



ACQUIRED  
BRAIN INJURY  
IRELAND

Submission to HSE

Assisted Decision Making  
(Capacity) Act 2015

Guidelines for Health and  
Social Care Professionals

April 2017



Acquired Brain Injury Ireland (ABI Ireland) welcomes the opportunity to make a submission to the HSE on the Assisted Decision-Making (Capacity) Act 2015 (the Act), A Guide for Health and Social Care Professionals (the Guide).

We appreciate this is a complex piece of legislation that has no precedence in practice. Our feedback is grounded in our experience as health and social care professionals (HSCPs). It reflects our clinical experience and working at the coal face with people an acquired brain injury (ABI). This piece of legislation is highly relevant to the lives of people with ABI and the HSCP teams who work with them on a daily basis. It will alter practice and demand changes in policies and procedures in the organisation and will require training to understand and implement the legislation.

We also appreciate that the development of the Guide is a dynamic process and there will be several iterations as practice and policy develops over time. The Guide as drafted is reasonable but there are still a number of 'grey' areas that are of concern to us and that need to be teased out further in order to provide effective guidance for HSCPs.

Our feedback on this initial draft is as follows:

### **1. The nature of brain injury**

Difficulty with insight or self-awareness is a common sequela of ABI. Following an ABI, a relevant person may have little or no awareness about their physical, cognitive, personality or behaviour changes and they may fail to see how acquired impairments impact their ability to effectively execute activities of daily living. Lack of insight can be caused by impaired self-monitoring, reasoning, attention and concentration, learning and memory, and reduced emotional coping or acceptance (denial). A person with impaired insight or self-awareness may not appreciate the implications of their impairments for decision-making or life planning.

- This is problematic as the relevant person requires insight in order to recognise the utility of appointing a Decision-Making Assistant. The Guide needs to reflect this in much more detail and describe in practical terms how the lack of insight into their condition impacts on the person's capacity to make decisions.
- Also, in relation to insight, it would be helpful to disambiguate an issue that constantly arises in disability services, namely, that making a choice to do a thing is not the same as being able to do that thing. For example, a person may make the choice to move out of a nursing home, but this is not the same thing as being able to live independently in the community. Particularly where the relevant person chooses to decline community supports or where the requisite community supports are not available. This is touched upon in Example 10 (although in this case there wasn't an insight difficulty per se), but further examples, particularly with complex presentations (e.g., dual diagnoses) are required in relation to how this kind of decision is assessed and then supported.

### **2. Appointment of individuals to support decision-making**

Significant others may also fail to appreciate the changes experienced by the relevant person due to ABI, fail to recognise insight or self-awareness deficits, and may similarly fail to see the challenges posed to decision-making and life planning.

- This is problematic as by-and-large, where a relevant person does have enough insight to appoint a Decision-Making Assistant, this is usually a significant other (family member, friend, etc.) and it may be that this Assistant is then not equipped to appropriately support the relevant person in making the decision.

Indeed, there needs to be a degree of mindfulness around the appointment of Decision-Making Assistants, Co-Decision-Makers, and Decision-Making Representatives. Our service has expertise in working with Wards with ABI and their Committees and is aware of the implicit risk to Wards in terms of their will and preference being undermined by well-meaning family members acting in what they perceive to be best interests. Whilst under the new Act Decision-Making Representatives are to be Court appointed, Co-Decision-Makers are not. Vulnerable adults often feel that they have no choice but to appoint a particular person (e.g., a parent) for fear of the consequences of not appointing the person.

- The Act and the Guide make a number of references to the appropriateness of the appointed Decision-Making Assistant and Co-Decision-maker (“appointed person has to be suitable...” “...important...not to put pressure...” “...bona fide interest...””) but the Guide does not specify what remit is held by/onus is placed on HSCPs to ensure the appointed person is suitable. Indeed, it is not clear who does this and how identified issues with appointed individuals are raised in order that this is handled appropriately. What if there is a disagreement between the relevant person, appointee, and services? Is there a requirement to raise concerns with the Decision Support Service? How is this done? It is also not clear how, where concerns are raised by HSCPs in relation to appointed individuals supporting decision-making, how actions taken under this Act then dovetail with other policies (e.g., HSE Safeguarding of Vulnerable Adults Policy) or legislation (e.g., Criminal Law (Sexual Offences) Act, 1993).

