Adults with Complex Needs: Is ADMCA a Help or a Hindrance?

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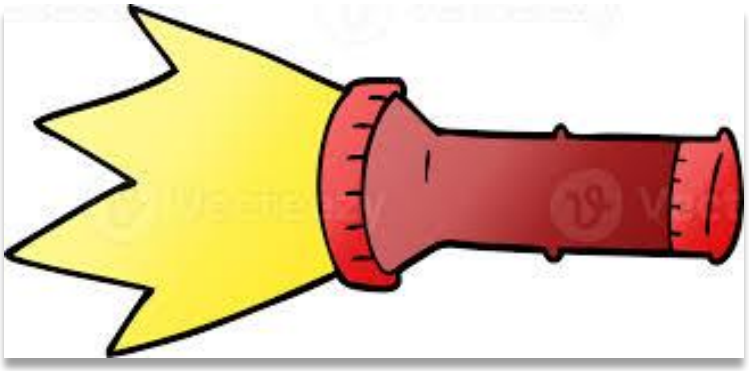
What's not in ADMCA…But



- Detention/coercion/treatment order is sought… NOT dealt with in ADMCA
  - Accommodation, "*including whether or not the relevant person should live in a designated centre*" BUT "*Nothing in this Act shall affect the inherent jurisdiction of the High Court to make orders for the care, treatment or detention of persons who lack capacity*".
  - New protection of liberty legislation planned
- Restraint/ restrictive practices NOT dealt with
- Nursing Home Support Scheme (NHSS, "Fair Deal") was amended post ADMCA

Nursing Home Support Scheme (as amended) (NHSS "Fair Deal")

- There is no 'general' requirement for a Decision-Making Representative (DMR) to apply for NHSS just because someone lacks capacity to make their own decision/ application or to provide financial information

- Changes to Specified Persons who can apply for NHSS on behalf of person
  - Person, spouse, children – no longer any adult relative (or solicitor)
  - A doctor, nurse or social worker or a decision supporter under the Act

- No more "care representatives" appointed to seek ancillary state support (the 'loan' or 'mortgage' to defer payments)
  - Instead need to apply to Circuit Court to appoint a Decision-Making Representative (DMR) to seek ancillary state support
  - Accounts for majority of DMR applications so far

When might a DMR be needed to progress NHSS application when someone may lack capacity?

- Making an application for the NHSS: NO.
  - This can be done by any Specified Person under the NHSS. If the person can't apply themselves and there is no qualified person, any registered doctor, nurse or social worker can apply.

- Getting financial information: Usually NO.
  - Most institutions will send the information directly to the Nursing Home Support Office.

- If the (optional) ancillary state support is sought: Often YES
  - Presumption of capacity but rebuttable
  - More complex financial decision, and more people may require formal support

- Signing contracts of care with the nursing home: ?? Depends on the nursing home/ group at present.

- If orders permitting detention are being sought from High Court: Usually YES.
  - The High Court won't deal with funding matters since the end of Wardship.

ADM Guiding Principles: "The Spirit of the Act"

Presumption of capacity always the starting position. (**But** rebuttable)

Merely making an unwise decision does not mean that the person lacks capacity. (Not "a right to make unwise decisions)

Must be no intervention unless necessary to do so in the individual circumstances

Any intervention **must** minimise (1) restriction of person's rights and freedom of action, (2) respect person's right to autonomy; (3) be proportionate to significance and urgency of the matter; and (4) be as limited in duration as possible

An intervenor **must**

- Give effect, as far as practicable, to past and present will and preferences if ascertainable
- Take into account beliefs and values of person
- Unless not appropriate or practicable consider view of anyone the person wants consulted / decision supporters
- At all times act in good faith and for the benefit of the person. (Benefit is not just medical "best interests" or safety above all other considerations)

An intervenor **may**, unless not appropriate or practicable, consider the views of any carer, anyone with a bona fide interest in welfare of the person, healthcare workers.

