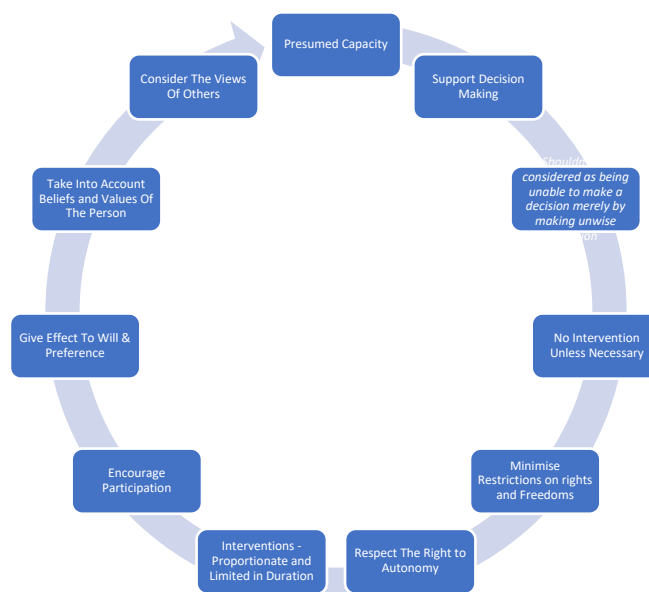


HSE Impact Assessment Draft Report

Disability Sector Reference Group

1. Introduction

The Assisted Decision Making (Capacity) Act was signed into law on 31 December 2015 and is now fully commenced. The Act provides for the reform of the law relating to persons who require or may require assistance in exercising their decision-making capacity, whether immediately or in the future. The Act applies to everyone over 18 and will have wide-ranging implications for all health and social care providers. Guiding principles are set out in Part 2 of the Act. The Act states that these are ‘Principles that Apply before and during Intervention in respect of Relevant Persons’. These are the key implementation measures and requirements for services. These principles are non-negotiable and service approaches including documentation will need to demonstrate compliance and evidence. Many of the guiding principles are currently integrated into service policy and good practice approaches. The challenge for services is to ensure a consistent application of the requirements set out in the guiding principles.



2. Context:

With the commencement of the Assisted Decision Making (Capacity) Act, the need for operational services in the Disability sector to consider the impact and develop associated outcomes-based actions was essential. An Assisted Decision Making (Capacity) Act Disability Reference Group was established to support the sector to implement the requirements of the Act. The Reference Group is represented by key stakeholders across the service sector. It is important to note that the HSE has a strategic plan on the impact of the legislation across the entirety of its service sector. Consistency and compatibility between the plans will be important, as will the need to draw out the specific different requirements for the Disability sector.

In line with the terms of reference for the Disability Reference Group, it was agreed that an impact assessment be completed within the sector. It was identified that it was necessary to reach out to the sector, gather perspectives and complete an impact assessment with identified outcome-based actions. All activity has been completed, and the learning has been shared with the Disability Reference Group. It was agreed by the Disability Reference Group to capture the learning in this report.

3. Activity Undertaken:

(Supported by the HSE National Office for Human Rights and Equality Policy & Clara Learning Ltd)

1. Review & analyse any existing relevant service specific impact assessments
2. Develop materials to support consultation process
3. Consultation process within the sector (this included an online survey and focus groups for information gathering purposes)
4. Analysis of information gathered
5. Learning to be shared with the Disability Reference Group

4. Methodology of the Impact Assessment:

The purpose of the impact assessment is to assist the Disability Sector ‘to fully understand the extent and complicity of the change’ and ensure that an integrated approach to managing the change is adopted (McAuliffe et al., 2006). The four areas of the impact assessment are:

- **Stakeholder Perspective:** This perspective is about how the change in legislations will impact on key stakeholders, including adults accessing services and their families).
- **Service Delivery Processes Perspective:** What systems/ structures/ processes/ outcome measures need to change or introduce to fully implement the Act?
- **Learning and Development Perspective:** This perspective consists of training and improvements required for the workforce to implement the Act. It ensures that staff have the required skills to implement the Act. This area also considers the need for data relating to the implementation of the Act. This includes measures and metric to support effective audit.
- **Resource Perspective:** This perspective indicates whether the implementation of the Act impacts on the resources (human and financial) of services. It is acknowledged that public and ‘Not for Profit’ organisations consider this perspective last. It is often a challenge in public and not for profit services to support the implementation and sustainment of the requirements of the Act.

5. Known Impacts:

Some impacts are already known based on previous engagements, knowledge from other jurisdictions and previous organisational experiences. Such potential impacts include:

- Increased volume of work

- Competing requirements of different legalisation
- Resistance within services
- The need to provide training
- Changes to current practice approaches and standard operating procedures
- Amendments to policy or procedures to bring in line with the legislation
- The need to evidence legislative compliance
- Impact on recording practices
- Increase number of complaints
- Challenges to outcomes of assessments of capacity
- The approach to engagement with family members
- Potential increase in complaints to other bodies (profession regulators, the Decision Support Service, Office of the Ombudsman)
- The transition of people using our services from wardship to the new arrangements
- Increase in court applications and attendance at court services

Many aspects of the legislation are current expectations in service agreements, national policy, best practice approaches and aligned to existing regulations (in some sectors). That should mean the impact maybe less significant, if services can currently evidence effective approaches in line with existing expectations (e.g. HSE Consent Policy). However, it is important to note that Act abolishes previous mechanisms for decision making (e.g. Ward of Court system) and introduces new structures (e.g. Co Decision Making Agreements and Decision Making Representatives). Such changes are having impacts across services, for all stakeholders.

