

# Alternatives to Guardianship in Financial Affairs



# **Alternatives to Guardianship in Financial Affairs**

A Bizchut Report

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# Introduction

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The idea to write this report arose during an Open Society Foundations seminar, which took place in Madrid in 2011 and dealt with possible ways to implement the directives of Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (“CRPD” or “Convention”). Many participants from various countries – including academics and representatives of field organizations – attended this seminar to take part in the efforts to turn all five sections of Article 12 of the CRPD into a legal and practicable reality, each of them in his/her own country. Excitement was in the air. It seemed as though we were on the verge of a revolution that would restore to persons with disabilities one of the basic rights of all human beings: the right to make decisions regarding their own lives. However, the various representatives kept describing genuine difficulties in recruiting partners for this revolution so long as they could not elaborate on the smallest details of their vision of full legal capacity and demonstrate its practicability.

One of the complex issues discussed at the seminar was what the reality would be like without a guardian for financial affairs and, instead, with full recognition of the legal capacity of every person with a disability to make any financial decision.

Many activists in the field pegged the financial issue as the biggest challenge to realizing the vision expressed in Article 12. Every day, many persons with disabilities are denied their right to make decisions regarding their money, manage their pensions, own property and even inherit. The fear of granting people with disabilities who are currently under guardianship power and control over property proved to be a significant obstacle. Relatives had concerns about the financial future of their family members. Social workers described cases of property loss and emphasized their duty to protect vulnerable people. Bankers relied on court rulings which found banks had been negligent and had breached their duty of care by allowing persons with disabilities to make harmful financial transactions. Ensuring legal capacity with regards to financial affairs, a right highlighted in Article 12(5) of the CRPD, proved to be a complex goal.

Many questions were raised on this subject:

- What are available options for a person who does not understand the meaning of the financial step he must take?
- What kind of protection is available to a person who makes a ruinous mistake with his/her money?
- Are there universal tools (such as banking plans or trusteeship services available to all clients) that can be made use of to guarantee reasonable protection in financial matters for people with disabilities?



Many activists in the field were concerned that they lacked practical answers to these questions. It was clear they had to learn the legal provisions for the various financial spheres in order to understand the new reality in which people with disabilities would find themselves without a guardian and with full legal capacity. Human rights activists and lawyers are not usually experts in civil, private and commercial law. Civil law lawyers, bankers, accountants and representatives of commercial companies are generally not experts in human rights and most certainly are not leading partners in the struggle to restore legal capacity to people with disabilities. There was a need to link the two disciplines – human rights and private law – in order to understand whether it was possible to find adequate answers in existing law.

In addition, the deeper our search for alternatives to guardianship went, the clearer we saw that there were two types of alternatives, which we divided into two categories – positive and negative. Positive alternative are the core of Article 12 of the CRPD, promoting autonomy and legal capacity by offering support, assistance, accompaniment and access. In recent years, discourse regarding Article 12 rightly put a great deal of emphasis on these alternatives. However, alongside positive alternatives, there are negative ones, meaning alternatives that restrict the person and protect against various kinds of harm, while maintaining the person's full legal capacity. Very little of the public discourse around Article 12 has been dedicated to this type of alternatives and their compatibility with the principles of Article 12 of the CRPD.

The purpose of this report is, therefore, to review negative alternatives to guardianship in financial affairs that are meant to afford protection from harm in this field. By focusing on financial decisions, the report in no way minimizes the significance of the many other decisions people make in their lives, and the equal need to implement useful and practical alternatives to guardianship in those areas. However, non-financial decisions are beyond the scope of this report.

Additionally, the focus on negative alternatives does in no way detract from the value of positive alternatives focusing on supported decision-making. On the contrary, the tools suggested in this report are complementary to the central and crucial tool of supported decision-making, which, as aforesaid, has been the subject of broad public discussion in recent years.

It is further stressed, that the report's premise is that harm is a broad and multifaceted concept. Loss of independence, autonomy and personhood are themselves severe forms of harm for any person and often have a greater impact than financial loss.

This report includes theoretical background for the discussion of alternatives for guardianship in the financial sphere and appendices which extend the discussion on matters that are tangential to it. Both the background and the appendices are meant to serve the main chapter in the report – Chapter 2, which contains a survey of the legal situation and the suggested alternatives to guardianship in three financial spheres:

• **Real estate**



• **Banking**



• **Contracts**



The purpose of this report is neither to outline policy nor resolve the various questions raised by the endeavor to implement Article 12; nor does it necessarily decide in favor of using of negative alternatives. It has a dual purpose: to describe each of the three financial spheres and to provide information regarding alternatives that might be available. It is very likely that the readers of this report will remain with more questions than they had before reading it. Nevertheless, if it makes it easier to identify the questions that must be resolved and clarifies the viable alternatives to guardianship, then it will have served its purpose.

The report was written primarily for an international audience in the hope that activists around the world will make use of it. The research process and the writing of the report included several meetings with organizations that work to promote the right of persons with disabilities to legal capacity and the application of these rights in Bulgaria, Sweden, and the Czech Republic among others. Experts and activists from other countries were consulted as well. The research and writing were also based on knowledge of related activity in other countries, including Kenya, Ireland and Canada. Thus the report takes into account diverse contexts and is peppered with examples from different countries. However, since law systems differ, there was no choice but to focus on the law of one country so as to understand alternatives to guardianship in financial affairs at a higher resolution. Therefore, Chapter 2 of this report is based on the laws of the State of Israel, where its author lives and works. Yet the concrete tools that appear in this report may be relevant more broadly; certainly the questions raised and the critical approach applied are relevant for different legal systems.

We recognize that in many countries, the institution of guardianship is not as officially enshrined as it is in others; yet, even among the former, there is a formal process for appointing a person or a body to act on behalf of the person with a disability (for example, an “administrator” in Kenya and a “deputy” in England). Even in countries where the use of formal tools is infrequent, people with disabilities are, in practice, often treated as though their legal capacity is restricted. For the sake of brevity, all these legal arrangements will be categorized in this report under the title “guardianship.” The problems with guardianship and the suggested alternatives are relevant to a variety of arrangements that deny legal capacity.