Functional Test of Capacity

Capacity Statements

Lack of Decision-Making Capacity – unable to

- Understand information relevant to decision
  - Information about reasonably foreseeable consequences of each of the available choices or of not making the decision for the person
  - Keep it as simple as possible: no need for person to 'be an expert'

- Retain that information long enough to make a voluntary choice
  - It's not a memory test! It doesn't matter if the person cannot recall choice later

- Use or weigh that information as part of the process of making the decision
  - People use or weigh information in accordance with their own beliefs and values; different people may give different weight to different factors and may give zero weight to something professionals think important
  - Eliciting values and beliefs important when assessing capacity
  - They may have dominant principles – home no matter what, for example

- Communicate by whatever means necessary

<u>Capacity is decision-specific and time-specific</u>

<u>It is the process of decision-making that matters not the actual decision made</u>

Lacks “insight”

- Often used/misused by capacity assessors. Best avoided
- Not a criterion for functional assessment of capacity & often doesn’t ‘map on’ to any of the criteria
- Complex concept & needs unpacking
  - “Denying the undeniable” – may be impossible to ‘understand’ and ‘use or weigh’ in such cases
  - Denial of problems as a defence mechanism if the person fears any admission of a problem will be used against them
  - Forgetting problems that have arisen due to memory impairment – may be remediable by explanation
  - Shorthand for others saying “I don’t agree with your decision” – perhaps a difference in values
  - Disagreement on predicting the future: “Lacks insight that they will fall at home”. (Remember how often your own predictions have been wrong in the past)

“Needs 24 hour care”

“The phrase “24-hour care” is a powerful slogan [when discussing the need for long-term care]… Unless families commit to intensive involvement, the 24-hour care need usually leads to nursing facility “placement,” where round-the-clock but thinly-stretched staff give the illusion of 24-hour care even though care from all nursing staff averages under 2 hours per person per day”.

(Kane & Cutler, Gerontologist 2015)

Place of Residence
Not Just About Risk or Capacity

- You are not able to care for yourself properly / not safe/ neglecting yourself.

- You will be better off in residential home where you will receive such care

- People use or weigh information in accordance with their own beliefs and values, and different people may give different weight to different factors.
  - There is a temptation to conclude that the people should place greater weight to physical, rather than emotional, security.
  - The dog, memories, familiarity may all outweigh potential hazards

How better off?

It'll be nice for you to be with other confused people?

- Often bewildering and upsetting
- NI paper: '…violence in care homes was regarded as intrinsic to the care, known about but largely hidden' (Scott, Int J Nursing, 2011)

You'll be less confused?

- 'Nursing home placement associated with accelerated short-term cognitive decline in Alzheimer's disease'. (Wilson, Am J Psych 2007)

You'll be happier?

- 'Increased feelings of loneliness and marginalization; psychiatric symptoms worsened and quality of life perceived more poorly'. (Scocco, Int J Geriatr Psych 2006)

You'll get better medical care?

- Antipsychotic medication
- Restraints
- Poorer access to clinics

You'll live longer?

- Shorter life expectancy in Alzheimer's disease admitted to LTC (McKee, J Gerontol 2006)

The fact is that all life involves risk […] But just as wise parents resist the temptation to keep their children metaphorically wrapped up in cotton wool, so too we must avoid the temptation always to put the physical health and safety of the elderly and the vulnerable before everything else. […]

Physical health and safety can sometimes be bought at too high a price in happiness and emotional welfare.

The emphasis must be on sensible risk appraisal, not striving to avoid all risk […] but […] being willing to tolerate manageable or acceptable risks as the price […] to be paid in order to achieve some other good – in particular to achieve the vital good of the elderly or vulnerable person's happiness.

