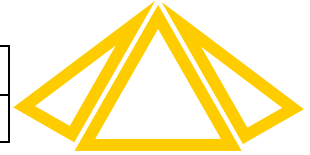


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1.0 POLICY:

We propose that the cornerstones of an overarching framework for supporting the consent of people with intellectual disabilities include the following key process:

1. Presumption of Capacity and Non- Discrimination
2. Accessible Individual Information and Support
3. Functional Support Approach
4. Individual Empowerment and Advocacy
5. Rights Review Committee

Introduction

Consent is the giving of permission or agreement for an intervention, receipt, or use of a service or participation in research following a process of communication about the proposed intervention. Consent must be obtained before starting treatment or investigation, or providing personal or social care for a service user or involving a service user in teaching and research (all defined as ‘interventions’ for the purpose of this policy). This requirement is consistent with fundamental ethical principles, with good practice in communication and decision making, and with National Health and Social Care Policy. The need for consent is also recognised in Irish and International law.

2.0 SCOPE:

The need for consent and the application of the general principles in this policy extends to all interventions conducted by or on behalf of Sunbeam House Services (SHS) services users in all locations. Thus, it includes social as well as health care interventions and applies to those receiving care and treatment in hospitals, in the community and in residential 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 a matter of common courtesy and of respect of 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 SHS code of conduct. Knowledge of the importance of obtaining consent is expected for all staff employed or contracted by SHS.

The relationship between the service provider and the service users should be a partnership based on openness, trust, and good communication. Good decision making requires a dialogue between parties that recognises and acknowledges the service users goals, values and preferences as well as the specialist knowledge, experience and judgement of support staff.

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Consent in Irish Law

It is a basic rule at common law that consent must be obtained for medical examination, treatment, service, or investigation. 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.

General Principles

Therefore, other than exceptional circumstances, treating service users without their consent is a violation of their 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 health or social care service on behalf of an adult service user who lacks capacity to consent unless they have specific legal authority to do so e.g. Ward of Court.

Health and Social Care professionals have a responsibility to keep themselves informed of professional standards relevant to obtaining consent in their practice. 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 Offenses 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”.
- Such as; if the service user has been made a Ward of Court or is the subject of an enduring power of attorney which covers the decision in question

What is a valid and genuine consent?

Consent is the giving of permission or agreement for an intervention, receipt, or use of a service or participation in research following a process of communication about the proposed intervention. The process of communication begins at the initial contact and continues through to the end of the service user’s involvement in the treatment process, provision of social care or research study. 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:

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- Have received sufficient information in a comprehensible manner about the nature, purpose, benefit and risks of an intervention/service or research project;
- Not be acting under duress; and
- Have the capacity to make the particular decision.

These criteria are discussed further in the next section

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. Use of threats to induce consent, such as withdrawal of any privileges is not acceptable.

Duress refers to pressures or threats imposed by others. However, this is distinct from the pressures that illness itself can impose on service user's, who may feel they have little choice regarding treatment as a result. Also, duress should be distinguished from providing the service user, when appropriate, with strong recommendations regarding a particular treatment or lifestyle issue or from pointing out the likely consequences of choices the service user may make on their health or treatment options.

Service users may also be subject to pressure from family and friends to accept or reject a particular intervention, such as, for example, to enter a nursing home if they are perceived to be at risk of harm at home. 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.

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 depend 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 their own decisions 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

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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.

Presumption of capacity

Those who provide health and 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, an examination, investigation, or treatment.

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 health and social care professional. Capacity should not be confused with a health and social care professional’s assessment of the reasonableness to the service user’s decision. The person who has capacity can make their own choices, however foolish, irrational, or idiosyncratic others may consider those choices. Similarly, the fact that a service has been found to lack capacity to make any decision on a particular occasion does not mean that they lack the capacity to make any decision 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 access 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 to question the presumption of capacity. This involves accessing whether:

- The service user understands in broad terms and believes the reasons for and nature of the decision to be made.

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- The service user has sufficient understanding of the principle benefits and risks of an intervention 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.

Making decisions if capacity is absent

There is currently no legislative framework to govern how a decision about treatment and care should be made for those who lack capacity to make that decision themselves.

However, Irish case law, national and international guidelines suggest that in making decisions for those who lack capacity, the health and social care professional should determine what is in their best interests, which is decided by reference to their values and preference if known.

The health and 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
- Consider which options for treatment would provide overall clinical benefit for the service user
- Consider which option, including the option not to treat, would be least restrictive of the service user’s future choices
- Support and encourage service users to be involved, as far as they want to and are able, in decisions about their treatment and care
- Seek any evidence of the service user’s previously expressed preferences, such as an advance statement or decision, and of the 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, on-going, personal relationship with the service user such as family or friends
- 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 decisions; or when there is significant disagreement regarding the best course of action.

