

Assisted Decision-Making Guide for Health and Social Care Professionals: Consultation Feedback Submitted 24/04/17

The HSE developed a draft Guide for Health and Social Care Professionals document to support health and social care professionals to implement good practice in relation to the Assisted Decision-Making (Capacity) Act 2015.

The guide provides a broad overview of the Act and its main implications for service users and staff in health and social care settings.

The HSE sought consultation on the draft guide via a survey monkey questionnaire. The format through which the HSE sought feedback was quite specific. There were 19 set questions which all related to the guide document.

The IASW sought feedback through its SIG structures. A number of groups responded and the IASW would like to thank these groups.

Below is the feedback that was submitted to the HSE on behalf of IASW on 24/04/17.

Yours sincerely
Frank Browne
Chair IASW

***1. Are you responding as an individual or on behalf of an organisation?**

- Individual
 Organisation

2. If you are responding as an individual, please let us know your name (optional)

3. If you are responding on behalf of an organisation, please state it's name:

4. If you are responding as an individual, are you:

- Carer / family member
 Service user
 Health and social care professional
 Other (please specify)

5. If you wish to be kept up to date on the work of the HSE Assisted Decision Making Project, please provide your email address:

office@iasw.ie

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

The Guide uses clear unambiguous language that is easy to understand.

7. Please detail any terms / concepts in the Guide which should be clarified / explained.

This guide is written for Health and Social Care Professionals. It would be useful to define Health and Social Care Professionals. Are they simply the professions regulated by CORU? Is this document intended to guide medical and nursing staff, who are not defined or described as health and social care professionals?

Page 6 – interveners. What is a special visitor and a general visitor?

Page 18 – it would be helpful to define a health or social care service, particularly whether this extends to nursing home care

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

This level of detail at this point in time is sufficient. Further detail may be required as matters develop in relation to the Act, for example as the DSS commences publishing Codes.

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

N/A

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

N/A

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

- Yes
- No
- Unsure
- No Opinion

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

We believe that we require more information on the precise role / remit of Decision Making Assistants. It appears from the Guide that the appointment of a Decision Making Assistant is not a formal written and witnessed arrangement. In such cases how is a HSE staff member to know whether a person claiming to be a Decision Making Assistant actually is acting in this capacity?

1.5.1 pages 12-13 – the Guide refers to Decision Making Assistants undertaking tasks such as “obtaining information or personal records” and the relevant person may have more than one Decision Making Assistant. It would be helpful for us as HSE staff to have clear guidance on when to share / release personal records, in light of our obligations in terms of confidentiality and data protection, particularly given that a Decision Making Assistants role is not written down or registered with the DSS.

Will the DSS publish Codes in relation to Assisted Decision Makers and Co-decision makers? The Guide is clear that there will be Codes in respect of Attorneys and Advanced Healthcare Directives but not explicit in relation to the Assisted Decision Makers and Co-decision makers. Codes would enhance clarity for all parties when supporting a person to make decisions.

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

- Yes
- No
- Unsure
- No Opinion

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

- Yes
- No
- Unsure
- No Opinion

15. Please give examples and reasons why.

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

- Yes
- No
- Unsure
- No Opinion

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

Case study examples for each section in 1.5 relating to the different decision making support arrangements would be very helpful in understanding the differences between each arrangement.

Section 3.2 (pages 34-35) - In this particular section there is reference to four processes but they are listed (A), (B) and (C). This section should be written exactly as the Act is written, i.e.

- (2) A person lacks the capacity to make a decision if he or she is unable—
- (a) to understand the information relevant to the decision,
 - (b) to retain that information long enough to make a voluntary choice,
 - (c) to use or weigh that information as part of the process of making the decision, or
 - (d) to communicate his or her decision (whether by talking, writing, using sign language, assistive technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party.

The use of (A), (B), (C) within this guide could cause confusion when there are actually four processes (A) – (D) needing consideration

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

Training to accompany this guide would be beneficial. The training could consist of small group exercises to discuss case examples. It would also provide the opportunity for professionals to share any concerns they have in relation to implementing this Act

Organisational culture and practice needs to be acknowledged. There has been some paternalistic and risk-averse practice in the care of adults in society and particularly with regards to services offered to people who may lack capacity. The guidance document and training could acknowledge this and commence the culture shift.

Service-User friendly documentation to provide to service users and families explaining the ADM Act and its implications within the healthcare setting. As professionals we will also play a role in educating service users, families and our colleagues

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

The Irish Association of Social Workers welcomes the opportunity for consultation on this significant piece of legislation and its implementation for those with whom we work.

The underlying principles of the Act are strongly in line with professional ethics and values of social workers and we strongly support the presumption of capacity, the functional nature of capacity and decision making and the need for service users to be as involved as possible in all decisions regarding their lives. In that manner we fully support the roll out of the Act as a matter of urgency.

We have a concern that acute hospital settings may not be ideal environments for assessing capacity and supporting persons to make decisions regarding their future care. Admission to an acute hospital is often a time of crisis for an individual and/or their family. The current acute hospital environment, with ongoing bed capacity issues, is not conducive to allowing the time and space for an individual's capacity to be both supported and/or assessed. The physical environment is also challenging in some sites and may contribute to poor decision making.

There are significant resource implications for social work teams in implementing the legislation. As key members of the MDT, assessing the psychosocial implications of an illness or admission to hospital, we are well placed to provide opportunities for individuals to express their will and preference for decisions relating to future care. The appropriate emphasis from the guidance document in maximising an individual's capacity and supporting decision making may require multiple interventions from a variety of HSCPs, all with resource implications.

The guidance document will need to be supported by strong codes of practice addressing the practical issues raised by the Act. For example clear guidance is required where there is disagreement within MDTs about an individual's capacity to make either certain or all decisions. To ensure truly person centred care all relevant staff, regardless of their profession, will have to be consulted in cases where a person's decision making capacity is in question. This will be challenging in the current hierarchical medical model that prevails in Irish hospitals

There are significant implications for Community Healthcare Organisations in terms of resources also. Medical social workers regularly advocate with our CHO and social care

colleagues to support an individual's discharge home if this is their wish. Whilst this is current practice, the Act will further support this work which is to be welcomed. However, where an individual is supported to discharge home despite concerns raised by the community resources (as opposed to going into residential care for example), significant home care package supports may be required. The current environment is that many patients (especially those under 65) are delayed in acute hospital beds awaiting funding for HCPs, this is only likely to increase once the Act is fully operational.

We feel that any comprehensive assessment of decision making capacity needs to be multidisciplinary in nature. Clarity will be required to ensure standardisation of the assessment processes across agencies. An individual requiring support regarding decision making should be guaranteed access to the same level of assistance regardless of location and service type.

Along with comprehensive codes of practice, training and education will be required for all staff engaged in this type of work. Is it envisaged that a list of professions/individuals will be drawn up to ensure access to suitably qualified staff for any individual requiring support and what training will be provided for them to ensure a high standard of professional conduct for service users?

On a practical note it will also be necessary to have access to any centralised register of co decision makers/decision making representatives to ensure that patient's prior expressed will and preference is respected where possible. This will also apply to those with advanced care directives. The code will need to outline who can witness these agreements in acute and post acute hospital settings.

The implementation of the Act may have implications for the National Safeguarding policy which is currently under review. Any code of practice will need to reference the policy in terms of its roll out.