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## The structure of the report

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The report is composed of five chapters, as follows:

The **first chapter** presents **background** to the discussion on alternatives to guardianship in financial affairs. The chapter opens with the right to legal capacity anchored in Article 12 of the Convention, and examines how this right should be manifested in different aspects of life, including in finances. The chapter then seeks to address the arguments raised against the full implementation of Article 12 and to confront the concerns at the heart of the opposition to abolishing guardianship.

The **second chapter**, the principle part of the report, **presents the alternatives to guardianship in three main financial areas: real estate, banking and contracts**. For each of these areas, it provides a brief legal background, presents background on concerns about the harm that might be caused and reviews the advantages and disadvantages of each of the suggested alternatives.

The **third chapter** discusses **dilemmas in the development of alternatives to guardianship in financial affairs**. Is the difference between a restriction that people willingly accept and one that is imposed on them all that clear? Is any restriction whatsoever tantamount to negating a person's legal capacity? How much weight should be given to concerns about potential harm to the person? What procedural aspects must be considered regarding the development of alternatives to guardianship? What is the cost that should be taken into account when developing such alternatives? The report does not resolve the different dilemmas; rather, it lays out the various considerations involved in each one.

The **fourth and concluding chapter** of the report discusses **practical steps that stem from these findings**.

Finally, the report contains **appendices for further enrichment**. **These include:** a description of the **research process that produced the report**, in the hope that it will be of help to those wishing to carry out such a process in their own country; **court rulings** in which some of this report's suggestions have been implemented; **presentation of the Swedish model for supported decision-making**, which is one of the longest established models in this field and demonstrates the importance of developing support services; and finally, we present the **findings of an academic study** based on focus groups of persons with disabilities and parents on guardianship, alternatives to guardianship and the financial issues involved.

• • •

This report is intended for policymakers, family members, and organizations working to incorporate the CRPD into domestic law and anyone else who cares deeply about this issue. No less importantly, this report is intended for persons with disabilities, on whom society still puts the onus to prove they are “worthy” of equality, who have to fight so that they will not be deprived of their legal capacity and who still see their lives being navigated by others.

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## Chapter 1

# Background

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### A. The right to legal capacity

One of the fundamental rights afforded to every human being in a just society is the right to manage one's own life and make decisions regarding it. This right is derived from the right to liberty, autonomy, dignity and independence. In legal discourse, it is enshrined in the term “legal capacity.” Legal capacity is the acknowledgment that a person has rights and the capacity to act upon these rights. By virtue of their legal capacity, individuals can sign contracts, get married, agree to medical procedures, write wills and most importantly be equal members of society. At the foundation of a legal system that espouses liberty, dignity and equality lies the principle that every person has an inherent right to legal capacity. This is in contrast to many non-egalitarian societies throughout history, in which legal capacity was granted only to certain groups and denied to many others, such as women, people of color, slaves, minority groups, members of other religions and so on.

The restriction of a person's legal capacity means, in practice, civil death. Those whose legal capacity is restricted can no longer negotiate their affairs, decide how to manage their estates or make significant decisions regarding their own lives. At the same time, the legal capacity denied to such a person is delegated to another, who makes these decisions on the other's behalf. This person, the “guardian” in legal parlance, in fact takes the helm from the person whose legal capacity was denied. The guardian sets the journey's course, its speed and its ports of call. Liberty, autonomy, independence and equality are severely undermined when a guardian is appointed. Persons under guardianship are found in a wholly inferior position insofar as their ability to conduct their lives and control their affairs is concerned.

The guardian – at times a family member, at times a public servant, at times an external and private body – is responsible for attending to all the affairs that are listed in the guardianship order. These affairs can be personal, medical or financial. The guardian is the authority entitled to make decisions regarding these matters and his signature is required to execute any decision concerning the person under guardianship. At the same time, the person under guardianship can no longer continue making many independent decisions regarding his/her own life.

In different countries, the relationship between the guardian and the person under guardianship is

arranged differently, as are the powers granted to the guardian and the person under guardianship. In Israel, for example, the guardian may not force a medical decision on a person who objects to it, nor may a guardian force a decision regarding a personal matter of fundamental importance (such as location of residence or a personal relationship) without explicit authorization from a court of law. In other countries, a person's placement under guardianship results in the complete negation of this person's legal capacity, thereby revoking her right to vote, to be elected for public office, to marry and so forth. Despite the differences between various legal systems, the appointment of a guardian de facto imposes a significant restriction on the person's right to make decisions regarding her own life and to manage that life according to her own judgment, and grants considerable power to the guardian.

The [Convention on the Rights of Persons with Disabilities \(CRPD\)](#) introduces a genuine revolution with regard to this issue. Article 12 of the Convention includes five sections, as follows:

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## Article 12

### Equal recognition before the law

“

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

”

Article 12 of the Convention poses a real challenge to the law that is in effect in most countries. This is because to the best of our knowledge, most legal systems include an option to restrict and deny legal capacity to persons with disabilities and call for appointing a guardian. This means that sections 2-5 of Article 12, mentioned above, are presently being violated in most countries: persons with disabilities do not enjoy legal capacity; they are not provided with support which could help them realize their legal capacity; measures affecting their legal capacity are not proportional; and the right of persons with disabilities to control their own financial affairs and to own property is denied on a daily basis.

Even when a guardian is not appointed, for the most part, the lives of persons with disabilities are in effect managed by other people. This is the case when family members prefer to avoid appointing a guardian for various reasons, but in practice make the decisions concerning the life of the person with a disability. A similar situation exists in countries where the institution of guardianship has not become common practice or where access to the court is more limited and the use of this legal tool is also more limited, yet society still regards decisions made by a person with a disability as subordinate to those made by family members or professionals. In Kenya and Uganda, for example, the majority of persons with disabilities are not subject to guardianship orders; despite that, medical, financial and personal decisions are often controlled by family members. Thus, whether due to formal legal procedures or social practices, persons with disabilities throughout the world do not enjoy the rights listed in Article 12.

The premise for this report is the principles of Article 12 of the CRPD; its point of reference is existing law and practice. The desire to narrow the gap between the two is at the core of this report.