<u>What good is it making someone safer if it merely makes them miserable?</u>

(Sir James Munby, EWHC, Re MM)

Capacity Assessment ADM Myths

- *We need to identify everyone who lacks capacity, so I need to assess capacity.*
  - Only if there is a good reason for assessment. (Presumption of capacity is not overturned by dementia, disability, mental illness, etc or merely by making what others consider an unwise decision). **AND**
  - An intervention would be reasonable and proportionate and the least restrictive option. (**NOT** 'if we find incapacity we must do something').
  - Assisted Decision Making (Capacity) Act 2015 **NOT** Capacity (ADM) Act
- *I want a 'capacity assessment tool'*
  - There is guidance but **NOT** a 'tick box' tool or MMSE/ MOCA equivalent
- *If I'm worried about a decision someone is making, they've got to convince me they have capacity to make it before they can be allowed to make the decision.*
  - The person doesn't have to prove anything! Nobody ever has to prove they have capacity: the onus is on the person challenging capacity
- *If I make a finding of lack of capacity, I have new powers to do things or to make someone accept my recommendations*
  - There are **NO** such new powers & ADM is not about coercion, detention

Statements/Reports of Capacity under ADM

- Who can perform assessments/ provide reports under the Act?
  - Registered doctor, nurses & midwives, SLTs, OTs, social workers.
  - No special role doctors or for psychiatrists or geriatricians

- When are they needed? In limited circumstances!
  - Part 4. Co-Decision Making Agreement – to DSS
  - Part 5. Decision Making Representation Orders – to Circuit Court
  - Part 7. Enduring Powers of Attorney – to DSS

- There are no "informal" assessments: Formal procedures, recording and reporting.

- Each of these has specific requirements for capacity assessment and statements – not 'generic'

The MDT and Capacity Assessments

- Most but not all multidisciplinary team members can do assessments (and some medical social workers, in particular, have been doing so and providing reports for the Circuit Court for Part 5 applications)
- Even if not doing the actual assessment, the MDT can inform assessments and provide ancillary reports, etc
- The right person to assess depends on the particular decision: geriatricians and social workers may be most familiar with NHSS and ancillary state support

- The "MDT" capacity assessment?
  - An individual professional needs to take responsibility: not "safety in numbers" or diluted responsibility
  - Some assessments are contentious – objections/ complaints
  - 'Joint assessments'?
    - Not uncommon – e.g. geriatrician and psychiatrist in IJ cases to (try to) resolve disagreements
    - But independent reports and sometimes disagreement persists

Using the New Tiers of Support in ADMCA

Wardship replaced by 3 tier hierarchy

Decision-Making Assistant

Helps access and explain information

Person still decides

Co-Decision Maker

Appointed by person

Makes **specified** decisions jointly **with** the person

Decision-Making Representative (DMR)

Last resort

Circuit Court-appointed

Makes **specified** decisions **for** the person as provided in court order

The new 3 tiers are options to support the person
They are problem-solving tools.
They are not mandatory interventions!
The lowest tier possible must be used

The 'Blanket Policy' Problem

All with dementia needing Ancillary State Support should have a DMR

For individuals in residential care, would a formal support arrangement provide greater protection to the person, their circle of support and to us as their service provider?

Misconception of the Act that :

- If capacity to make a decision is in question, capacity assessment is needed and
- If a person is found on assessment to lack capacity to make a decision, a formal support arrangement is needed

Focus on needs / protection of service provider and administrative 'tidiness'

"…*over 200,000 adults living in Ireland could have decision-making capacity difficulties and may benefit from the new supports provided… It would be wrong, however, to presume that any one of those 200,000 people will necessarily come within the ambit of the Act. That will depend on their individual circumstances*". (Áine Flynn)

NO! This is contrary to ADMCA (and would cause chaos to services, courts and be unfair on relevant persons)

(5): There shall (MUST) be no intervention in respect of a relevant person unless it is necessary to do so having regard to the individual circumstances…

(6) An intervention in respect of a relevant person shall (MUST)—

(a) …[minimise] the restriction of the relevant person's rights…,

(c) be proportionate to the significance and urgency of the matter

No blanket policies re use of supports!

Decision Making Representation Order (Part 5) Applications

Who makes a Part 5 Applications (for Decision Making Representation Order)?