However, whilst the challenges can be significant the importance of the Assisted Decision Making (Capacity) Act cannot be underestimated. The legislation is building on a rights-based approach and modernising our duties as to how we work alongside those

that require care and/or support. It replaces out of date laws and places duties on services to demonstrate person centre approaches, based on will and preference. It challenges practice approaches that are a source of concern and requires compliance with approaches where current policies are inconsistently applied. This is a positive development in our society, however with any change the opportunities provided are accompanied by challenges.

6. Surveys & Focus Groups:

In line with the agreed plan, targeted surveys and focus groups were undertaken to help understand what impact may mean. Key information was shared to enable effective contributions.

Surveys

Disability services were surveyed by means of a Survey monkey link on their perceptions of the impact the Assisted Decision-Making (Capacity) Act has on their services and people accessing such services, their perceptions of the resources required to be in compliance with the Act. In addition to the quantitative responses, survey responders were asked to expand on their responses with free form comment boxes. 5 key impact themes emerged:

Theme 1 - Families and concern for changed role of families

Across all of the questions, the role of families and the role that disability services will have in educating families on their role was a repeated message.

Representative comments include:

- “This will mean a huge cultural shift for families. Staff supporting families to understand the assisted decision making Act and what it means for service users’ lives will take time and resources”

- “We already follow best practice guidelines in relation to our residents. Biggest impacts will be assisting elderly families of day service users understand the legislation”

Theme 2 – **Resources and staff busyness can limit ability to effectively implement the Act**

There were a significant number of comments predicated on the understanding that implementing the Act takes more time than current practice, and that there are insufficient staff resources to do so. Some challenged the ability to implement the Act effectively in the absence of additional human resources

Representative comments;

- “Embedding ADM has an impact in terms of resources and costs related to coordination, oversight and training. There is a need for increased levels of Multidisciplinary team input, to support individuals and teams, but also with assessments of capacity.”
- “It has significant implications for frontline staff in terms of resources required to fulfil obligations under the act including the level and volume of documented records regarding capacity building, informed decision making etc.”
- “Ireland is overregulated for service delivery and the country has become a money industry for legal firms as opposed to a person centred state for service delivery. Law and standards are welcome however they must be commensurate with resources and ability to maintain and increase service delivery”

Theme 3- **Training and the requirement for it**

Training was often mentioned in the same comment as the resources challenge. Some commenters acknowledged the HSELand resources but made reference to not having enough time to complete them, or that they do not specifically focus on disability service.

A number of the comments on training made reference to the need for training to enable staff and services be effective in related theme areas.

Representative Comments

"We require adequate resource and training for staff to invest in maintaining our strong links with family members and to promote their understanding of the implementation of the Assisted Decision Making"

"If we want to enable access for training in this area for staff, resourcing is required immediately. Staff can barely stay on top of mandatory training currently. Our second highest rating therefore is training, as currently the modules are too long, they are comprehensive, but staff need to have access to concise training that is specifically relevant to their role."

"Some of the information on HSE land is not disability specific, which is a challenge. There is still so much work required to embed the ADM principles into practice, and this is work in progress, much more resources and training are required to be available for staff"

Theme 4 - **Frustrated at absence of clarity on the codes and organisation policy**

(At the time of the surveys the Code of Practices were not issued, and organisational policy was not finalised)

A reasonable proportion of the responses referenced the wait for Codes of Practice, for a final version of the Amending Bill and related organisational policy procedures and processes, before committing time to staff training or preparation.

Representative comments;

“There remains a lack of clarity on the Act until amendments have been published, codes of practices finalised and published etc. A lot of the education and resources available do not focus enough on the operational implications of the Act”

“This is challenging to answer currently as regards to specifics in the absence of clear guidelines and codes and indeed experience of practical application and practical experience of processes to come.”

Theme 5 - **Confusion or misapprehension on the Act and how it will work**

There were misapprehensions or confusions about the Act and how it will work revealed by some of the comments.

Representative comments

“There is anticipation of challenges around levels of decision making supports - what is the appropriate level, when to register agreements etc..”

“However, it is unclear to me under what context a person who is deafblind and has an intellectual disability will require the support of a decision making rep, co decision making assistant or decision making assistant.”

“There is a lack of clarity around individuals' access to personal banking situations and role of bank in completing functional assessment and how banks will interpret this. Access to the appropriate support and practice to ensure will and preference is necessary”

Focus Groups

The purpose of the focus groups was to provide updates, signpost existing resources and gather feedback on key operational and practice impacts, challenges and complexities.