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## B. Decision-making in the financial sphere

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The right to legal capacity influences and pervades all aspects of a person's life. Section 12(5) of the CRPD makes specific mention of decision-making concerning property. The section states:

“

Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

”

This directive appears in the wake of widespread and severe violations of the right of persons with disabilities to manage their financial affairs. It is most often the case that persons with disabilities who have had guardians appointed for them are barred from managing their own bank accounts, performing transactions related to property owned by them and sometimes even lose ownership of it. They cannot freely use their salary, and their ability to enter into contractual transactions is restricted. Sometimes, parents do not include sons or daughters with disabilities in their wills, whether because of the disability itself or out of concern that doing so would turn the execution of the estate into an even more complicated matter and could lead to the intervention of the state. Even if some decision-making, in other areas of life, is left in the person's hands, it is clear that the violation of legal capacity in the financial sphere severely undermines independence and autonomy in far wider areas of life.

And so, it appears that the financial sphere carries unique complexities and sensitivities as far as the implementation of Article 12 of the Convention is concerned. In light of the aforementioned, this report seeks to focus on the financial sphere and expand upon it

## C. Contesting claims against full implementation of Article 12

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Three arguments are commonly made by stakeholders in the current system (judges, social workers, doctors, etc.) for appointing guardians and restricting people's legal capacity. Since these arguments are prominently used where financial decision-making is concerned, this section addresses and contests each of these claims:

### 1. Legal determination that a person cannot handle his/her own affairs independently

One of the most common arguments for appointing a guardian is that people with disabilities cannot handle their own affairs independently, and therefore their judgment must be replaced by that of a guardian.

As against this point of view, we argue that many people in the general population do not know how to manage their affairs independently and require assistance. This is even more notable in the realm of finance, which often requires professional knowledge that most people lack. In fact, it is common to seek assistance from a range of consultants and advisors – investment consultants, mortgage consultants, accountants, bankers, etc. At the same time, many people tend to get help from family members on these matters. In other words, people with disabilities who require support, guidance and assistance in making decisions are no different from other people who are also in need of such help.

The determination that people with disabilities who require assistance in order to manage their affairs must be under guardianship constitutes discrimination. In some cases, the rhetoric on this issue conceals other considerations: often a person with a disability knows how to make decisions independently, but the decisions are considered unreasonable or contrary to proper norms in the opinion of professionals. For example, a person might decide to get a driver's license, contrary to the opinion of relatives, or to eat sweet foods despite being diabetic. These people are capable of making decisions regarding their own affairs, but the content of the decisions, oftentimes, is not in keeping with the values of society or the worldview of professionals. Appointing a guardian in such situations, and revoking the person's liberty, is an indirect way of interfering with the person's decisions. This example raises the question of what society's level of obligation should be in intervening to protect people from the consequences of their decisions and the possible harm which might result from them. The answer to this question is not simple and will be discussed in brief in chapter 3.C.

In sum, revoking a person's legal capacity by appointing a guardian is not the proper solution for those who require assistance in order to make decisions in their lives and manage their affairs.



## 2. Casting doubt on a person's legal capacity and ability to make decisions

Another argument raised to justify guardianship has to do with doubts about a person's legal capacity. For example, one of the conditions for making a contract legally binding is that the both parties intended to enter it, of their own free will and without coercion ("*animus contrahendi*"). The absence of *animus contrahendi* in a legal action might serve as cause for appointing a guardian who can execute the action. In fact, laws in many countries instruct that guardians be appointed for people who cannot understand the significance of their actions or control them.

Often the demand to appoint a guardian does not come from the authorities but from a third party, following questioning of the person's legal capacity. When a person with a disability must make an important decision in life (having surgery, moving to a new home, opening a bank account, etc.), the relevant third party (doctor, landlord, banker, etc.) may cast doubt on his/her level of understanding of the decision and its consequences. This concern is amplified in view of lawsuits for negligence and for failure of the service provider to fulfill the requirement of necessary caution. Furthermore, in cases where there is no official guardian, the decision-making process is often conducted with family members, without the participation of the person with the disability and without recognition of the person's right to make the decision.

The first thing that should be said regarding the claim of "absence of legal capacity" is that the right to legal capacity is not a matter of ability or level of functioning, but rather the inherent right of every human being. Furthermore, the tests to determine the level of understanding are often based on the medical model and err in being sweeping and general without giving consideration to the various natures of different decisions. Beyond that, even if a person does not understand the nature of the action he seeks to take, the service provider and the community are required to make information related to the decision accessible and provide support in making the decision, instead of altogether denying him/her the ability to decide. Finally, there are a number of tools in contract law that may help us to overcome the "absence of legal capacity" claim. These will be expanded upon in chapter 2.C. of this report.

However, this argument, as opposed to the others listed here, constitutes a real challenge to the implementation of Article 12 in certain contexts. For example, contract law includes a basic requirement that the parties understand the content of the contract they are signing. It is easy to see how the resort to this test involving people with certain disabilities might empty the positive message Article 12 carries. Therefore, in order to guarantee equality for people with disabilities in the context of legal capacity, there is a need to develop new tests that will change the way society thinks about legal capacity and its implementation. This point is further developed in the chapter below on contracts (chapter 2.C.).

## 3. Concern about harm

An additional and central argument raised as a justification for appointing a guardian is the concern about harm that may be caused to a person without a guardian. This report attempts to focus on this concern and the need to develop alternatives to guardianship that mitigate it.

## D. The concern about harm and the need for protections

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### 1. The paternalism trap

The discussion about “protection” in the context of people with disabilities is problematic and stands at the top of a steep and slippery slope.

For many decades, in the name of protection, the rights of people with disabilities were restricted in all areas of life: people were banished from their communities and placed in institutions; women with disabilities were sterilized. To this day, medical treatment and medication are forced on people with disabilities, and people are placed in sheltered workshops rather than being integrated into regular workplaces, and so on. Understandably, the very mention of protection arouses discomfort and opposition from those concerned about the human rights of people with disabilities. Furthermore, the discussion of protection from harm, in connection with people with disabilities, is characterized by a great deal of paternalism. While the point of departure in discussions about protection from harm regarding the general public is that every person has full legal capacity,<sup>1</sup> this assumption is often lacking in discussions about people with disabilities. Finally, many people without disabilities who are exposed to harm because of their own negligent behavior are not scrutinized as closely as those with disabilities. In practice, the very discussion of protection for people with disabilities is discriminatory and the possible good intentions behind it do not change this fact.

