



National Office for Human Rights and Equality Policy

Webinar series

Assisted Decision-Making (Capacity) Act 2015 Commencement and Implementation

Webinar 4: Functional Assessment of Capacity (17/05/22)

This is a transcript of the Q&A in the chat function at the live event, wherein panellists responded to questions from attendees.

What is the address for these resources?

Many resources to support staff to prepare for commencement are available at www.assisteddecisionmaking.ie. You can email adm@hse.ie to join our mailing list to receive our newsletter and stay up to date. E-learning programmes are available on HSEland, and more e-learning programmes will be made available on HSEland shortly.

If you believe someone has been taken advantage of (e.g. dementia patient) in relation to their will, is there any recourse in this Act to protect this patient?

Testamentary capacity as such is not covered by the 2015 Act. However, if someone has concerns that a person is being taken advantage of, they can contact the Decision Support Service - and of course there is also HSE safeguarding.

Sorry - I missed reason why Section 15 wardships have re-commenced - can anyone explain?

Please see the notice issued by the Office of the Wards of Court Notice in Relation to Applications for Wardship <https://www.courts.ie/news/notice-relation-applications-wardship-0>.

Please clarify the different wardships.

There are two kinds of wardship - s. 15 (regular wardship) and s. 12 (emergency wardship). Section 15 applications had ceased on 22nd June but are now operational again.

So, if there is no need at the time to make a decision to be made, there is no need to request a e.g. assistant decision maker?

Yes, no need to use a supporter unless the relevant person wants one.

Who carries out the assessment for Co-Decision Maker or Decision-Making Representative if this has been discussed and agreed with the person and is being done outside of an acute hospital situation?

Assessment for a Co-Decision Making agreement can be done by a range of Health Care Professionals - medical professionals; nurses; Speech and language therapists; occupational therapists. We are still waiting for the Rules of Court - in relation to assessment for a Decision-Making Representative.

When you talk about needing a decision to assess, do you feel whether someone can indicate choice on discharge home is one of those types of decisions or does it need to be more specific to the concern related to discharge home?

Yes, webinar 3 on 'Positive Risk taking and 'unwise' decisions' (which will be available on www.assisteddecisionmaking.ie) goes through some helpful scenarios.

A patient involuntary admitted under Mental Health act, no insight into Mental Health diagnosis. Patient's will and preference is to return home to family home, family does not want patient home due to challenging/threatening behaviour. Patient only wants to go back to family home will not engage in any discussions/ services becomes hostile and threatening when this subject is approached. How do you work with patient in this circumstance when will and preference cannot be met?

Even if the person lacks insight, the person can still be supported to make decisions about treatment or care. Person's will and preferences should remain at centre of decisions, but open meeting with family and person can help alleviate tensions. Open Dialogues system used in Finland and being piloted in West Cork is open meeting with person and people around them. Person always remains at centre of these meetings. Advanced Healthcare Directives (AHDs) can be helpful in mental health when person goes into crisis, where person's will and preferences are set out in advance. Possible that person can be treated and supported in community, so all options and alternatives should be explored with person.

What if you know someone's will and preference is to remain in their own home, however due to cognitive impairment and other issues is unable to carry out any independent living skills and despite supports in place cannot manage in the community and won't engage with all supports - extremely vulnerable and at risk. Assessed as having capacity to choose where to live but on day-to-day functioning is unable to live independently - alcohol related brain damage, executive functioning issues, very challenging to support this person in the community.

You may find it useful to watch back on webinar 3: 'Positive Risk taking and 'unwise' decisions' which is available on www.assisteddecisionmaking.ie.

An older person in a HSE nursing home has recently expressed a wish to visit the grave of a child she lost many years ago. She seems to have capacity in general. Should we check with family to see how difficult this might be for her - we now believe that it should be facilitated while she is fairly well.

She should be supported and has expressed a wish and be mindful of the supports she may need after the visit in terms of counselling have these in place.

Are all the recordings available for staff to view going forward, for how long, or are there plans for a HSEland module?

Yes, recordings of all the webinars will remain on the website www.assisteddecisionmaking.ie for anyone to watch back. We will launch a new suite of e-learning modules on HSEland later this year in relation to specific provisions of the Act.

