

St Patrick's Centre, Kilkenny

Protocol for Gaining Consent from People Supported

1.0 ISSUE

1. Assisting the Person Supported, to make a decision, based on their will and preference
2. Releasing any personal or sensitive data belonging to the people supported, to third parties
3. Utilising personal or sensitive data, belonging to people supported, in tracking success and for training purposes, internally and externally

In anticipation of the Assisted Decision Making (Capacity) Act 2015 (ADM) being commenced, we are relying on the following for guidance, in relation to consent, from the people we support. In the meantime, we will endeavour to observe and follow the spirit of the new legislation, both in this protocol and in practice.

2.0 DECISION MAKING

There is no specific procedure, for making medical or other decisions, on behalf of people with intellectual disability. 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 (HSE National Consent Policy 2013).

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.

3.0 LEGISLATION / POLICY

For the purposes of 1 – 3 above, St Patrick's Centre will comply with the following guidelines and legislation.

- A. Guiding Principles, Section 8, Assisted Decision-Making (Capacity) Act 2015
- B. Mental Health Act 2001
- C. Data Protection Bill 2018
- D. HSE National Consent Policy 2017
- E. Article 29 Data Protection Working Party – Guidelines on transparency under Regulation 2016/679
- F. General Data Protection Regulation (GDPR)
- G. Supporting People's Autonomy (a guidance document) HIQA

Transparency is not defined in the GDPR. However, Recital 39 of the GDPR states

'It should be transparent to natural persons that personal data concerning them are collected, used, consulted or otherwise processed and to what extent the personal data are or will be processed'

Articles 13 and 14 of the GDPR contain a provision that requires a data controller to inform a data subject, if it intends to further process their personal data for a purpose other than that for which it was collected/obtained. Information in relation to further processing must be provided prior to that further processing.

Pending the aforementioned ADM, there is currently no legislative framework to govern how a decision should be made, for those who lack capacity, to make that decision for themselves.

Referencing the HSE National Consent Policy, HIQA guidance, 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 interest, which is decided by reference to their will and preferences – if known.

The Health and Social Care professional should:

- Presume capacity unless otherwise demonstrated.
- Consider whether the capacity of the person supported is temporary or permanent.
- Support and encourage the person supported to be involved, as far as they want to and are able, in decisions about them
- Seek any evidence of the previously expressed preferences of the person supported, such as an advance statement or decision, evidence of will and preference and of the previous wishes and beliefs of the person supported
- Consider the views of anyone the person supported asks you to consult
- Consider the views of people who have a close, on-going, personal relationship with the person supported such as family or friends
- Consider the views of people who have an in-depth knowledge of the person such as support workers (all disciplines)
- Consider involvement of an independent advocate to support/represent the person regarding the decision making process.

The National Consent Policy also specifically states the role of the family is not to make the final decision, on behalf of the supported person, 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.

Creating a Circle of Support (Decision Supporters) where there are relevant and representative members to support the person. These members may include the person, family member, staff member, MDT member and independent advocate.

In adherence with the Guiding Principles set out in Section 8 of the Assisted Decision-Making (Capacity) Act 2015, Decision Supporters shall:-

- Permit, encourage and facilitate the person to participate or to improve his or her ability to participate as fully as possible
- If making a decision for the person, take into account the person's own known past and present will and preferences, so that the decision is as close as possible to the decision the person might have made for him/herself, in so far as that is possible
- If making a decision for the person they take into account:-
 - His or her beliefs and values
 - Any other factors which s/he would be likely to consider if able to do so
 - Consider the views of others s/he names as people to be consulted
 - Act at all times **in good faith and for his/her benefit**
 - Consider all other circumstances which it would be reasonable to regard as relevant
 - Consider the views of any carer / person with a genuine interest in his / her welfare
 - Consider the likelihood of his / her recovering the ability to make the decision for him / herself against the urgency of the matter to be decided
- All decisions (interventions) taken concerning the life or affairs of a person supported by decision supporters shall be:-
 - The decision that **least restricts that person's rights and freedom**
 - The decision that is most respectful of that **person's dignity, bodily integrity, privacy and continued right to have autonomy and control over his / her financial affairs and property**
 - A decision that is proportionate to the significance and urgency of the matter requiring a decision
 - In place for as short a time as possible taking into account the particular circumstances of the matter needing to be decided

4.0 PROTOCOL

1. Assume capacity unless otherwise demonstrated
2. A functional assessment test for capacity should be carried out with the person supported, in order to determine whether a person lacks capacity to make a decision.
The assessment must relate to the particular decision being made and the specific time that the decision is to be made.
3. The ADM sets out a legislative basis for the Functional Assessment Test for Capacity as follows;

As per S. 3(2), the Functional Test for Capacity finds a person will lack capacity to make a decision if s/he is unable:

- To understand the information relevant to the decision;
 - To retain that information long enough to make a voluntary choice
 - To use or weigh that information as part of the process of making the decision; or
 - To communicate his or her decision (whether by talking, writing, using sign language, assistive technology)
4. Should the person supported be deemed to lack capacity after the functional assessment test for capacity is carried out, a decision will be made to his / her benefit
 5. No blanket decision will be taken. This protocol is to be applied for any and every decision necessary
 6. In order to establish the preference of the person supported, a round table meeting will be convened to assist the person supported with their decision. That meeting should include the following:-
 - a. The person supported making the decision
 - b. The Social Worker / Advocate
 - c. The Key Worker supporting the Person Supported (if appropriate)
 - d. A family member of the Person Supported
 - e. An external person with sufficient experience working with people with disabilities
 7. Reference should be made to any relevant documentation such as Conditions for Success, Incident and Accidents reports and any relevant MDT recommendations that might assist informing the decision.
 8. The outstanding decision is to be discussed in the presence of the person being supported to make the decision, subject to their availability or wish to attend.
 9. The decision supporters should be aware of the potential of undue influence and ensure that person supported is protected from same.
 10. In coming to a decision, the decision supporters should consider Culturally Valued Analogue (CVA) when arriving at same.
 11. When coming to a decision, the decision supporters should give consideration to the greater good and / or longer-term benefits when arriving at same.
 12. When the decision is made, the meeting should be documented and a note of the outcome of the decision placed on the file of the person supported.