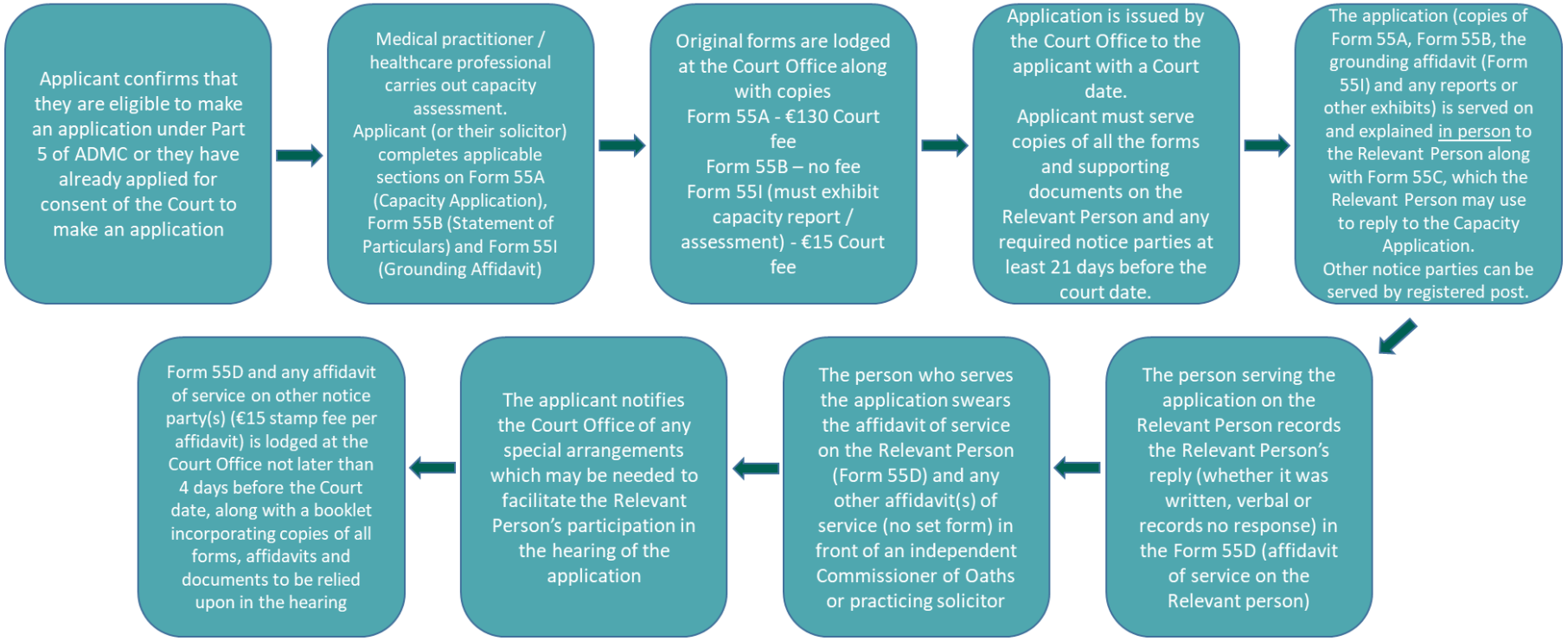
- Person themselves, or any adult with “a bona fide interest in their welfare
- Person, spouse/cohabitant, adult child, specified supporters can apply directly
- All others (including HSE) must seek prior consent of the Court to apply (HSE seeking to be allowed apply directly)
- The Capacity Applicant is distinct from the healthcare professional Capacity Assessor who provides the Capacity Report.

Part 5 applications are governed by Circuit Court rules

Circuit Court Rules for DMRO (Part 5) Applications

Court service graphic to explain the process in.

