Citizens **Information** Board
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Assisted Decision-Making (Capacity) Act 2015 – Consultation on a draft *Guide for Health and Social Care Professionals (April 2017)*

Citizens Information Board Response to Consultation Questions

Q7. Is the document easy to understand and/or does it use clear language?

The Document is inevitably complex because of the nature of the Act which introduces a wide range of new provisions and related concepts into the social and health care system. Notwithstanding this complexity, the Guide provides a lot of clear and detailed information about what is required for health and social care professionals to implement the provisions of the Act. It is inevitable that some of the language will have to be of a legal and technical nature and that there will be a need for some repetition.

The Glossary is helpful but could be usefully expanded to include the following:

Capacity Assessment
Consent (including Informed Consent)
Decision-making capacity
Risk-taking
Supported Decision-making

The Document could be improved by the inclusion of:

1) A Plain English Guide at the beginning as to what the Document contains

2) A Statement of the basic changes in attitudes and practice in health and social care required by the Act

3) A synthesis of the key provisions of the Act relevant to social and health care provision

The Document should be prefaced by a strong statement that implementing the provisions of the Act will require some shift in attitudes and practice relating to both supported decision-making and capacity assessment. This is particularly the case in respect of people with an intellectual disability and older people with dementia or other cognitive impairment. The alternative approach which is already reflected to some extent in the approach to consent to medical treatment will need to be replicated throughout the whole of the health and social care system and reflect people's right to make choices about where they live, to take risks and to be fully

supported in making and implementing their decisions. The shift in approach highlights the need to make a clear distinction between decision-making autonomy and decision-making execution. It also brings into sharp focus the need to ensure that difficulties with communication are never interpreted as an absence of decision-making capacity.

Some additional reference might be made in the Document to the fact that the approach to decision-making provided for in the Act is collaborative rather than individualistic in the sense that rather than individuals making decisions on their own, there is provision in the Act for people to make decisions with the support and help of others.

The following are illustrative examples of texts that from the Guidance Document that could be included in a Synthesis at the beginning:

From p.41
General or 'blanket' assessments of a person's capacity are not consistent with the functional approach to capacity in the 2015 Act and should not be made. Capacity is issue-specific, which has the benefit of facilitating people to make their own decisions whenever possible and minimises the restriction on a person's decision-making autonomy. This also means that no 'short-cuts' for assessing capacity are possible: assessment must be based on the actual decision that a relevant person faces and not on an overall basis.

From p.39/ 3.2.4 Communicating a decision
Relevant persons who access health and social care services may have difficulties communicating or in being understood because of, for example, cognitive impairment or disability, limited English language proficiency or because they are deaf or hard of hearing. In spite of apparent communication difficulties, every effort must be made both in communicating information and in facilitating the relevant person to communicate his or her decision.

From p.43
Any unnecessary capacity assessments and findings of lack of capacity, or unnecessary interventions, contravene the Act. The starting position for health and social care professionals when a relevant person is facing a decision must be: 'Is there anything I can do to help the person make, communicate and implement their own decision?' and not 'Might this person lack capacity to make the decision?

From p. 29
The 2015 Act requires that an intervener shall 'give effect, in so far as is practicable' to the will and preferences of the relevant person. It is therefore a very serious step to seek to override the relevant person's expressed preference, or to coerce him or her to receive an intervention or treatment he or she does not wish to have.

8. On a scale of one to five, with one being too little and five being too much, please rate the level of detail provided in the document

9. Please indicate what section/s of the document contain too much detail:

10. Please indicate what section/s of the document contain too little detail:

Risk-taking

The question of risk-taking and people making what may be perceived by others as unwise choices and decisions is complex and requires more elaboration in the Document. This is particularly the case in situations where, for example, people requiring long-term care and support choose to remain in their own homes when the risks of harm may be much greater than if they were to move to a nursing home.

There is a need for more guidance around supporting people taking risks in accordance with their will and preferences with particular reference to:

- Recognising that risk-taking by a person may be necessary in some instances to enable him/her assert his/her basic rights

- Achieving the optimum balance between risk-taking by individuals and carrying out a duty of care/safeguarding role

- How to manage risk-taking to improve quality of life, e.g., enhancing the social and environmental context within which a person lives

Establishing the will and preferences of people

There is a need for more guidance in the Document on how to establish the will and preferences of people, both those who have been assessed as lacking capacity and those whose decision-making capacity is not in question but who have communication difficulties.

People who have not to date made their own decisions

There is need for more guidance on how the provisions of the Act are to be applied in the case of people who have capacity but who have become accustomed to other people making decisions for them, e.g. those who have lived most of their lives in residential care or those whose parents/relatives make decisions for them.

11. Does the Guide provide sufficient information for you to implement the requirements and obligations of the Act in your daily work?

12. Please provide more detail where it is not sufficient for your needs

13. Do the vignettes and examples help with your understanding of the Act in your daily work?

The vignettes and examples are somewhat helpful. The style used on p.59 is very useful and should be replicated in the other examples.

Case Example 16 may not be helpful given that 'Tom' does not have any real choice as the decision that he has to move out of the residential centre has already been taken and is outside his control. While the example does have some relevance in that it refers to a communication matter relating to capacity assessment, even if he is deemed to have capacity, he still will have to move out of the residential centre.

14. Are there any gaps in the Guide that you think should be covered?

Supported decision-making

The Document lacks clarity about how and when the different levels of supported decision-making contained in the Act are triggered and come into effect – Decision-making Assistant, Co Decision-maker and Decision-making Representative. It is crucially important that health and social care professionals understand how these processes operate.

Role of independent advocate

The references to the role of an independent advocate lack specificity, particularly as there is no legislative provision currently for people to have an independent advocate.

There is a need to for guidance on the following:

- Who can act as an independent advocate
- How the role of an independent advocate would relate to other decision-making support roles provided for in the Act
- The working relationship between independent advocates and health and social care professionals
- How access to an independent advocate is to be triggered
- How to deal with situations where there is a conflict of perspective between the independent advocate representing the views of an individual and the views of either health or social care staff or relatives of the individual

15. Please give examples and reasons why.

16. Are there ways in which the Guide can be improved?

See answer to Q. 7 above

17. If yes, please be as specific as possible with your suggestions for improvement

18. What supports do you think you will need in order to comply with the legislation?

19. Do you have any other comments on the Guide? Please be as specific as possible in your comments.

There is a need for greater clarity in the Document on the respective provisions of the Assisted decision-making (Capacity) Act and the provisions of the Mental Health Act 2001. In particular, the statement in the Document (p.17) that “a health and social care professional is not obliged to comply with any direction in an advance healthcare directive by a person who is involuntarily detained and which relates to his or her treatment under the Mental Health Act 2001” may present difficulties in practice. While it is stated that it is expected that this provision will be amended when the Mental Health Act 2001 is updated and reformed to take account of the recommendations in the 2014 Report of the Expert Group on the Review of the Mental Health Act, there is need for specific guidance on how the matter is to be dealt with in the intervening period.

Thank you for taking the time to complete the questionnaire.

If you have any other comments you wish to make, please email them to adm@hse.ie.