How does a person make an Advanced Healthcare Directive - does a solicitor need to be engaged?

No need for a solicitor or even a healthcare professional (though it may be wise to discuss with your Dr to ensure directive meets your needs and is clear). There will be material for the public on how to do this.

In relation to the delay to full commencement of the Act, I am assuming that we should 1) continue to detail our efforts to work in line with the Guiding Principles, 2) focus on supporting people in line with their will and preference whenever possible and 3) avoid assessments of capacity unless absolutely necessary. In the meantime, I assume that we should still work in line with the Guiding Principles, regardless of the delayed commencement date.

Absolutely, these also underpin the revised HSE Consent Policy.

Is the main effect of the delayed commencement date a further unavailability of the supports available through the Decision Support Service?

As far as we understand the possible delay is due to the amending legislation still not been completed.

Can someone without an official cognitive impairment still lack insight?

People can be deemed to lack insight for many different reasons. The main message is that we should not use insight to deprive people of their capacity to make decisions in relation to their treatment or care or detain them on this basis. We should focus on the supports the person needs to make the decision regardless of their insight. This may be an Advanced Healthcare Directive (AHD) in advance or other supports such as information in format person understands, time, independent advocacy etc.

Can existing Circles of Support continue to support a person with decisions and demonstrating will and preference without recourse to the three tiers of support, particularly representative?

Absolutely - a person can be supported to make decisions in ways that are not set out in the Act. However sometimes having one of the supports under the Act (such as Decision-Making Assistant or DMA and Co-Decision-Make or CDM) might make it easier for the people in the circle of support to interact with services providers.

A few of the speakers mentioned Enduring Power of Attorney (EPA). There is confusion around the legality of this document once the Assisted Decision Making Act (ADM) comes into law - some are saying that this is not valid and a person has now to prepare a new one - could cost up to 500/600 euro to do this? Is this correct?

All prior EPAs continue to be valid after the Act commences - no new EPA is required.

It does not automatically follow that an involuntary detainee also lacks capacity to make decisions.

Yes, the presumption of capacity applies in this situation also, and the assumption that someone does not have capacity if involuntary needs to be challenged under the Act.

Regarding Eddie in the scenario - The act has intentionally moved away from best interests? Practitioners must consider the context of acting in good faith and for the benefit of? Who did the capacity assessment?

Yes. These scenarios were submitted to us by staff, we have kept the original wording as far as possible for the panellists to explore and challenge.

For someone with a moderate Intellectual Disability (ID) and autism who only understands information in the here and now how do you support them to be involved in a decision if information provided too far in advance causes anxiety and self-injurious behaviours?

It is certainly a challenge. Any information should be individualised in terms of the level of information provided, the manner in which it is provided and also the timing. Some people will benefit from much time to process; others as you say need a shorter lead in as it may create additional anxiety. In some situations, additional supports could be brought in to help the person manage any anxiety or self-injurious behaviour. In some cases, it may be appropriate to provide the information on a phased basis. And remembering the person needs to be provided with relevant information - so that needs to be teased out too. I think the best approach a staff member can take is to look at what would best support that individual to make that particular decision and build the decision-making supports around that.

The most critical issue is to be mindful of those situations which cause stress and anxiety the focus of support should be to keep stress to a minimum.

Has consideration been given to the possibility of a) inappropriate referrals/requests for a functional assessment of capacity and how these are dealt with and or b) the possibility of new 'waiting lists' for functional assessments of capacity?

We need to remember that formal functional capacity assessments are a last resort, and we may need to go back and assess supports person needs, talk to people close to them, and explain that a formal assessment may not be needed in many cases. If inappropriate requests received, should explain this under Act.

Can I request that all the speakers' names and roles are included on the Webinar?

The panellists were introduced at the start of the panel discussion:

Amanda Casey - Principal Medical Social Worker, Mater Misericordiae University Hospital

Ruth Connolly - Principal Clinical Psychologist, Muiriosa Foundation

Catherine Devaney - Health and Social Care Professions Clinical Advisor, Older Persons

Caroline Howorth Director of Adult Clinical Services, and Speech and Language Therapy Manager in St Michael's House.

Brendan Kelly- Professor of Psychiatry, Trinity College Dublin.