"Capacity Application" means an originating application to the Court for a declaration under section 37 of the Act



*The Applicant (or their solicitor) completes applicable sections on Form **55A** (Capacity Application), Form **55B** (Statement of Particulars) and Form **55I** (Grounding Affidavit)*

Court Rules for Capacity Reports in Part 5 applications

A Capacity Application must be supported by a report from medical practitioner or healthcare professional, which must:

(a) include details of the extent to which the person making the report has treated the relevant person and include details of any examination or assessment undertaken for the purposes of making the report, and;

(b) report on matters within the person's expertise which relate to the relevant person's capacity, considered in accordance with section 3 of the Act [functional test of capacity] *to the extent relevant to the relief sought in the Capacity Application* [i.e the specific decisions], *including the likelihood of recovery of the relevant person's capacity.*

What decisions? The 'Kitchen Sink' Problem

- Personal Welfare: Includes one or more of
  - accommodation
  - education and training
  - social services
  - healthcare
  - participation in research
  - other matters relating to person's wellbeing

- Property and Affairs: Includes one or more of
  - buying and selling property
  - applying for benefits
  - carrying on a business
  - paying debt and liabilities
  - providing for other persons
  - Court proceedings

- Not of equal complexity, and within each domain there are many decisions of varying degrees of complexity

- All of these (often bar research!) being listed for assessment – sometimes by HSE instructions, sometimes by solicitors - in Part 5 applications often triggered solely by the need for Ancillary State Support in NHSS

- "*What is/are the particular decision(s) that need(s) to be made <u>at this time</u>*?"

What's the problem? ADM is not 'Wardship Lite'! Consistent with the least restrictive principle?

Survey of lawyers making guardianship applications in Saskatchewan (Surtees Alta L Rev 2012).

- 9% agreed with "*An applicant should only ask for powers which they need as of the date of the application*." → Yes
- 53% with "*An applicant should ask for powers they need [now] and those which there is a <u>reasonable likelihood they will need in the future</u>, as this will reduce the need for further applications.*" → Maybe depends on how likely, when and specificity of decision:
  - *You are likely to need to decide whether to have a kidney transplant in the next year* vs
  - *You are likely to encounter some healthcare crisis in the decades ahead*
- 38% with "*An applicant should ask for powers they need [now] and those which there is a <u>possibility they will need in the future</u>, as this will reduce the need for further applications*." → No

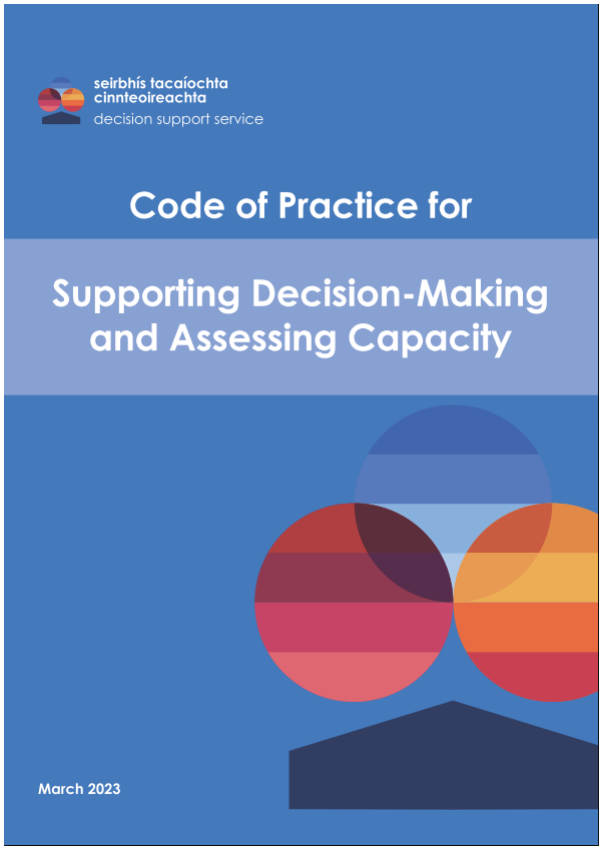
What's the problem?

