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<tr><td colspan="2"> </td><td>ST. PATRICK'S CENTRE,
KELLS ROAD, KILKENNY</td></tr>
<tr><td colspan="3">POLICY TITLE: Capacity & Consent Policy</td></tr>
<tr><td>Prepared by:
Geri Wilson & Áine Forde</td><td>Approval Date:
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Signed: ____________________
CEO (Interim)
Signed: ____________________
Board Member</td></tr>
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Mission Statement

To enable people to live a good life, in their own home, with supports and opportunities to become active, valued and inclusive members of their local communities.

To enable a supported, self-directed living (SSDL) model of provision which is underpinned by our beliefs, values and vision.

<table>
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1.0 Introduction

The purpose of this document is to provide a guide to the principles underlying capacity and consent in lieu of the Assisted Decision-Making (Capacity) Act 2015 (the Act) being commenced in all parts, for all persons supported by St Patrick's Centre, Kilkenny (SPC). The Act only applies to people over 18. The Act will affect the work of everyone working in health (physical and mental health) and social care, including those working in statutory, voluntary, community and privately funded organisations.

All persons have equal legal rights. Some people may need assistance and support to exercise their individual rights. A relevant person who may lack capacity to make his or her own decision due to a disability, lifelong condition or acquired condition may require assistance and support to exercise his or her individual rights. This includes people with intellectual or physical disability, cognitive difficulties due for example to acquired brain injury, dementia and people with mental health problems. These rights are protected under the Constitution of Ireland, the European Convention on Human Rights and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

This policy is in line with the HSE National Policy for Safeguarding of Vulnerable Adults at Risk of Abuse and the SPC Protocol for Gaining Consent from People Supported.

2.0 Rationale

SPC will comply with the Assisted Decision Making Capacity Act 2015 when commenced in all parts but in the interim will apply the principles of the Act as outlined below. It will apply to all persons supported by SPC. All are treated equally under this policy.

3.0 Scope

This policy applies to all employees of SPC but includes agency personnel, Volunteers and anyone who is acting under the auspices of SPC. The need for consent and the application of the general principles included in this policy extends to all decisions required from the people we support. 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.

4.0 Relevant Legislation/Policy

- Assisted Decision Making Capacity Act 2015
- HSE National Policy for Safeguarding of Vulnerable Adults at Risk of Abuse 2014
- HSE National Consent Policy 2019
- SPC Protocol for Gaining Consent from People Supported **Appendix 1**
- SPC Consent Policy 2015
- SPC Process for Consent Protocol **Appendix 2**

5.0 Capacity

The Act defines Capacity as 'decision-making capacity' and it is the ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by the person supported in the context of the available choices at that time.

Presumption of capacity means that it shall be presumed that the person has capacity in respect of a specific matter unless otherwise shown. The onus of proving that a person lacks capacity to make a decision is on the person who is questioning a relevant person's ability to make a particular decision.

A relevant person means a person whose capacity is in question or may shortly be in question in respect of one or more than one matter i.e. a person who may have difficult in reaching a decision without the support of someone.

A person can be said to lack capacity to make a decision if they are not able to: -

- Understand the information relevant to the decision
- Retain that information long enough to make a voluntary choice
- Use or weigh that information as part of the process of making the decision
- Communicate his or her decision in whatever way they communication (not only verbally)

People may differ in the amount of assistance they may require to make decisions but this does not necessarily mean that they lack decision making capacity.

6.0 Guiding Principles

As stated, there is a presumption of decision making capacity unless the contrary is shown.

- No intervention will take place unless it is necessary.
- A person will be treated as unable to make a decision only when all practicable steps to help that person to make a decision have been unsuccessful
- Any act done or decision made under the Act must be done or made in a way which is least restrictive of a person's rights and freedom
- Any act done or decisions made under the Act in support or on behalf a person with impaired capacity must give effect to the person's will and preference.

7.0 Functional Capacity

The Act states that when using a functional approach:

'A person's capacity shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at the time.'

Functional capacity is therefore:

- Issue specific – capacity is assessed only in relation to the decision in question
- Time specific – capacity is assessed only at the time in question
- Dependent on how a relevant person makes a decision and not the nature and wisdom of that decision

In keeping with the functional approach to capacity, the question of who should assess capacity will depend on the particular decision to be made. In the context of health and social care and treatment decisions it is the health and social care professional who needs the decision to be made. For example, where consent to medical treatment or examination is required, it will be the health and social care professional who is suggesting the treatment that must decide whether the relevant person has the capacity to consent to the treatment and he or she must assess the relevant person's capacity if this is necessary.

Statutory Guiding Principles for 'Interveners'.

- Presumption of capacity: already applies
- Steps must be taken to maximise capacity and encourage participation
- 'Right to be unwise'
- Minimal intervention
- Respect for dignity, bodily integrity, privacy and autonomy
- Give effect to past and present will and preferences
- No reference to 'Best Interests'
- Act in good faith and for the benefit of the relevant person

8.0 Consent

The principles of the presumption of capacity supporting decision making and adopting a functional approach to capacity are supported by the HSE National Consent Policy. There is a close relationship between informed consent and capacity as only persons with the requisite decision making capacity can provide a valid consent to an intervention or receipt or use of a service.