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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 health or 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, on-going personal relationship with the service user, in particular anyone chosen by the service user to be involved in treatment decisions, in the discussion and decision-making process pertaining to health and social care interventions.

Their role in such situations is not to make the final decision, but rather to provide a greater insight into his/her previously expressed view 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 health/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.

The health and social care professional may treat the service user provided the treatment is immediately necessary to save their life or to prevent a serious deterioration of their condition and that there is no valid advance refusal of treatment. The treatment provided should be the least restrictive of the service user’s future choices. 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 intervention. Even in the presence of incapacity, the expressed view of the service user carries great weight:

- **Cannot express opinion:** This includes service users who are in a coma or have severe dementia or have sufficient clouding or consciousness to impair effective communication. Decisions should be made in the best interest 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 interventions and to seek their agreement if possible. However, it is important to remember that the primary duty of the health and 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 an intervention. Such preferences should in general be respected. Most health and social care decisions regarding

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those who lack capacity arise in the community, and except in emergencies, it may often be impractical or undesirable to try to impose care, treatment, or investigation on someone who refuses it. Legal advice should be sought in respect of refusal of any major intervention including surgery, prolonged detention or other restrictions on liberty.

Wards of Court

If a ward needs a healthcare intervention for which written consent is required by the service provider, the approval of the President of the High Court should be obtained. In practice a request for consent, for example to carry out an elective surgical procedure or administer an anaesthetic is normally made by the clinician concerned to the Office of Wards of Court. However, emergencies will arise where it is not possible to obtain timely approval and in those circumstances the necessary treatment may be administered in the service user’s best interests.

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 interventions conducted by or on behalf of SHS on service users in all locations. Thus, it includes social as well as health care interventions and applies to those receiving care and treatment in hospitals, in the community and in residential care settings.

3.0 ROLES AND RESPONSIBILITIES:

The person who is providing a particular health and social care service or intervention 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.

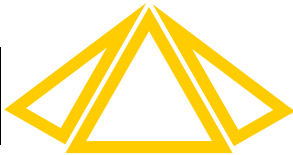
When should consent be sought?

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

If there is a significant time- lapse between the initial seeking and giving of consent and the actual date of intervention, it is helpful to check if the service user can remember the treatment information given previously and if they have any questions in relation to that information. If the service user isn’t satisfied that he or she can remember the earlier information or if he or she has cognitive difficulties that might interfere with his or her recollection of the earlier discussion or there is a change of service users condition or in the information about the propose intervention

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which may result in a change in the nature, purpose or risk associated with the procedure, a fresh consent following provision of appropriate information should be sought.

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 holds out their arm for a blood pressure reading). In all situations common courtesy and respect for the service user is required. Before accepting service users consent, those who provide health and 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 health and social care to document clearly both the service user’s agreement to the intervention and the discussions that led up to that agreement if:

- The intervention is invasive, complex or involves significant risks;
- There may be significant consequences for the service user’s employment, or social or personal life;
- Providing clinical care is not the primary purpose of the intervention e.g. clinical photographs or video clip to be used for teaching purposes or blood testing following needle stick injury to staff;
- The intervention is innovative or experimental;
- 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 clinician seeking consent, and for the fact that the service user has chosen to make their mark in this way to be recorded in the healthcare record.

Confidentiality and data protection

Sharing information on a strict ‘need to know’ basis between staff involved in a service user’s care is essential to the provision of safe and effective care. Similarly, an integral component of modern health and social care is the use of audit and quality assurance programmes to ensure that the care provided is of the highest quality when benchmarked against national and international standards. 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 safeguards exist to

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ensure that their personal information is protected. For example, this could be done in hospitals providing such information on admission.

When consent is refused

If an adult with capacity to make an informed decision makes a voluntary and appropriately informed decision to refuse treatment or service, this decision must be respected, even where the service user’s decision may result in his or her death. In such cases it is particularly important to accurately document the discussions with the service user, including the procedure 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 health and social care services should also consider and discuss with the service user whether an alternative treatment/measure is acceptable to the service user.

For example in the case of a service user who is refusing a blood transfusion for religious reasons, the service user should be referred for a haematology consultation to ascertain whether any alternative treatments would be acceptable.

In the context of social care, for example, where a frail older 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.

If there is uncertainty about the service user’s capacity to make a decision, the H.S.E guidance on **accessing capacity to consent** should be followed.

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