- "Healthcare" in particular is very broad: from taking paracetamol to brain surgery

- HSE Consent Policy Updated 2023 takes the position (after legal advice/ consultation with State Claims Agency): if the person cannot consent for themselves and there is no relevant decision support arrangement, use the ADMCA Guiding Principles
- If all consistent with the intervention, proceed
    - Treatment is for the overall benefit of the person
    - Treatment is consistent with the person's will and preferences if ascertainable
    - Consider the views of others (e.g. family and friends)

- Discusses situations where decision support arrangement should be considered

How should Assessors conduct the assessment?



Assessors need to understand

- Responsibility in assessing capacity is to the Court and to the relevant person, not to the HSE/hospital/bed management.
- They may be required to explain, justify their report and conclusions
- It's not a technical exercise
  - It's a law
  - It's a human rights law & the stakes are high for the person.
- Doing a good assessment and report doesn't require a lot of knowledge but it does require diligence and the right attitude
- Assessors have agency!
  - What specific decision(s) are the subject of referral?
  - Why is the person's capacity to make this decision in question?
  - Why is a capacity assessment under the Act required?
  - Are you the right person to assess?

How should Assessors record the Capacity Statement?

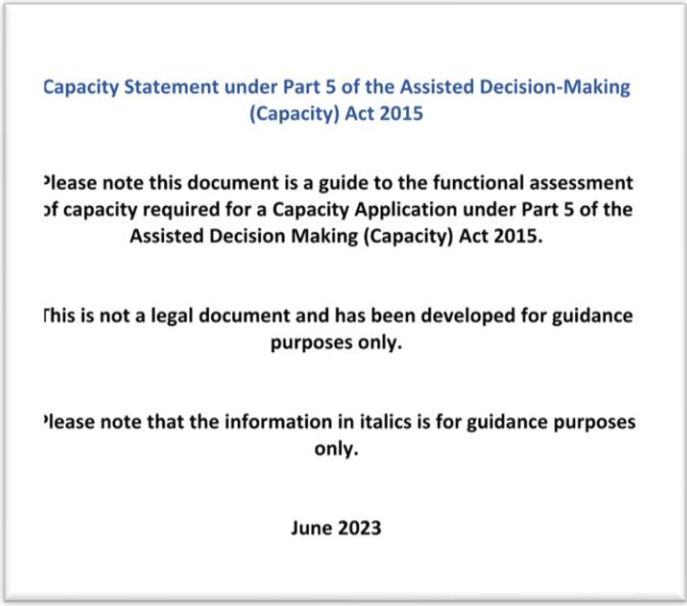
The report must satisfy court rules including an explicit breakdown of the 4-strand functional test & the likelihood of recovery

This is a HSE-developed template that has been acceptable to the Circuit Court.

Our advice to staff: Use the template! –

- It will guide assessors through what is needed and help prevent sub-standard reports.
- It will also help lay people negotiating the application forms

There may be a role sometimes for additional reports to assist the court



Capacity Statement under Part 5 of the Assisted Decision-Making (Capacity) Act 2015

Please note this document is a guide to the functional assessment of capacity required for a Capacity Application under Part 5 of the Assisted Decision Making (Capacity) Act 2015.