However, the consideration of protection from harm must be taken into account when discussing implementation of Article 12 of the Convention and abolishing guardianship, for several reasons. First of all, we are not operating in a public vacuum. Protecting persons with disabilities from harm is raised time and again as an argument against abolishing guardianship and restoring legal capacity. Even if the argument is invalid, offensive and harmful, we must address it, most certainly in internal discussions among human rights activists so that we will know how to deal with it properly. Secondly, people with disabilities themselves speak about the need to develop certain protections for them. For example, people with intellectual and psychosocial disabilities who were interviewed during a study about approaches to guardianship (Appendix D) noted that sometimes they wanted the involvement of others to protect them from mistakes that they may make or from exploitation by others. However, since the issue is largely unheeded by advocates for people with disabilities and mostly left in the hands of other actors, the protections provided today are draconian and harmful. Thirdly, family members are concerned about the financial wellbeing of their relatives with disabilities. This concern must be taken into account even if it leans towards over- protection. It is family members who frequently support the person with a disability financially. With the right guarantees in place that their relative with a disability will

<sup>1</sup> There are a number of exceptions to this rule, for example, in Spain, Portugal and Latin-American countries, irresponsible financial behavior can be cause for appointing a guardian, without regard to disability. Such persons are referred to as “prodigos”. They are seen to be wasting their property irrationally and therefore deemed to be in need of guardianship. In Armenia, people without disabilities with drug or alcohol addiction are likely to be under partial guardianship, while people with disabilities are under full guardianship.

not risk financial harm, many family members would encourage their relative towards greater independence can be important partners in the struggle against guardianship.

Because this report attempts to encourage an open and thorough discussion within the disability community, it will focus on the alternative tools to guardianship that may provide protection from financial harm, while supporting the independence and autonomy of people with disabilities.

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## 2. Characterization of the concern about harm

In our deliberations on the development of alternatives to protect people from harm, we must consider three types of concerns (even if they are exaggerated or erroneous). These concerns are repeatedly raised by professionals and family members. Sometimes they are also raised by people with disabilities as well.

1. **Fear of exploitation** – The concern that people will be open to exploitation by society, including, inter alia, the “temptation” to purchase expensive products they do not need, being convinced to sign guarantees which confer on them the responsibility for other people’s debts, or having their bank accounts emptied out by others, etc.
2. **Fear of actual harm** – The concern that people may make decisions that will cause them serious harm, such as a decision to spend all their money and savings, carry out unnecessary medical procedures, quit their jobs frequently, sell property at a loss or contrary to their interest, etc.
3. **Fear of harm by omission** – The concern that people will cause themselves harm by not tending to their affairs, including neglecting health, living in difficult circumstances (such as on the street or in poor hygienic conditions at home), failing to repay debts or to realize eligibilities, etc.

We refer to the various types of harms in each of the spheres in the next chapter, in which negative alternatives are examined.



## E. Why guardianship is not the answer

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One of the reasons why the discussion about harm and protection raises discomfort and even serious opposition by people with disabilities and human rights organizations is that the solution found in law is to appoint a guardian and revoke the person's legal capacity. Therefore it is important to emphasize at this early stage that appointing a guardian is not a proper solution for many reasons. First of all, guardianship is a clear violation of Article 12 of the Convention because it sweepingly negates a person's legal capacity and transfers the right to make decisions to another person. A different reason, which will not be discussed in this report, is that the protection that guardianship affords is partial and lacking even according to those who advocate giving the greatest weight to considerations of protection.

Just as it is unthinkable to imprison people to protect them from harm, it is also unthinkable to revoke their legal capacity and create a category of second-class citizens. The fact that people are exposed to harm justifies providing them with assistance, instituting efficient penalties against their exploitation and where necessary, possibly imposing certain restrictions, but it certainly does not justify the denial of legal capacity and the appointment of a guardian.

Article 12(4) of the CRPD provides that any measure connected to the exercise of legal capacity must be proportionate and adjusted to the life of each individual. Guardianship does not meet this requirement, first and foremost because there are significantly less harmful measures that can serve the same aim of protection from harm and at the same time safeguard the person's legal capacity.

The primary purpose of this report is to examine these alternative measures that can provide protection in the financial field without negating a person's legal capacity and without appointing a guardian.

## Chapter 2

# Alternatives to Guardianship in Financial Affairs

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This chapter will discuss alternatives to guardianship in financial affairs. The alternatives in each area are based on several understandings:

**Concern about harm is genuine:** Concern about harm and the need to develop protections must be seriously taken into account: first, because the concern is based on incidents that have actually occurred; second, because it is one of the primary reasons for appointing a guardian; and third, because people with disabilities may also be concerned about possible harm.

**Existing universal solutions:** People with disabilities are not the only ones who have to cope with concerns about financial harm. Concern for adolescents, people in debt, people living in poverty, wealthy parents wishing to transfer property to their adult children and many others have led to the development of various means of intervention or prevention of harm in the financial sphere. These solutions are universal in that they are not meant solely for people with disabilities. Universal solutions that apply to the population at large are not only clearly preferable in considering alternatives but they are consistent with the CRPD which promotes “universal design” as a general obligation (Article 2 and 4(1)(f)).

**Heterogeneity of the field:** The term “financial affairs” covers a wide variety of financial activities which differ one from another in their character, scope and in how they are governed legally. These various activities must be studied and understood in order to set appropriate professional standards for alternatives to guardianship.

**Third party service providers are significant players:** Third parties are a significant player in the financial field. Usually these are commercial entities with no particular knowledge regarding the rights of people with disabilities. The banker, the grocer, and the customer service representative are primary players in many financial interactions. Any proposed alternative must take into account the need to educate these providers and increase their awareness.

As stated, our goal is to present alternatives to guardianship that protect the person in financial affairs. We have chosen to focus on three primary components within the broader field of financial affairs:



• **Real estate**



• **Banking**



• **Contracts**



These areas come up time and again as significant issues when guardians are appointed. As will be explained briefly here and in detail in Appendix A, this report is based on research which included meetings with people with disabilities, family members and professionals, as well as meetings with organizations working to promote the implementation of Article 12 in various countries. In all these meetings, it was clear that solutions must be found for these fields, and there was agreement that providing appropriate answers to the concern about harm would make it much easier to convince others that abolishing the institution of guardianship was desirable and possible.

