



CarerAid Project

END OF PROJECT

REPORT **2024**

Supporting family carers through the provision
of legal advice in relation to the
Assisted Decision-Making (Capacity) Act



Acknowledgement



Coimisiún na hÉireann
um Chearta an Duine
agus Comhionannas
Irish Human Rights and
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Family
Carers
Ireland

No one should have to care alone

CarerAid Project | A Summary

- **The CarerAid project provided free monthly legal advice clinics for family carers in relation to the Assisted Decision-Making (Capacity) Act.**
- **37 legal advice clinics took place during 2024 – 20 were related to people with dementia / 17 for people with an intellectual disability.**

Referrals in relation to a person with dementia:

- 40% sought advice on how to make an application for a Decision-Making Representative Order (DMRO) for the purposes of Fair Deal.
- 23% sought advice on how to apply for a DMRO to make a decision relating to financial affairs on a family member's behalf.
- 13% sought advice on the necessity of a DMRO for other decisions such as the sale of property or personal welfare decisions on a family member's behalf.

Referrals in relation to a person with an intellectual disability:

- 39% sought advice on how to support a family member who may require the assistance of a Co-Decision-Making arrangement (CDM) or may require an application to be made to appoint a Decision-Making Representative (DMR) to make certain decisions relating to their financial affairs.
- 13% sought advice on how to support a family member who may benefit from a Decision-Making Assistance (DMA) arrangement or may require the assistance of a CDM to make certain decisions relating to their financial affairs.
- 4% sought advice on how to support a family member to be discharged from wardship.

KEY ISSUES

- Difficulties finding legal practitioners willing to take on cases related to the 2015 Act.
- Lack of clarity and consistency from service providers, in particular financial service providers, on how the Act will be integrated into their policies and practice.
- Lack of clarity on the role of decision supporters and decision support arrangements.
- Lack of legal aid for family carers applying on behalf of family members with diminished capacity.
- Difficulties in navigating the court process as a lay litigant.
- Difficulty navigating and using the Decision Support Service (DSS) online portal.
- Delays in processing support arrangements with the DSS.
- Difficulty obtaining a legal statement of capacity which must be provided by a legal practitioner, and which is a necessary proof in order to register an Enduring Power of Attorney (EPA).

CarerAid | End of Project Report 2024

CarerAid Project

Following the commencement of the Assisted Decision-Making (Capacity) Act 2015, in April 2023, Community Law & Mediation and Family Carers Ireland came together to deliver free legal advice clinics and training for family carers in the area of assisted decision-making. The project referred to as CarerAid, was delivered by Aoife Doonan BL and were funded by the Irish Human Rights and Equality Commission (IHREC).

About the Project

The CarerAid project involved monthly legal advice clinics delivered throughout 2024. Each monthly clinic consisted of three or four consultations with family carers lasting approximately 40 minutes each. The consultations took place over Zoom or over the phone, depending on the preference of the carer. Carers were advised that the CarerAid clinic was only for legal information, advice and referrals related specifically to the Assisted Decision-Making (Capacity) Act 2015.

The CarerAid project also included three training sessions designed to provide an overview of the 2015 Act in practice. The sessions were delivered on March 26th, September 18th and November 21st 2024. The November session was recorded giving carers and staff the opportunity to rewatch the session or act as a training resource for carers in the future. Each session included important information to help carers and staff of Family Carers Ireland understand the Act and how it is impacting families since it has come into effect in April 2023. These training sessions took place over Zoom and provided participants with an opportunity to engage in a Q&A session after the presentation.

CarerAid Project Outcomes

The CarerAid monthly legal advice clinic has facilitated 37 consultations with family carers between January and October 2024. The referrals received by the clinic focused on queries relating to the five decision support arrangements set out in the 2015 Act, three of which support people who currently, or may shortly, face challenges when making certain decisions, namely, a Decision-Making Assistance agreement (DMA), a Co-Decision-Making agreement (CDM) and a Decision-Making Representation Order (DMRO), and two types of arrangements for people who wish to plan ahead for a time in the future when they might lose capacity, namely, an Advance Healthcare Directive (AHD) and an Enduring Power Of Attorney (EPA). These decisions can be about their personal welfare, health, social care, and their property and affairs. The Act abolishes the current wardship system and requires all adult wards of court to be discharged from wardship within three years of commencement of the Act.

Of the 37 consultations carried out by the clinic:

- 20 referrals were related to advice on how to support a family member with Dementia and 17 referrals were related to advice on how to support a family member with an intellectual disability (a condition that has affected the person since birth or early childhood), developmental disability or an acquired brain injury.

- Referrals from family carers caring for a family member with Dementia sought advice either on how to apply for a DMRO for family members who they believed may no longer have capacity to make certain decisions on their own or on how to support a family member who may lose capacity in the future and wished to set up an AHD or EPA.

- 40% of these referrals sought advice on how to apply for a DMRO in order to make an application for the Nursing Home Support Scheme known as the Fair Deal Scheme on behalf of a family member. 23% percent of the referrals sought advice on how to apply for a DMRO to make a decision relating to financial affairs on a family member's behalf. While 13% of the referrals sought advice on the necessity of a DMRO for other decisions such as the sale of property or personal welfare decisions on a family member's behalf.