### **3. The role of the Multi-disciplinary Team (MDT)**

Overall, the Guide assumes that there is a full MDT readily available and accessible for consultation just prior to or during assessment. However, this is rarely the case in reality, especially in a community setting where there are often only partial MDTs who may not have ready access to the specific expertise that they need (e.g. access to psychiatrist). ABI Ireland’s experience is that there may be many weeks of a gap in securing the full MDT input. Similarly, in relation to the requirements for supporting communication of a decision, it can be difficult to access a Speech and Language Therapist, and where English is not the first language of the individual, there is significant difficulty in accessing foreign language translation services or specialist communicators (e.g., Irish Sign Language interpreters). This is particularly true for under-resourced community teams, particularly in the voluntary sector. The Guide needs to reflect this reality.

#### 4. Trigger for assessment of capacity

The Guide needs to provide greater clarity in particular around the trigger for assessment to establish capacity.

- The Guide needs to direct HSCPs to be mindful that capacity queries may arise not only in cases where the relevant person is declining services or making unwise decisions, but also where assent/consent is given. The Guide would benefit from greater clarity in discussion around decision-making capacity where the relevant person is assenting to services, in order to ensure that the decision is informed and the relevant person understands the reasonably foreseeable consequences of that decision (i.e., being mindful of uninformed/non-capacious acquiescence in ABI or ID populations).

Greater clarity is also needed regarding the levels of work that is required before you get to the stage of making an assessment. Both the Act and the Guide are clear that unnecessary capacity assessments or unnecessary findings of lack of capacity are unlawful/not in the spirit of the Act.

- However, the Guide is not clear in outlining, for instance, how the differing capacity requirements for appointing a Decision-Making Assistant versus a Co-Decision-Maker is established, without undertaking a capacity assessment (i.e., what is the tipping point for assessment?). Does a relevant person have to cycle through each successive level of assistance (or at least through the Co-Decision-Maker) before proceeding to Court? In theory, this is the appropriate course of action in order to ensure the least restrictive supports are given under the Act. However, this will then necessitate multiple assessments (1) lack capacity, therefore Co-Decision-maker, and (2) lack capacity even with a Co-Decision-maker?
- How is it possible to identify that capacity is “about to be lacking”? Is this solely on the basis of a medical diagnosis? How is a timeline given to a relevant person in relation to when capacity is about to be lacking? How does the HSCP know when the relevant person no longer has capacity, in order to trigger an Advanced Healthcare Directive, without undertaking a capacity assessment?
- Clarity is needed in relation to who is it that decides that an assessment is required. It is not clear from the Guide who is accountable for initiating the capacity assessment in the first instance (e.g., an individual practitioner or MDT).
- Where an assessment is triggered, who decides what the absolute essentials of information is required in order to ensure understanding?
- It is noted that the HSCP who triggers the capacity assessment is the HSCP who undertakes the assessment and completes the intervention. This is unlikely to always be the case, particularly in small voluntary organisations (e.g., it is anticipated in our service that referrals to clinical psychology will increase significantly, particularly in the period after commencement; this has been the experience reported by many services in the UK after the commencement of capacity legislation in England and Wales (Mental Capacity Act 2005), and Scotland (Adults with Incapacity Act 2000), e.g., Whyte, in preparation).

A broad concern is that instead of the stated positive aim of legislation to create “an obligation on health and social care professionals to support a person to make their own decisions as far as

possible, and where the person's capacity is in question, to provide all practicable support to facilitate the person to make the particular decision" the effect may be to cause staff to question more of their clients' decisions. This could happen because of the very broad legislative definition of relevant persons cited in the Act and Guide as "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 difficulty reaching a decision without the support of someone)". This may have a number of unintended consequences:

(1) Staff will query if the person does not understand the nature and consequences of the decision, whenever the decision appears unwise to that staff member/staff team.

(2) staff will escalate all decisions they judge to be unwise, even if they either 'assume' capacity is present, or really believe capacity is present, because they will not want to hold the risk of being wrong, or not want to hold the risk of not having escalated the issue, and not having an expert report, in the context of regulatory inspections from the likes of HIQA or accreditation inspections from the likes of CARF.

(3) Whereas in the past, capacity assessments conducted by Clinical Psychologists in services were largely around existing Wards of Court (i.e., people who services knew lacked capacity) the broad definition in the Act and Guide may serve to call into question the decisions of everyone with any intellectual or neurological disability, or everyone with mental-health needs.

(4) The "may shortly be in question" line in particular may be interpreted by staff as meaning everyone, because to be safe, staff will interpret that as 'anyone could get worse at any time'.

- There is no concern in relation to staff escalating real issues for expert assessment, but staff will need some guidance on the threshold level of risk present below which there is no need to escalate concerns for expert assessment, and expert assessors will need guidance on same. For example, financial incompetence and risky sexual behaviour are one thing, but for example "won't wear an overcoat when it's raining" (because they may get a cold, and they could get worse, and they could be hospitalised), should be cited as an unsuitable referral for expert capacity assessment.
- A clear flow-chart would be a valuable addition to address these points.