This chapter discusses each financial field – real estate, banking and contracts – separately. In each sub-chapter, we will present the relevant legal arrangement and the concerns about harm regarding that area. We will also present existing alternatives to guardianship and other alternatives that may be considered for expansion, and discuss the advantages and disadvantages of each. It should be emphasized that civil law on this matter varies in different countries. Though all the alternatives presented here must be adapted to the specific law in effect in each country, we hope it will be beneficial to present the alternatives as a basis for local research and for a discussion of the benefits of implementing alternatives to guardianship in financial affairs.

Some of the alternatives proposed in this chapter inevitably involve restrictions on conducting the specific transactions discussed. Restrictions may be self-imposed or externally imposed. Obviously the more choice is available, the better the alternative aligns with Article 12. The question of self-restriction or restriction by others is not addressed in this chapter. It is discussed in Chapter 3 of this report on the dilemmas arising in examining alternatives to guardianship.

#### **Methods of collecting information:**

In order to consolidate the information for the study in each of these fields, we conducted conversations with:

1. People with disabilities and handling appeals from dozens of people with various disabilities including psychosocial, intellectual, and communication disabilities.
2. Professionals in the financial sphere, including bankers, lawyers, officials in government ministries, and academics researching legal and commercial aspects of the financial field.
3. Family members of people with disabilities, some of whom serve as guardians and others who unofficially but closely follow the lives of family members with disabilities.
4. Professionals closely following people with disabilities – social workers, housing program managers, and rehabilitation counselors.

We held meetings in mixed groups involving an expert in each of the three financial fields, people with disabilities and family members to consider the problems and the alternatives. We arranged focus groups of people with psychosocial disabilities, people with intellectual disabilities, and parents of people with disabilities, during which they examined positions, concerns, and experiences related to the questions that are the basis of this report (see Appendix D). Finally, we reviewed professional literature.

These steps provided the basis for the analysis that follows in the next chapter.

## A. Real estate



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### 1. Introduction

In this chapter, real estate refers to assets that are not movable property, e.g. land and anything built on it or attached to it, such as structures including homes and apartments. The concern about harm involving real estate issues includes a number of possible scenarios: selling a property at a loss; registering ownership of an apartment in someone else's name; parents wishing to bequeath an apartment to a son or daughter but concerned about their ability to exercise good judgment in ownership; siblings who have jointly inherited land and worry that one of them may act with poor judgment.

Concern about harm in this field causes many people to refrain from bequeathing their properties to family members with disabilities, or to condition the transfer of ownership (or the execution of the estate after their death) upon the appointment of a guardian. Furthermore, siblings sharing an inheritance are often likely to favor the appointment of a guardian for siblings with disabilities, because they are concerned about their judgment. The high value of property transactions may give rise to ulterior motives in appointing a guardian. For example, in the siblings' example, the motivating factor for appointing a guardian for the sibling with a disability may be for the others to gain a free hand in the disposal of the inheritance.

### 2. Alternatives to guardianship in real estate

In this chapter, we present alternatives to guardianship in matters of real estate. Real estate registries, which exist in many countries, offer effective alternatives to guardianship that prevent exploitation and leave the person's legal capacity intact. Since the law varies by country, we will focus on solutions based in Israeli law.

#### a. Land Registry options

*What are land registries and caveats?*

Most countries have land registries with different kinds of mechanisms that can be helpful in preventing harm. One example that will be presented in detail below is the use of caveats which is common in some countries (e.g. Israel) and less common in others (e.g. Ontario, Canada). A caveat is a contractual obligation that is registered in the land registry by a lawyer. It constitutes an obligation on the part of the landowner or the person holding the right to the land (not necessarily someone with a disability) to make a specific transaction or refrain from making one. Anyone can learn about the existence of a caveat by studying the land registry, which is open to the public. It is meant to inform anyone interested in a given property that there is a condition regarding the property. The court can cancel a transaction that was made contrary to the caveat. For our purposes, we should distinguish between two types of caveats.

- One type is a caveat registered by the person himself. People who own a property and may be concerned that for one reason or another (psychological distress, family pressure, etc.) they might act contrary to their own interests, can register a caveat in the land registry, restricting their power to sell their own property.
- Another type is a caveat registered by others that restricts a person's power to execute actions regarding his/her property. Thus, for example, a person may bequeath the property to a relative subject to registering a caveat that limits the heir's power to transfer her rights to the property or to use it for particular purposes.

### *How can caveats be used?*

The caveat must include both the restriction and the conditions for changing it. However, in every case, from the moment the caveat is registered, the agreement of all the beneficiaries is required to change it. For example, if the caveat is worded as “refraining from making a transaction without authorization by David,” a transaction cannot be made without David's authorization and the caveat cannot be erased without his authorization.

A caveat is a tool that can include a variety of possibilities, at different levels of flexibility. Thus, for example, in the event that a person wants to restrict his/her ability to sell an asset and would like to condition any transaction on the authorization of one of a friend (Bob or Lily), s/he can write the following caveat: “I must not perform a transaction on the asset without the authorization of Bob, and if Bob does not want this responsibility or cannot take it upon himself, Lily, will be appointed or else another person, after consultation with Lily.”

**Example:** A caveat can include restrictions of various kinds. Thus, for example, Miriam can transfer ownership of an apartment to her son, conditional upon her good friend David continuing to live in the apartment until his death. In another example, Miriam could bequeath the apartment to David even though she has concerns over his financial judgment. She could do so conditional upon the following caveat: “David must not make a transaction on the asset at a value lower than the current appraisal of the asset by a property appraiser.” Thus, Miriam ensures that David does not sell the asset for less than its market value.

### *Disadvantage of caveats*

We must give thought to people's fears of registering a caveat because it grants vast power to others and limits their own ability to change their minds. Most of the time, there are legal solutions for this. For example, along with a caveat, a third party, such as a lawyer, may be given power to revoke the caveat should it be abused.

### *Caveats based on a court's decision*

It is also possible to underpin the registration of the caveat by obtaining a court decision in a manner that limits the person's ability to perform a transaction on the asset without the agreement of the court or a person appointed by the court. This measure provides a higher level of protection, so that even in cases where a person changes his/her mind (e.g. Bob from the previous example),

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the land registry cannot revoke the caveat without the court's authorization. On the other hand, the registration of the caveat by court ruling further undermines the freedom of the person whose ability to act has already been limited.

