to be witnessed by a person other than the staff member seeking consent, and for the fact that the service user has chosen to make their mark in this way to be recorded in their service user file.

Confidentiality and data protection

Service users have a right to expect that information about them will be held in confidence by those who provide social care services to them. Confidentiality is central to trust in this relationship. Staff are expected to comply with the provisions of the Data Protection Acts 1988 and 2003 which state that personal



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information obtained from service users for the purposes of informing care or service provision should not be disclosed to a third party unless the service user has consented or unless the specific requirements of the legislation are complied with.

This also applies if a third party, such as a family member, makes a complaint regarding the care of a service user: it is essential in these circumstances to ensure that the service user has consented to their personal information being made available for any internal investigations/ reviews.

Sharing of information on a strict 'need to know' basis between staff involved in a service user's service is essential to the provision of safe and effective service. Similarly, an integral component of modern social care is the use of audit and quality research programmes to ensure that the care provided is of the highest quality. Consent from the service user is not usually sought in these circumstances except where identifiable data is being made available to a third party. However, it is good practice to make service users aware that such practices occur and that safeguards exist to ensure that their personal information is protected.

When consent is refused

If an adult with capacity to make an informed decision makes a voluntary and appropriately informed decision to refuse a service, this decision must be respected, even where the service user's decision may result in his or her harm or death. In such cases it is particularly important to accurately document the discussions with the service user, including the service/task/support that has been offered, the service user's decision to decline and the fact that the implications of this decision have been fully outlined.

Those who provide social care services should also consider and discuss with the service user whether an alternative service/measure is acceptable to the service user. In the context of social care, for example, where a frail disabled person is assessed to require home supports in order to keep them safe refuses these services, alternative measures should be discussed with the service user.

Withdrawal of consent

A service user with capacity is entitled to withdraw consent at any time. Where a service user does object during service delivery, it is good practice to stop the service, establish the service user's concerns, and explain the consequences of not completing the task/s and respect the withdrawal of consent.

About the Assisted Decision Making (Capacity) Act 2015

The Assisted Decision Making (Capacity) Act was signed into law on the 30th December 2015. This Act applies to everyone and is relevant to all health and social care services. The Act is about supporting decision making and maximising a person's capacity to make decisions. The Act will have significant implications for health and social care providers in the provision of safe person-centred care, based on respecting the individual rights of each person.

Key features of the Assisted Decision Making (Capacity) Act 2015:

- It applies to everyone and to all health and social care settings.
- It provides for the individual's right of autonomy and self-determination to be respected through an
 Enduring Power of Attorney and an Advance Healthcare Directive made when a person has
 capacity to come into effect when they may lack decision-making capacity.



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- It provides for legally recognised decision-makers to support a person maximise their decision making powers.
- It places a legal requirement on service providers to comprehensively enable a person make a decision through the provision of a range of supports and information appropriate to their condition.
- It abolishes the Wards of Court system.
- It provides for a review of all existing wards to either discharge them fully or to transition those who still need assistance to the new structure.
- It repeals the Lunacy regulations governing the Ward of Court system.
- It establishes a Decision Support Service with clearly defined functions which will include the
 promotion of public awareness relating to the exercise of capacity by persons who may require
 assistance in exercising their capacity.
- The Director of the Decision Support Service will have the power to investigate complaints in relation to any action by a decision-maker in relation to their functions as such decision-maker.

ASSISTED DECISION MAKING

The Assisted Decision Making (Capacity) Act 2015 (the "Act"), but requires commencement orders to bring it fully into effect. Recently piecemeal sections of the Act have been commenced, however the more comprehensive sections remain in limbo. The Act provides for a new test for capacity, creates a concrete framework to assist individuals in making decisions, radically overhauls the antiquated Wards of Court system, modifies the law regarding Enduring Powers of Attorney (EPOA), and creates a new legal office – The Director of the Decision Support Service.