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 in which the person supported has received sufficient information to enable him/her to understand the nature, potential risks and benefits of the proposed intervention or service (HSE 2013).

Consent must be obtained before starting treatment or investigation or providing personal or social care for people we support or involving persons supported in training and research. This requirement is consistent with fundamental ethical principles with good practice in communication and decision making.

This is well established in Irish case law and ethical standards. The requirement for consent is also recognised in international and European Human Rights and under the Irish Constitution.

For the consent to be valid, the person supported must: -

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

Therefore, other than in exceptional circumstances, treating persons supported without their consent is a violation of their legal and constitutional rights and may result in civil or criminal proceedings been taken by the person(s) supported. No other persons such as a family member, friend or direct support worker and no organisation can give or refuse consent to a health or social care service on behalf of an adult supported person who lacks capacity to consent unless they have specific legal authority to do so.

9.0 List of Appendices

Appendix 1 - SPC Protocol for Gaining Consent from People Supported
Appendix 2 – SPC Process for Consent Protocol

10.0 Appendix 1

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 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 the 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 he/she would be likely to consider if able to do so
    - Consider the views of others he/she 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 <u>PROTOCOL</u>

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 he or she 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.

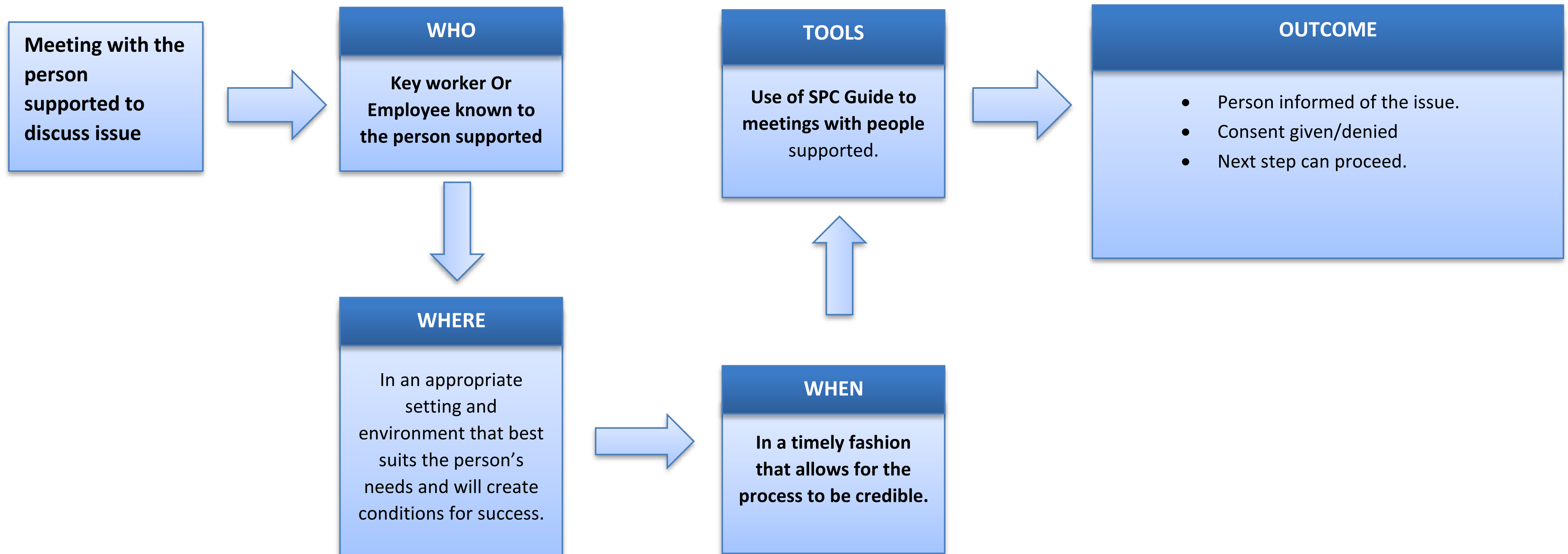
11.0 Appendix 2

PROCEDURES TO SUPPORT

THE PROTOCOL FOR GAINING CONSENT FROM THE PEOPLE WE SUPPORT.

The following procedure is set out to support the implementation of the protocol for gaining consent from the people supported in St Patricks Centre.

The person supported must be central to the procedure and be supported to be actively engaged in the procedure.



STEP TWO

In line with protocol, round table discussion will take place to support a decision to be taken.

This step should reflect the level of impact on the person supported.

WHO

- The person supported making the decision if appropriate
- The Social Worker / Advocate
- The Key Worker supporting the Person Supported, if appropriate
- A family member of the Person Supported, if appropriate
- An external person with sufficient experience working with people with disabilities and issue at hand

WHERE

In an appropriate setting and environment that best suits the person's needs and will create conditions for success.

WHEN

In a timely fashion that allows for the process to be credible.

TOOLS

- Conditions for Success forms.
- Incident & Accidents reports.
- Any relevant MDT recommendations that might assist informing the decision.
- Culturally Valued Analogue (CVA)

EVIDENCE

- The least restrictive on the person's life
- The most respectful of the person's dignity, bodily integrity, privacy and continued right to have autonomy and control over his / her financial affairs and property
- 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

STEP THREE