Appendix B provides a few examples of court rulings in which the court instructed that a caveat be registered, with the person's consent, as part of a process of revoking guardianship.

### *Caveats in inheritance*

A caveat, as stated above, is a measure that can also be used by owners of an asset who wish to bequeath or transfer it to another person. Miriam can transfer ownership of an apartment to her son, David, while registering a caveat that David cannot sell the apartment before the age of 30. If it is an inheritance, the person bequeathing the property can write in the will that along with the transfer of the rights to the apartment, a caveat will be registered, and the contents of the caveat can be included in the will. Another option is to determine, via caveat, who will inherit the property after the current heir (heir after heir). For example, if David's friend, Lily, wishes to bequeath an apartment to him, she can write in her will who will inherit the apartment after David's death (for example, David's daughter), and even instruct that a caveat be registered barring David from performing any transaction on the asset. Thus Lily can ensure that David's daughter inherits the apartment after his death. This measure is often used when parents want to ensure that the apartment they are leaving to their son or daughter will later transfer to their grandchildren, rather than be shared among the original heirs and their spouses, thus reducing the concern that the son or daughter with disability will be coerced into rescinding their inheritance to others rather than passing it on to their own children.

### *Conclusion*

To conclude, land registry options are a legal measure often employed to help people, with or without a disability, maintain control over the fate of their property. Each country has its own land registry arrangements, which impact the possibility of registering a caveat or a similar tool. However, the more regulated the land laws of a country are, the more frequently this measure will be used by people who wish to secure their rights over their properties. Caveats are already being used today in Israel as an alternative to guardianship in matters of real estate. It is a simple, effective, and largely limited tool. As long as the caveat is registered by the owners of the asset prior to its transfer to another person, it constitutes a legitimate exercise of the person's property rights. On the other hand, forcing the registration of the caveat upon owners of the asset constitutes improper use of the measure, severely restricting their property rights. As a direct result, the measure becomes less legitimate.

#### **Advantages and disadvantages:**



This restriction is precise and effective.



Some forms of caveats not written in by the person with disability herself may unduly restrict her property rights. On the technical level: Registration of a caveat requires a lawyer. Furthermore, sometimes the asset is not legally registered with the land registry and therefore it is not possible to register a binding caveat.

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## b. Trusteeship

### *What is a trust?*

In a trust arrangement (sometimes referred to as a trusteeship), one person, the trustee, manages the property for another person, the beneficiary—in the context of this chapter, it is real estate. The person who creates the trust grants control of the property to the trustee by contract (deed of trust or trust agreement). From the moment the property is transferred to the trustee, the person who created the trust no longer has power over the asset. However, some trusts leave power with the person who created the trust to influence the actions of the trustee, while others do not. Often, the person who created the trust can revoke the trust, especially when such a condition is included in the deed of trust.

The trustee has the duty to manage the property in the best interest of the beneficiary, subject to the terms of the trust agreement. By creating a trust, people can ensure that control of the property is in the hands of someone they trust to have good judgment, with the fruits going to the beneficiary.

### *How can it be used?*

Trusts are often created when elderly parents seek to provide financial security for sons or daughters whose ability to manage a certain property are a source of concern for them, whether because they are minors, their worldviews are different from their parents', their understanding is limited due to a disability, or any other reason). In such a case, the parents can appoint a trustee who is obliged to manage the asset for the financial benefit of the son or daughter.

A trustee can be a trusted person who agrees to serve as a trustee, or a professional (such as a lawyer) paid to serve as a trustee. The deed of trust includes the identity of the trustee and of the beneficiary. In relevant cases, professional fees are included. The deed of trust can also include an obligation to consult with professionals; criteria for use of the asset; and a decision-making mechanism in case of disagreement between the trustee and the beneficiary. The trust process allows for flexibility regarding ownership of the asset: it can be registered with the land registry under the name of the beneficiary with a caveat that it is managed by a trustee, or registered under the name of the trustee noting that s/he manages the asset in trust.

If the asset is an inheritance, it is possible to note in the will that after the estate manager divides up the estate, s/he will become the trustee of the asset transferred to one of the descendants, or will be responsible for appointing a trustee.

**Example:** A New-York Based program, Federation Employment and Guidance Service, helps individuals, their families or friends establish a trust account in a pooled trust. Personal advocates guide beneficiaries to plan and manage activities, obtain needed entitlements, provide advocacy, help match beneficiaries to additional resources, and make informed decisions. This is an example of how trusteeship can serve as a legal platform for providing support and services.

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## Conclusion

In sum, a trust can render unnecessary the negation of a person's legal capacity caused by the appointment of a guardian, and also makes it possible to include the beneficiary in decision-making along with protection and supervision. However, a trust is a more complex alternative with broader application than the registration of a caveat. While a caveat only places limitations on the use of the property, a trust authorizes another person to manage it and sometimes replaces the beneficiary's ownership of the asset. On the other hand, a softened version of a trust can provide support to the beneficiary in managing the asset. This service may be appropriate for a person who wishes to enjoy the revenue and benefits of owning the property without the full burden of managing it.

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### Advantages and disadvantages:



A trust is a specific and flexible solution which does not require a court of law.



If the property is registered in the trustee's name, the beneficiary's right to hold or manage it according to his/her will is limited. The solution is expensive and requires paying a lawyer to prepare the contract and in many cases a monthly payment to the manager of the trust fund as well. There is no effective supervision over the judgment of trustees and when there is a disagreement between the trustee and the beneficiary, the trustee has the upper hand.

## c. Providing revenue and benefits separate from ownership

The owner of a property enjoys various benefits it affords, such as the right to live in it or the revenue from leasing it. Owners can decide, when handing a property over to someone else, to separate the revenues and benefits it affords from ownership in a contract.

This alternative is in effect a type of caveat. It may serve people who are debating between their desire to provide financial security to a loved one and concern about that person's ability to manage the property.

**Example:** Miriam is worried that her good friend David might find himself without a place to live. In this case, she can decide to bequeath her apartment to her daughter, Sarah, subject to the right of her good friend, David, to live in it for the rest of his life. She can further specify in her will that Sarah may not sell the apartment without finding alternative housing for David. In order to provide additional guarantee that this clause is carried out, Miriam can register a caveat in the land registry as part of the execution of the estate.



