

- **Name of the study:** Life In a Family Guardianship Arrangement as Perceived by People with Disabilities and Their Guardians: Interrelationship in Decision-Making, "Personhood" and Self-Determination
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Abstract

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Guardianship is a legal arrangement designed to protect people with disabilities who are unable to take care of their affairs on their own. The court appoints another person, usually a family member, as guardian. The guardian is responsible for the safety and well-being of that person and is authorized as specified in the appointment to manage his or her financial affairs and make decisions in all areas of their life. The person appointed a guardian by the court is obliged by law to comply to the guardian. In most cases the guardian is a relative, usually a parent, and the kinship relationship precedes the legal appointment. Thus the family relationship continues while the legal relationship dictates the duties and authority of the guardian regarding the adult family member. Few studies explore the experiences of people with disabilities who have been appointed a guardian and of the guardians themselves. This doctoral thesis aims to shed light upon the experiences and perceptions of people who have been appointed a family member as their guardian and of their family member guardians. The study examines the relationship between the two sides through two main axes: the first axis deals with guardianship and the conduct within it. First, how does each of the parties perceives the guardianship arrangement, and second, what is the interrelationship between the two sides in decision-making. Is the arrangement "fiduciary", in which one side receives exclusive rights and responsibility to make decisions for the other, or is it based on "reciprocity" where both sides share in the decisions, even if they are not of equal status in the process. The second axis deals with two central theoretical concepts that are expressed in the relationship between the guardian and the

person: "personhood" and "self-determination". The concept of "personhood" refers to the degree and ways in which the guardian perceives the family member as a complete "person" and a full member of society. The concept of "self-determination" refers to the degree and ways in which the person who is appointed a guardian controls the aspects that are important to them in their lives.

Qualitative methodology was chosen, as it enables exploration of the subjective experience of the guardian and the person appointed a guardian, and their ideas regarding the two axes described above. In order to examine both sides' experience and the interrelationship, semi-structured interviews were conducted with pairs of guardians and family members with disabilities for whom they were appointed as guardian. Thirteen pairs were interviewed - in nine pairs the guardian is a parent, in two pairs a brother, in one pair a daughter, and in one pair the guardian is a friend of the family. Nine men with disabilities and four women were interviewed, and except for one interviewee, all were 30-50 years old. Eight of them have an intellectual developmental disability, three have an autistic spectrum disorder, and two have a childhood head injury. In the analysis, attention was paid to the nuances that reveal hidden perceptions, and a dyadic analysis was conducted to examine the similarities and differences between the parties.

The research yielded significant insights regarding the underlying questions. First, most guardians see the appointment as a given fact, and few doubt its necessity or object to its infringement on the autonomy and independence of the person who has been appointed a guardian. Most people who have a guardian are content with having a relative responsible for them. Apparently, the family member who is also a guardian sees the appointment as a natural continuation of their kinship role. The interviews revealed a connection between guardianship and parenting - it seems that parenting 'blurs' the guardianship, since the parent does not pay much attention to their legal status as a guardian for the son or daughter. On the other hand, guardianship overshadows the role of the parent, and is integrated into it. The official status of

the son or daughter dependent on their parent as their guardian impairs their freedom to make decisions and their autonomy as an adult.

The interrelationship between the parent appointed as guardian and between his or her son or daughter shows that decisions are made using a wide range tactics by both parties. Although the guardian has the authority to decide on his own, there are few cases where the family member who has been appointed a guardian does not have any influence. Some of the guardians reported that at some point they realized that they were unable to impose their will on the person or that it was not appropriate to do so. This led to the insight that even though both sides accept the authority of the guardian, in practice there is a negotiation between them in which the family member who is appointed a guardian also has a certain ability to influence. The study revealed the complexity of the guardians' perception of "personhood" of the family member with a disability. On the one hand, there are many expressions of their seeing him or her as a unique individual, who is not characterized solely by disability, and that they see them as part of the family and relationship with others. On the other hand, almost all the guardians see him or her as a "child" and not as a full-fledged member of society, and some of them implicitly expressed attitudes that see his or her life as less valuable than that of people without disabilities. This leads to the insight that in the context of a family relationship, the degree to which the family member appointed a guardian is perceived as a "person" is not categorical but multidimensional.

Regarding self-determination, some of the people with disability experience the guardian as supportive and enabling self-determination, while others see the guardian as impeding their ability to control their lives to the extent that they wish, especially regarding finances. It also emerged that for some of the interviewees who have been appointed a guardian, the possibility to make choices and realize their individual wishes is less important than the sense of belonging to the family. These findings led to the insight that self-determination may include a choice by the individual to reduce his autonomy in favor of establishing harmonious relationships with the family.

It is evident that the family members, both guardians and people with disabilities who have been appointed a guardian are not yet familiar with the objections to guardianship, which led to the amendment of the Legal Capacity and Guardianship Law in Israel. Further research is proposed to deal with the complexity of the relationship between guardianship and family kinship. This topic, which was revealed as central to understanding life within the guardianship arrangement, could be examined in depth in a study that will compare pairs with a parent guardian, a sibling guardian, or a paid guardian. In addition, a longitudinal study could reveal the impact of the decision to appoint a guardian on the family relations between the two parties.

Other relevant areas for continued research are the differences and similarities between guardianship and "supported decision-making". There is also need for research among populations that were not included in the current study, and especially people who are non-verbal, people with psychiatric disabilities, elderly people with dementia whose children serve as their guardians, as well as groups in Israel that are underrepresented in this study, such as ultra-Orthodox Jews and Arabs.

Keywords

uardianship, parents of adults with disabilities, self-determination, personhood

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