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# **Family Members Serving as Decision-Making Supporters: Issues and Challenges in the Appointment Process and Role Fulfillment**

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# Abstract

## Background

Supported decision making (SDM) is a relatively new legal arrangement established under Amendment No. 18 to the Legal Capacity and Guardianship Law which came into effect in April 2018. SDM serves as an alternative to guardianship and is intended to preserve the autonomy of persons with disabilities and older adults. As part of the implementation of the amendment, accompanying regulations were promulgated and took effect in June 2024.

From the time that Amendment No. 18 came into effect and until 2022, approximately 1,500 appointment orders for decision-making supporters were issued, most of them appointing family members to act in this capacity. Unlike volunteer or professional supporters, family member supporters do not receive formal training or official guidance. Previous studies, however, indicate that family member supporters encounter challenges and have questions related to their role. Accordingly, the Supervision Unit for Guardianship and Alternatives to Guardianship at the General Guardian's Office (Ministry of Justice) asked the Myers-JDC-Brookdale Institute to conduct a study examining the needs of family member decision-making supporters during the appointment process and the types of support they require.

## Study Objectives

1. To assess the conduct of the preliminary information meetings for individuals interested in SDM arrangements
2. To assess the conduct of the guidance meetings held after issuance of a temporary appointment order
3. To map the questions, challenges, and needs of family members serving as supporters in supported decision-making, and to examine whether the services they need are available
4. To examine, among individuals interested in SDM (whether or not they participated in a preliminary information meeting), if they are aware of the option of imposing financial safeguards in addition to the appointment orders and the extent of actual use of such safeguards (in accordance with Section 68 of the Legal Capacity and Guardianship Law)
5. To examine reasons for not applying for an appointment order despite expressed interest, or for not completing the application process (i.e., an application was submitted but no decision-making supporter was appointed by the court)

## Methods

The study employed a mixed-methods design and included the following research tools:

1. Eight **semi-structured interviews**: five interviews with professionals from the General Guardian's Office and three interviews with family members serving as decision-making supporters by virtue of a court order.
2. **An online survey** administered in two versions to two target populations:
  - **Family member decision-making supporters** appointed by court order and currently serving in the role
  - **Individuals who are not family member decision-making supporters** but who had previously expressed interest in the arrangement or for whom the issue may be relevant.

In total, 2,054 respondents completed the questionnaire: 1,178 reported holding an appointment order as a decision-making supporter, and 1,068 reported serving as guardians (620 served only as guardians, and 448 served both as family member decision-making supporters and as guardians).

## Findings

- **Interest in SDM**: The primary motivation for choosing SDM was the desire to preserve the person's independence and to avoid the bureaucratic burden and infringement on autonomy associated with guardianship.
- **Information and guidance meetings**: Participation rates in these meetings were low. Only 22% of supporters participated in a preliminary information meeting, and only 11% participated in a post-appointment guidance meeting. The main reason was lack of awareness of the service (reported by more than 65% of respondents).
- **Financial safeguards**: Awareness of the option to establish financial safeguards (such as a cautionary notice in the Land Registry or restrictions on bank accounts) was limited: only 37% were aware of this option, and only 25% had safeguards imposed.
- **Challenges in the role of decision-making supporter**: The most prominent challenges included the need for consultation (48%), the need for additional information (47%), and difficulties in dealing with official bodies—such as banks—that do not understand the decision-making supporter's role (38%).
- **Role confusion**: Approximately 51% of supporters who also serve as guardians reported difficulty distinguishing between the two roles.

## Summary and Recommendations

The study found that the main challenges faced by family member decision-making supporters include the need for consultation or guidance, clarification of the meaning of the supporter role, definition of the supporter's authority and its limitations, and assistance in interactions with official bodies that are unfamiliar with the role of the decision-making supporter and its authority. The preliminary information meetings and post-appointment guidance meetings do not fully realize their explanatory potential and the promotion and implementation of the meetings – and possibly their frequency – should be improved. In addition, respondents demonstrated a lack of clarity regarding the differences between the role of a decision-making supporter and that of a guardian.

The findings also indicate that few respondents are aware of the option of financial safeguards and that their use is uncommon, possibly due to limited accessibility to the information.

## Key Recommendations

**Raising awareness and improving access to information:** Lack of accessible information about supported decision making constitutes a major barrier to beginning the process. Efforts should be made to raise public awareness and improve outreach. Awareness of preliminary information meetings and guidance meetings—and of the obligation to participate in them as part of the appointment or validation process—should be increased. Given the moderate levels of satisfaction with these meetings, consideration should be given to improving them and diversifying the ways information is provided through them. In addition, awareness of financial safeguards should be increased and information about them made more accessible.

**Consultation and Guidance:** Family member decision-making supporters require consultation regarding their role and answers to concrete questions that arise in practice. It is recommended to provide accessible informational materials (e.g., videos, booklets), written summaries following information and guidance meetings, and short-term formal guidance. The General Guardian's helpline for supported decision making should be more widely publicized.

**Regulating status vis-à-vis third parties:** Consideration should be given to issuing official supporter identification cards to assist in interactions with official bodies. It is also recommended to consider establishing a dedicated hotline for third party and service provider inquiries, and to examine the possibility of establishing a "registry of court orders," similar to the model used in Ireland.