### Advantages and disadvantages:



Like any caveat, this is a specific and flexible tool which does not require a



Of the alternatives presented in this field, this one has the greatest impact, because the property does not belong to the individuals concerned, but is rather in the possession of someone else; they are only defined as the beneficiaries. For this reason, other alternatives in which the property is registered in the name of the individuals concerned are preferable.

### 3. Summary: real estate

In the sphere of real estate, effective tools exist for providing protection without appointing a guardian. It is hard to think of harm in this field that cannot be prevented by one of the three measures presented here. However, it is clear that use of these alternatives may limit the person's property rights. This depends, *inter alia*, on the person's degree of involvement in determining the conditions of the alternative chosen and on his/her consent to them. Looking at the alternatives themselves, the caveat is clearly the preferred choice because it is flexible, inexpensive and simple. However, for people who require assistance in managing their assets, it is possible that a caveat would not be sufficient. In such cases, a simple solution might be to sign a power of attorney to a trusted person to serve as a supporter in decision-making (see Appendix C) or hire a lawyer to help manage the property. Only in cases where there is cause for concern about the possibility of harm due to the person's judgment is a trust preferable to a power of attorney. Appendix B presents a court ruling regarding a person with a psychosocial disability who found it difficult to manage affairs relating to apartments he owned. The combination of registering a caveat along with appointing a person who provides decision-making support made it possible for him to be free of guardianship. This is an example of how these alternatives can be effective in revoking guardianship and restoring legal capacity.

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## B. Banking

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### 1. Introduction

People's bank accounts are a central crossroads through which their money flows. Their income and property – salary, government benefits, and investments – are usually found in their bank accounts, be they ordinary checking accounts or special accounts. Such accounts are essential in everyone's life. Owning one makes it possible to arrange for preauthorized direct debit payments, take out a loan, and use a credit card and checkbook. However, in countries where people with disabilities are extremely poor and receive no state financial support, they do not necessarily have a bank account.

Often, the appointment of a guardian is directly related to concerns about harm in the banking sphere. These concerns include wasteful spending of savings, falling into debt, overcharging credit cards, or adding bank account signatories who may exploit the authority given to them. Concerns about all of these scenarios often leads to the appointment of a guardian. The more assets people with disabilities have, the more interested their family and friends are in examining their ability to manage their affairs independently and whether or not a guardian should be appointed. This means that sometimes, people with disabilities whose income has grown (due to winning a lawsuit, gaining an inheritance, receiving a government benefits, or earning a salary) may suddenly find themselves under guardianship on the grounds that their money must be protected.

### 2. Guardianship's impact on banking issues

Different countries have different procedures affecting the relations between banks and customers under guardianship. In Israel, a person who has been appointed guardian must inform the bank of the appointment. The customer's bank account is then converted into a special account, and any transactions must hereafter be authorized by the guardian. Even when a guardian authorizes the person to conduct certain transactions independently, banks do not always respect this authorization. They often prefer to be particularly cautious and demand the signature of the guardian for all transactions, thus fully restricting the person under guardianship. The bank is expected not to open an independent bank account for a person under guardianship, although it is easy to circumvent this prohibition in cases where the bank does not have access to the national database listing the names of people under guardianship.

The internal regulations of one of Israel's major banks exemplify the enormous power guardians have in managing the bank accounts of individuals under guardianship, including denial of all the powers individuals previously enjoyed. From the moment a guardian is appointed for a customer, the bank adds the guardian to all the channels of direct information (such as the bank's website), provides him/her with a bank card for accessing information and withdrawing cash, and allows him/her to order checkbooks, deposit checks and arrange for preauthorized direct debit payments from the account. The bank will not approve the addition of an authorized signatory nor will it honor checks which had been signed by the customer before the guardian was appointed or

approve cash transactions made by the customer unless these transactions are first authorized by a court order. In sum, the appointment of a guardian severely undermines the person's financial rights in the banking context.

### 3. Legal obligations in the banking sphere

In order to propose alternatives to guardianship in this area, it is important to understand the legal issues that banks face today when interacting with customers with disabilities. From a legal perspective, the bank has three obligations that pull in different directions.

- First of all, there is the **obligation to honor customers' autonomy** to conduct whatever transaction they wish regarding their account. The bank holds customers' money, invests it, at times advises the customers, at times loans them money, but it can never restrict the management of money belonging to them without legal authorization to do so.
- At the same time, the bank has an **obligation to make its services accessible**, as part of the prohibition against discrimination. Just as it is obvious that people who use wheelchairs must not be prevented from flying alone and that the airline has an obligation to make flights accessible to them, it should also be obvious that the banks must make their services accessible to people with disabilities as well as provide accommodation in particular cases. The obligation to ensure accessibility includes both physical accessibility and accessibility to the bank's services. This matter is handled inadequately in many countries, pointing at the need to draft international standards for accessible bank services. Examples include having a specially trained tellers and bank consultants in the branches to provide customers with an accessible service, as well as brochures on the various banking services made accessible to people with various disabilities.
- On the other hand, the bank has a **duty of care**. This is a term from tort law, meaning, in brief, that as an expert in the field, the bank has an obligation to protect its customers from harm. If the bank does not take sufficiently cautious measures, it may be charged with negligence and ordered to pay damages to its customers.

The tension between the bank's obligation to honor the customer's wishes and make its services accessible and its obligation to fulfill the duty of care is strongest when customers want to make a transaction with a high level of risk and it seems clear that they do not fully understand the consequences. On the one hand, the bank must honor the customers' wishes and execute the transaction. On the other hand, society expects and the law requires that the bank refrain from making a transaction which would cause its customers harm.

Several legal advisers for banks told us that in the face of this tension, the duty of care prevails. Civil suits and court rulings place increased liability on banks. Since the legal discourse plays such a dominant role in banking, many people with disabilities are confronted with the bank's refusal to fulfill their wishes. Thus, for example, the bank requires that customers who either have or are perceived as having intellectual disabilities appoint guardians before they are permitted to have a bank account. Many banks recommend that family members of people with intellectual or psychosocial disabilities be appointed guardians when their family member reaches the age of 18. People who hold power of attorney for their elderly parents facing Alzheimer's disease are required by the bank to be appointed as their parents' guardians in order to keep the account

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active. All the bank representatives we interviewed discussed the banks' difficulties in working with clients with disabilities. They stated their clear preference that someone else be responsible for their financial transactions—in other words, a guardian.