The targeted focus groups were split into;

- HSE Operational Services
- S38 / S39 Providers
- Self-Advocates
- Families

It was important to identify the issues associated with the implementation of the Act. The aim of each of the focus groups, was to provide an update on the Act and to gather feedback on key operational and practice impacts, challenges, and complexities. The key questions for consideration (which were adapted as required for each group) were;

- a) What would support effective implementation of the requirements of the act
- b) Anticipated challenges
- c) Advice as to how to roll out key information
- d) Any other matters to be considered from your perspective
- e) Keen to understand important messages from you

Focus Groups – Summary of Key Themes

- a) Families

Level of family concern has not been effectively addressed. There is a fear of losing valuable relationships with families. Families may be reluctant to engage with the Act and may perceive it as diminishing their rights and roles.

b) Next of kin

Moving away from practices associated with next of kin remains a challenge for services, as parents (of adults) presume, they are the decision makers.

c) Codes of practice/Operational Policy, Procedures and Processes

Step by step guidance is required regarding how the Act is applied within services. A performance framework would be useful to enable organisations to evaluate how they in compliance with the Act and its principles, e.g. a self-assessment tool to set a baseline of compliance and to understand what is required.

d) Communications – easy read documents

A question regularly emerged as to how adults accessing services and their families understand the Act and its impact on their lives. Ensuring necessary supports was highlighted e.g., easy to read and accessible documents (braille, other languages), as well as making available a glossary of terms. Communication and providing it in a manner that is accessible to the person was considered vital.

e) Cultural and practice shifts

It was identified that more work is required in services to progress both cultural and practice shifts across all sectors. It was noted that the banking sector and government agencies e.g., Social Welfare, and Social Protection Departments, need to be updated about the Act regarding access to bank accounts, pensions and benefits.

f) HSE National Safeguarding Policy

Questions were raised as to how the Act will interface with the HSE National Safeguarding Policy and guidance.

g) Role of the Decision Support Service (DSS)

Many questions were raised in respect of the role of the DSS, referral processes, making arrangements, data sharing and accessing the register.

h) Operational Risk Tolerance

There is a need for clear policies, practices, and governance around risk and unwise decisions. It was acknowledged that risk tolerance needs to be understood and consistently applied.

i) Health Information Quality Authority (HIQA)

There is an awareness that there are inconsistencies within HIQA regulations and the Act, with a need for the organisation to review its terminology.

j) Wardship

Many comments emerged from the focus groups on Wardship and what the future holds once such arrangements are no longer in place.

k) Rigidity of current funding streams

Some commented on the importance of moving towards personalised budgets as current approaches can be limiting the persons decisions making options, in their pursuit of independent living.

l) Co-Decision Makers

Some observed that there is a risk of disempowering the person when co-decision makers may be involved and questioned how services guard against such disempowerment.

7. Conclusion and Learning:

It is acknowledged that a range of resources are available for staff to enable compliance with the Assisted Decision Making (Capacity) Act 2015. These resources can be found on www.assisteddecisionmaking.ie which has been redesigned to be easier to navigate:

- Frequently asked questions on the Act
- A short Explainer Video on the Act containing simple core messages on the Act from the voices of staff and people who use our services
- Recordings of webinars on key provisions within the Act, including supporting decision- making, advance planning, and the role of advocacy
- A quarterly newsletter providing updates on the Act and the work of the HSE National Office of Human Rights and Equality Policy
- The Assisted Decision-Making (Capacity) Act 2015 – Personal and Professional Reflections – a collection of essays written from both a personal and professional perspectives highlighting the importance of the Act

- A recorded presentation An Introduction to the Assisted Decision-Making (Capacity) Act 2015
- Additional resources from other organisations
- Information on training

The information in this Report has been shared via presentations with the Disability Reference Group in a timely manner following the surveys and focus groups, where actions and developments have been implemented. This includes accessible information for adults accessing services and their families as to where to access supports and resources. In addition, other matters have been escalated to different forums for action and decisions, e.g. banking matters for adults with a disability.

In summary the key learning messages from the impact activity undertaken, specifically focused on the disability sector, are:

- The cultural shift for families, where services will be intermediaries in supporting education for families.
- Resource limitations/operational readiness - staff busyness, time, and costs related to training, conducting functional assessments, and supporting people with decision making.
- Training – the need for disability specific resources and training with time to undertake such training.
- Services anticipating challenges, especially on levels of decision making supports, where conflicts may emerge with families.
- Communications – the need for easy read and other accessible formats of communicating the act to adults with disabilities and their families.
- More work and time needed to progress necessary cultural and operational changes in the sector.

However, adults with disabilities reminded professionals, through their focus group, that ‘nothing about me is decided without me’. Adults accessing services have concerns where a person does not have family or informal circle of supports. Some have concerns regarding the high turnover of staff in services and the costs associated with applying for decision making support arrangements. Importantly the most common message was the importance of information in accessible manner to enable adults build capacity.

The purpose of this report is to capture the activity and learning from the impact activity to enable the Disability Reference Group to consider if any further actions are required.

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