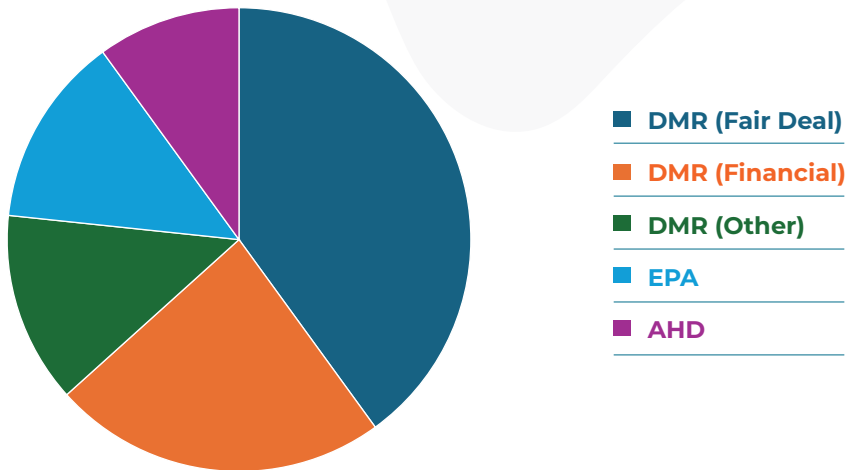
- Furthermore, 13% of the referrals sought advice on how to support a family member who currently has capacity but may lose capacity in the future to set up an EPA for decisions relating to personal welfare and financial and property affairs, and, 10% of referrals sought advice on how to support a family member who may lose capacity in the future to set up an AHD for healthcare decisions.

- In relation to referrals from family carers caring for a family member with an intellectual disability, autism, down syndrome or other developmental disability and/or an acquired brain injury, carers primarily sought advice on how to support family members who may not have capacity or may have diminished capacity on whether a formal decision support arrangement was necessary to provide that support.

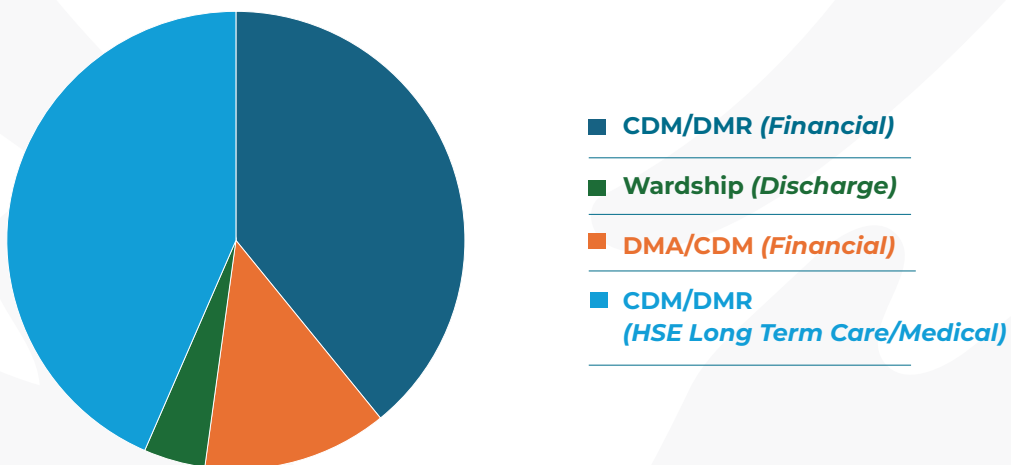
- 43% of these referrals sought advice on how to support a family member who may require the assistance of a CDM or may require an application to be made to appoint a DMR to make certain decisions relating to the family member's long-term care and residential needs and/or medical needs provided by the HSE. 39% of the referrals sought advice on how to support a family member who may require the assistance of a CDM or may require an application to be made to appoint a DMR to make certain decisions relating to their financial affairs. While a further 13% of the referrals sought advice on how to support a family member who may benefit from a DMA or may require the assistance of a CDM to make certain decisions relating to their financial affairs. Finally, 4% of the referrals sought advice on how to support a family member to be discharged from wardship.

It is important to note that these queries sometimes overlapped, and referrals often related to one or more issues set out above.

Family Carers caring for a family member with Dementia (*mental confusion due to a condition such as Alzheimer’s disease, senility or some other degenerative disease*)



Family Carers caring for family member with an intellectual disability (*a condition that has affected the person since birth or early childhood*), developmental disability or an acquired brain injury



Key Issues

Similar queries and concerns arose across the legal advice clinics. Key issues that arose in all areas included:

- Difficulties in accessing legal representation and finding legal practitioners willing to take on work and cases related to the 2015 Act.
- A lack of clarity and consistency from service providers, in particular financial service providers, in relation to how the new assisted decision-making framework will be implemented and integrated into their policies and practice.
- A lack of clarity and understanding surrounding the role of decision supporters and the purpose of the decision support arrangements.