## 5. Terminology

There is a change of language from "in the best interest" to "acting in good faith" in the Act. It would be useful to have "good faith" defined and teased out more in the Guide. Currently these could appear to be synonymous or may become so over time.

- What level of HSCP is undertaking assessment and intervention (care assistant, trainee, staff grade, senior grade, etc.)?
- What is the definition/benchmark/baseline for skill and experience?
- What if there are difficulties accessing relevant multidisciplinary professionals?

The Decision Support Service, and Director, is new nomenclature, replacing the terms Office of the Public Guardian and Public Guardian as used in previous drafts of the legislation.

- The Guide could draw attention to these changes as some expert clinical staff have very likely already commenced using the older terminology in reports to the Courts (e.g., in relation to existing Wards or for those with whom functional capacity assessments have recently been completed).

## 6. Communication

Communication is such an integral aspect of how this Act is implemented, there needs to be more guidance and details provided in the Guide than just a list of resources in an Appendix.

## 7. Advanced Healthcare Directives (AHD)

It will be helpful to have guidance on whether there should be any attempt to see whether the relevant person has changed their mind since instructing an AHD. It can be the case that what people anticipate as their wish because of fear and uncertainty prior to becoming incapacitated may not be what they wish in the actual lived experience.

## 8. Role of the HSCP and their employer

The Guide needs to consider the role of the HSCPs in the implementation of the Act within the context of them being employed by an organisation in the community and voluntary sector. (Not all HSCPs are employed directly by the HSE) Furthermore, the role and responsibility of the employer vis-a-vis the relevant person using their service and the role of their employees (HSCPs) must be addressed. Guidance is needed for organisations' responsibilities as HSCPs only operate within an organisational context. Some of the issues that need addressing in this regard are:

- How do the HSCPs build their knowledge and skills to engage in the Act and what is the role/responsibility of the employer in this regard?
- What specific skills and competencies do HSCPs need to be equipped with by their employer to ensure effective implementation of the Act on a day- to-day basis?
- How do organisations (the employers of the HSCPs) engage? What are their obligations/responsibilities?
- Can the Guide include guidance and direction on training needed and policy development that is necessary to implement the Act?
- How does the HSCP interact with the Co-Decision-Maker, Decision Making Assistant/Representative? What are the obligations on the employer in this regard?
- How does the HSCP interact when there is an EPA in place? What are the requirements/roles of employer?
- On the basis of the examples and template provided, the assessment of capacity should and will be a lengthy process and the time required to appropriately undertake and document

the assessment is significant.

- It must be acknowledged that any intervention that supports decision-making is likely to have particular resource implications. For instance, if a relevant person living in a residential service wishes to leave, had lived independently pre-injury, has the capacity to make the decision to leave, but does not have the ability to live independently, then will the resources be made available to support this individual to live in the community (e.g., housing, rehabilitation support, home help support, etc.)? What happens if the person does not have the capacity to make the decision to leave, but expresses clear and consistent will and preferences for independent living?

## 9. General comments

As they currently stand, the Guide is too general in nature. For the community of people that we serve, they are not specific enough in order to honour the requirements of the law. They are trying to cover too many areas in too general a way to have relevance. As an organisation, we would welcome more specific guidelines on the tools to use (e.g., in relation to assessing financial capacity) and issue-based guidance on the assessment of capacity, particularly where this Act interacts with other legislation (e.g., in relation to the decision to consent to sex).

In addition, the Guide is very repetitive and requires editing to avoid this. The Guide would benefit significantly from flow charts regarding processes, decision making trees, graphics and a wider variety of illustrative examples across the continuum of care for a variety of clinical populations (i.e., less hospital-based).

## 10. Contributors and contact details

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## Supporting Information

### About ABI Ireland

ABI Ireland is a dedicated provider of community-based neuro-rehabilitation services for people with an acquired brain injury (ABI) and their families. As a brain injury can affect a person's ability to manage their own life, ABI Ireland works in communities across Ireland to support and empower people to rebuild their lives. ABI Ireland also campaigns, educates and advocates for the rights and needs of this hidden group in society.

### ABI Ireland Services

ABI Ireland provides a diverse range of accredited neuro-rehabilitation services. The core services include:

- Clinical neuro-rehabilitation team
- Residential rehabilitation
- Transitional living
- Day resource/clubhouse
- Home and community rehabilitation
- Case management

Additional support services are also provided and include ABI information, family support and carer training.

[www.abiireland.ie](http://www.abiireland.ie)