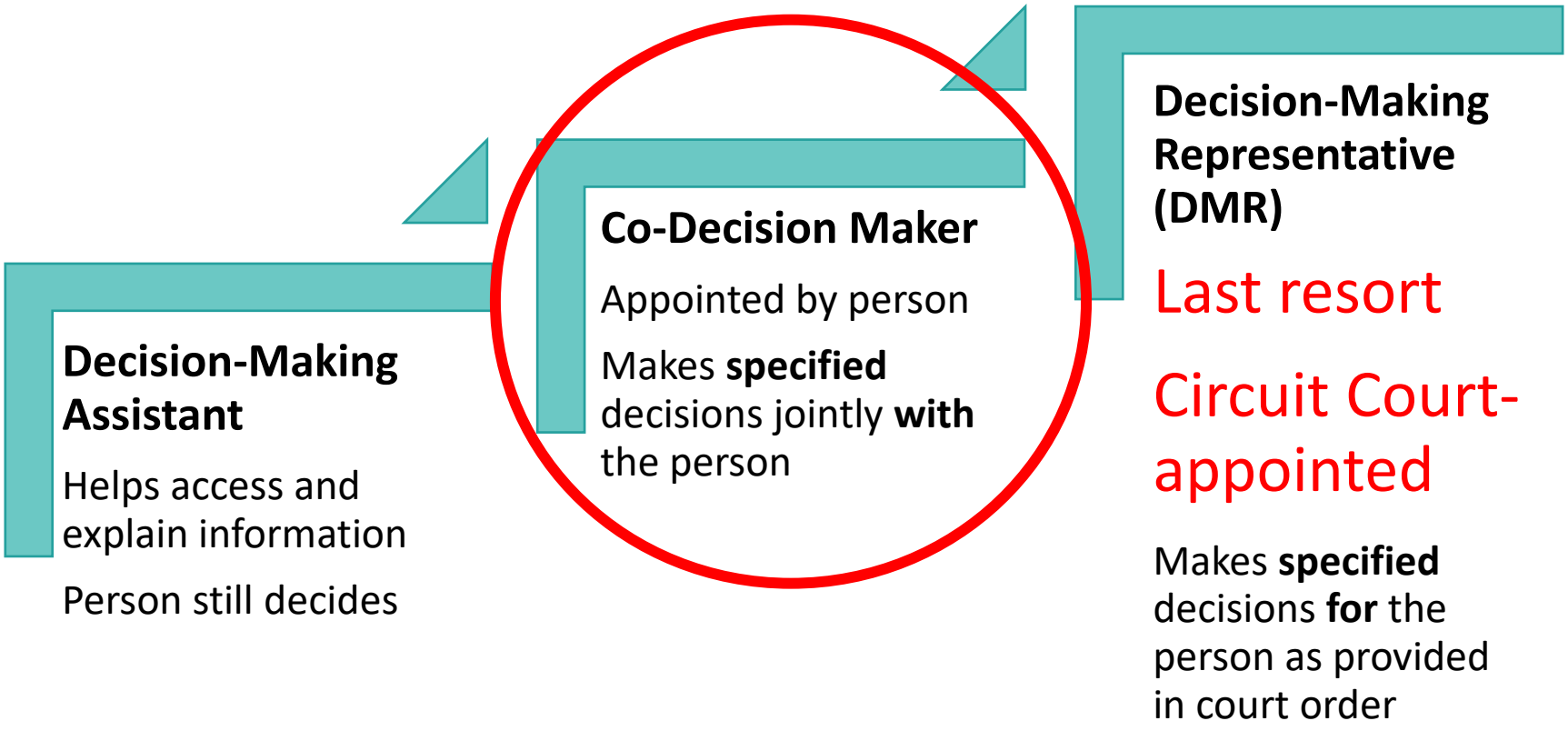
This is not a legal document and has been developed for guidance purposes only.

Please note that the information in italics is for guidance purposes only.

June 2023

Co-Decision Making

Wardship replaced by 3 tier hierarchy



Co-Decision-Making agreement (CDMA)

A co-decision maker (CDM) is "*a relative or friend of the Appointer who has had such personal contact with the appointer over such a period of time that a relationship of trust exists between them*" and is appointed to make a relevant decision(s) jointly with them.

Has capacity to decide

Has capacity to decide jointly with CDM

Doesn't have capacity to decide even jointly

Understands ✅

Retains ✅

Use and weigh ✅

Communicate ✅

Lacks capacity but has 'partial capacity'

If there is no trusted person available, the court might decide that a DMR should act as a co-decision maker

CDMA (Part 4 of ADM)

- New and complex concept
- Courts obliged to consider when a Part 5 DMR application is made: would a CDMA work instead?
- Complex process
- Specific CDMA capacity statement (for DSS): Capacity assessor states that:
  - Appointer has the capacity to enter/vary the CDMA
  - Appointer requires assistance to make the decisions in the CDMA
  - Appointer has the capacity to make the decisions in the CDMA with the assistance of the co-decision-maker

Thank You