Key issues that arose in relation to applying for a DMRO in the Circuit Court included:

- A lack of legal aid for family carers applying for decision support arrangements with or on behalf of family members with diminished capacity.
- Difficulties in navigating the court process as a lay litigant and unfamiliarity with their role in proceedings.

Key issues that arose in relation to applying for all other decision support arrangements which must be registered and notified with the Decision Support Service (DSS) included:

- Practical difficulties in navigating and using the online portal for the creation of decision support arrangements, in particular EPA applications.
- Delays in processing support arrangements with the DSS. The DSS are currently working on digital applications submitted in July and manual applications submitted in June.

A particular issue which commonly arose in EPA referrals and in the training sessions is the difficulty in obtaining a legal statement of capacity which must be provided by a legal practitioner pursuant to Section 60(1)(b) of the 2015 Act and which is a necessary proof in order to register an EPA.

Assisted Decision-Making (Capacity) Act 2015 in Review

The Court Service Annual Report 2023 provided an overview of the work carried out by the Courts Service in the area of assisted decision-making since the 2015 Act came into effect on 26 April 2024. The 2023 Report states:

The Circuit Court is responsible for considering applications when there is a concern in relation to a person's decision-making capacity. During the first eight months of the operation of this process in the Circuit Court in 2023, 413 applications were made, resulting in 270 orders. The 2015 Act also provides for the discharge of all adult Wards of Court from wardship within three years from 26 April 2023. In 2023, the Office of Wards of Court Office received 82 applications for discharge.

A dedicated area on our website has been established to provide information to all court users about the Act. This includes general information on the Act, contact information for queries and application forms to use when applying to Court. Court forms have been

designed with a user-centric approach to make complex legal applications as straightforward as possible, while recognising all requirements of the legislation. Despite this, the numbers of applications to the Circuit Court for decision making support and to the High Court for discharge for wardship were lower than anticipated. Factors that contribute to the numbers in each jurisdiction include:

Circuit Court:

- The number of litigants without legal representation and their unfamiliarity with their role in proceedings. 35% percent of applicants are unrepresented.
- A low base of expertise in the legal profession as a whole and the slow emergence of specialist practitioners focusing on the Act,
- A lack of legal aid for family members applying on behalf of relatives with capacity issues. Legal Aid is assessed on basis of the family member's income rather than that of the Relevant Person.

High Court:

- Contentment with the existing wardship processes.
- Cost and effort in applying for discharge from wardship.
- The life expectancy of the Ward.
- The absence of support for sometimes elderly committees, and
- Uncertainty and cost associated with the new supervision regime.

Enduring Powers of Attorney

- 2023 also saw a continuation of the trend of high numbers of registrations of Enduring Powers of Attorney (EPA). The ADMC Act has changed the arrangements for registering an EPA, and from 26 April onwards, people interested in taking out an EPA needed to do so with the Decision Support Service.

Report of the Director of the Decision Support Service

The report of the Director of the Decision Support Service, which was published as part of the Mental Health Commission Annual Report 2023, provides information on the activities of the Director from the commencement of the Act on 26 April 2023 until the end of 2023. The report sets out:

In 2023 the Decision Support Service received:

- 15 submitted Decision-Making Assistant agreements and acknowledged notification of nine.
- 29 submitted applications for the registration of Co-Decision Making agreements and registered ten.
- 185 Decision-Making Representative Orders from the court and registered 83.
- 407 submitted applications for the registration of Enduring Power of Attorney and registered 38.
- two applications for notification of Enduring Power of Attorney and accepted one.

From the beginning, the DSS sought to deliver a person-focused and digital first - but not digital only - service. These principles are viewed as complementary. The primary purposes of the DSS are:

- to inform people about the decision supports available under the 2015 Act,
- to facilitate the registration of decision support arrangements and
- to supervise their performance in line with the guiding principles of the Act.

To carry out these purposes effectively and to plan for increasing volumes of applications, the service must be efficient. The DSS adopted a digital-first approach in line with government policy and based on research on the experience of other jurisdictions. However, it is acknowledged that while technology can be a great enabler of access, it will present obstacles to certain service users.

In the first eight months of operations, the DSS has been very encouraged by the percentage of applicants opting to use the DSS digital portal. By promoting and supporting the adoption of the digital processes as far as possible, the DSS will be able to concentrate on addressing the accessibility issues of the minority of service users who require a non-digital alternative.

Concluding Remarks

There is no doubt that further work must be done to address the concerns of the people at the centre of the assisted decision-making framework under the 2015 Act. Looking forward, it is positive that user-friendly information and guidance documents relating to the 2015 Act are increasingly becoming more accessible and available to potential decision supporters and relevant persons. In 2024, the HSE, the DSS and the Courts Service have released guides, templates and other resources to assist persons seeking to apply for a DMRO or register a decision support arrangement with the DSS. Civil society and NGOs have also been instrumental in assisting persons to understand and engage with the new assisted decision-making framework.

The continued engagement between the key stakeholders and the impacted families and relevant persons at the centre of this framework will hopefully start to provide a clearer path forward towards effective support in decision-making and progress in maximising a person's capacity to make decisions for themselves.



FIND OUT MORE

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