CAPACITY PRIOR TO THE ENACTMENT OF THE ACT

Capacity refers to an individual's ability to make their own decisions. Prior to the enactment of this legislation capacity was black or white — an individual either had or did not have capacity. An EPOA could have been put in place prior to incapacity, appointing an attorney who would act for them if incapacity was suffered at some point in the future. If no EPOA was executed, the only legal mechanism for those deemed incapacitated was wardship, whereby the person fell under the supervision of the High Court and a committee appointed to assist. The wardship system relies heavily on medical evidence and is essentially a cognitive skills test, and has long been held to be an unreliable proof that a person has lost capacity to manage all of their affairs.

CAPACITY UNDER THE ACT

The legislation has seen a shift to the broad-minded functional test for capacity, that is an issue and time specific test and it is altogether more different to the all or nothing test that exists for wardship. This functional approach allows for changes in a person's capacity over time. Capacity for decision-making is defined as the ability to understand, at the time the decision is being made, the nature and consequences of the decision in the context of the available choices.

A person lacks the capacity to make a decision if they are unable to:-

- Understand the information relevant to the decision
- Retain that information long enough to make a voluntary choice



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- Use or weigh that information as part of the process of making the decision, or
- Communicate their decision.

However, a person should not be said to lack capacity if they:-

- Require information to be explained to them in a way that is appropriate to their circumstances
- Can only retain the relevant information for a short period of time
- Did lack capacity for a particular decision at one time but may no longer lack capacity to make that decision
- Lack capacity for some decisions but have capacity to make decisions on other matters.

The Act introduces a system of supports, giving those with diminished capacity greater autonomy, enabling them to have their own voices heard, and facilitated.

DECISION MAKING SUPPORT STRUCTURES

a) Decision-Making Assistant

The assistant will help the person making the decision to obtain the information needed to make the decision, explain the information to the person and obtain the person's will and preference in relation to the decision. The assistant will also communicate the decision if necessary and follow up on the decision to ensure it is implemented. The appointment is done by way of a formal written agreement, the content and formalities of which are the subject of Ministerial Order (which is awaited).

b) Co-Decision-Making

An individual may appoint someone else to jointly make one or more decisions about their welfare and property and affairs. The co-decision-maker will obtain the information needed, advise on decisions and make decisions jointly with the appointer based on their will and preferences. The co-decision maker will help the person express a decision and ensure that the decisions are implemented. A written agreement setting out amongst other things, the types of decisions that will require intervention, must be registered with the Director of the Decision Support Service within five weeks of signing. It does not come into force until registered. Notice of registration of this agreement must be given to certain specified family members who may object to registration proceeding. Each Agreement is reviewed by the Director of the Decision Support Service. The Co-Decision-Maker must file a report with the Director every year, setting out what they have done during the period, including details of all transactions relating to the person's finances, together with details of any costs and expenses paid.

DECISION MAKING REPRESENTATIVE

The Act provides for intervention by the courts in certain circumstances where it is believed a person lacks capacity to such an extent that they require decisions to be made on their behalf entirely by someone else. This is a court appointed representative. Essentially this appointment applies to individuals who cannot make decisions even with assistance, whose incapacity is much more acute than for the options set out above.



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WARDS OF COURT PROCEDURES

The Act will eventually see the end of wardships, with no new wardships once the Act is commenced. Given the divergence of capacity requirements, it may be found that some wards of courts have capacity, and if so they will be immediately discharged from wardship and their property returned to them. Where a ward is declared to lack capacity, the court may discharge the person on registration of a Co-Decision-Making Agreement. Where the ward is declared to lack capacity even with the appointment of a Co-Decision-Maker, a Decision-Making Representative will be appointed and the property of the ward returned to them.

ENDURING POWERS OF ATTORNEY

A new regime for EPOAs is to be introduced which will be similar to the current system of 1996 EPOAs. However there are fundamental differences including the execution and registration process containing more safeguards, regular reporting and accounting obligations of attorneys to the Director and a complaints procedures to the Director with powers of investigation.