Niamh Kelly - Senior Occupational therapist, Mayo General Hospital

Mary McCarron - Chair of Ageing and Disability, Trinity College Dublin

Fiona Morrissey – Disability Law Researcher and Advocate.

Shaun O'Keeffe- Consultant Geriatrician, Galway University Hospital.

Is there a primary professional identified to complete the function capacity assessment? Is there a national functional capacity assessment document/framework devised for use or is this going to be general assessment ensuring use of all principles of the ADM (Assisted Decision Making) act are adhered too?

This should be answered for you as part of the final set of questions on the webinar.

What guides are available to assist healthcare professionals to carry out a function capacity assessment? We seem to be lacking these tools to carry out a functional capacity assessment.

A lot of information is available in the revised National Consent Policy and will be code from the Decision Support Service (DSS).

Who would carry out the functional capacity assessment of capacity in Eddie's case?

Eddie's case was an example submitted to us from frontline staff. Prescribed professionals will complete functional capacity assessments, where required. The detail of this will be discussed more towards the end of the webinar.

Should the client's lack of insight into the risks she will possibly encounter when she goes home not be considered, especially if the clients lack of insight puts huge expectations on her family's ability to support her in the community? Often the clients will go home (when they lack insight) puts huge strain on carers, yet the carers needs aren't considered if we just follow the clients will and preferences??

The emphasis should be on supports the person needs when they go home. This can be done in consultation with the family and people close to the person. However, person's preferences should be at centre, and we should consider how we can respect their wishes and support them in way that is also respectful to people around them. The person may need supports that take strain off their family, and we should consider what options are available to person here.

Can I ask If Ida has capacity to make a decision to discharge home and her will and preference is to return home, however Ida would like carers to support her discharge, but no carers are available and her home is not suitable to support her care needs, how would you proceed?

It is important that we are open about what is and isn't available to support people at home and this varies hugely depending on where you live. If we are clear with Ida about the reality of what will be available, and she still chooses to go home then we need to support that decision. Previous webinar on Risky Decisions addresses some of these issues also.

Functional capacity assessments are not just a last resort if we consider everyone applying for an Enduring Power of Attorney (EPA) or Co-Decision-Maker (CDM) requires one. Can all prescribed professionals do this assessment, not just GP?

For EPA/CDM all prescribed professionals can do assessment.

Independent advocacy plays an important role. Can you elaborate on what advocacy supports are available?

Independent advocates can play a valuable role in supporting a person to make their own decisions. You can find a list of advocacy services here:

<https://www.hse.ie/eng/services/yourhealthservice/feedback/services/>

Including

Sage Advocacy www.sageadvocacy.ie/

NAS – advocacy.ie

Irish Advocacy Network - <https://www.peeradvocacyinmentalhealth.com/>

Patient Advocacy services – patientadvocacyservice.ie

Inclusion Ireland- <https://inclusionireland.ie/>

Third Age - <https://www.thirdageireland.ie/>

Aslam - asiam.ie

If Joelle made a decision that impacts negatively on her son's development, can he take a case against HSE after he turns 18?

If all supports provided under Act, no reason case would be taken, no more than any other parent of a child with a disability.

What do the abbreviations EPA/CDM stand for?

Apologies for the jargon. EPA is Enduring Power of Attorney. CDM is Co-decision maker.

Could it be clarified please if 'functional assessments of capacity' actually breach UN CRPD (Convention on the Rights of Persons with Disabilities) [irrespective of Declarations/Reservations disappointingly lodged by Irish Gov/Justice]?

Yes, functional assessments of capacity not in compliance with CRPD which is why we are saying they should be last resort and focus should be on supports.

UHL have A PALS service in place with 6 team members.

Thanks for the information Paula. Independent advocates can play a valuable role in supporting a person to make their own decisions. You can find a list of advocacy services here:

<https://www.hse.ie/eng/services/yourhealthservice/feedback/services/>.

Does the panel envisage a situation where all the different levels of decision-making new roles under the Assisted Decision Making Act (ADM) replace Enduring Power of Attorney (EPA) over time?

Very difficult to know. An EPA represents your personal choice so helpful in a way having a Decision-Making Representative (DMR), who might be a stranger to you.

Could you please repeat the term used to describe the professionals who can complete the functional Assessment of capacity?

Prescribed Class of Professionals.