In sum, most of the banks today do not know how to integrate the obligations of Article 12 of the Convention into their work. It seems that change on this issue must be made through primary legislation or at least through the country's banking regulator. Nevertheless, there are a number of measures that can help protect customers from financial harm without requiring the appointment of a guardian. These measures are already in daily use by banks and for the most part do not require special adjustments.

## 4. Restrictions in banking

There are three types of restrictions which are applied to bank accounts today that are important to note in a discussion about alternatives to guardianship:

- A. Internal restriction** – A restriction customers impose on themselves for their own reasons. For example, they can determine that earnings will be deposited into a long-term investment plan. If they withdraw the funds before the plan's expiration date, they must pay special fees. Couples may also restrict themselves by requiring that both parties sign a bank form permitting transactions above a certain sum.
- B. External restriction** – A restriction on the customer imposed by an entity external to the bank. This type of restriction applies to all the person's bank accounts at all of his/her banks. For example, individuals who are unable to pay their debts may find themselves under a writ of execution. If they do not meet the demands of standard debt repayment, the writ of execution may declare them "debtors of limited means." The goal of this declaration is to prevent these individuals from accumulating new debt. To accomplish this, the writ imposes various restrictions including a ban on holding credit cards and checkbooks, a stay of exit order, restrictions on the account and cancelation of credit for the account previously extended by the bank. A court or an agency implementing writs of execution may place a lien on the assets of individuals who owe money to others: the lien may be placed on their savings or checking accounts, salaries, assets, etc. From the moment the lien is in place, the bank restricts the account activity according to the terms of the lien.
- C. Bank restrictions** – The bank can decide to restrict a customer, subject to regulatory procedures. Generally, the restriction will be on the credit limit and whether the customer may obtain a bank issued credit card or checkbook. The restriction is based on a means test, the customer's financial history and information from credit card companies and other banks.

Regulations regarding such restrictions vary from country to country and bank to bank. It is important to study and understand them in order to know whether they also fulfill the need to protect people with disabilities from harm without having to resort to the draconian tool of guardianship.

In this chapter we will see how these existing restrictions can serve as alternatives to guardianship. All the alternatives introduced in the chapter can be self-imposed ones or externally applied by a court. In chapter 3.A we will address the fine line between restriction and coercion and the ethical dilemma that these alternatives evoke.

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In addition to these restrictions, there is also a possibility to appoint a guardian over a certain account. If, for example, the person has a significant amount of money, it is possible to appoint a limited guardianship solely over the bank account holding that amount, thereby protecting these funds, while an account holding a smaller amount can continue to be managed by the person. However this report aspires to propose alternatives to guardianship and therefore the following pages will be dedicated to alternative measures regarding banking that do not involve the appointment of a guardian.

## 5. Alternatives to guardianship in banking

Since alternatives in this area they vary from bank to bank, and often from branch to branch within the same bank, the alternatives will be presented in general terms only. The list presented here is meant to serve as the basis for a deeper examination leading to clear and systematic regulation.

### a. Adding a partner to the bank account

Often, individuals themselves, or those around them, worry that they will make poor decisions in managing their bank accounts. In such cases, it is enough to provide assistance, advice and guidance without interfering in the management of the account. However, in cases where individuals are aware that they need restrictions or greater intervention, they can add a trusted person as a partner to their accounts.

**Example:** Miriam is thinking of appointing herself as guardian over her son, David. David is 17.5 years old. Based on her experience, Miriam thinks her son might go into debt if he owns an independent account once he turns 18. Miriam and David may discuss opening a joint account in which Miriam will act as a silent partner only to make sure that David does not take large loans or go into debt.

This decision can be crucial. From a legal perspective, a partner in an account becomes owner of half the money in the account, and may be liable for any debt incurred in the account. However, there are arrangements whereby adding a partner to an existing account does not grant the partner ownership of funds, but only authority to conduct transactions in the account. Upon becoming a partner in the account, the trusted person acquires a number of tools to assist in financial management. These include assistance in managing the account and the relationship with the bank, monitoring bank account activity and requiring that certain financial transactions have both signatures. Frequent use is made of this tool today by people with advanced Alzheimer's. In these situations, a son or daughter is usually made a partner to the account and assists in managing or manages it for the parent.

In sum, although this alternative is available today, as long as it includes transferring ownership of half the property to the partner, it is a problematic one. If the partnership does not include rights to the money in the account but does include authority to manage and supervise it, it may be a more proportionate alternative in appropriate cases.

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### Advantages and disadvantages:



The procedure is simple and familiar to the banks.



It grants a great deal of power to another person and could open the door to exploitation or undue influence. For example, the partner could empty the bank account or transfer large sums from it to his/her personal account. Furthermore, legally, the partner could become owner of half of the amount in the account.

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### b. Special combination of signatures

According to this measure, bank transactions are made conditional on a given combination of signatures. For example, in business accounts it is possible to stipulate that the signatures of both the company's CEO and its accountant are required to approve a transaction above a certain amount (these kinds of conditions are also called "internal controls"). In the same manner, it is possible to define a special combination of signatures for a personal account. The person whose signature is required is not a partner to the account, but his/her signature is still necessary to conduct certain transactions. For example, a requirement can be made that all transactions above a certain amount require an additional signature.

This measure is different in substance from appointing a guardian. Whereas guardians are authorized to conduct any transaction they think is right in a bank account without the approval of the owner of the account, authorized signatories do not have the authority to make any decision by themselves and their signature alone is not sufficient to approve the transaction. Furthermore, while a guardian is the one who makes decisions, here the signature of the account owner is required for every transaction, in addition to that of the authorized signatory.

There are two ways to appoint an authorized signatory. One is by going directly to the bank; the other is by a court order. When the appointment is made by going directly to the bank, without the court's intervention, the owner of the account preserves the right to cancel the requirement of the additional signature, thereby recovering full control of decisions at his or her discretion. That power often completely undermines this alternative if its goal is to prevent people from making rash or poor decisions, even when they are convinced that the decision is correct and should not need anyone else's approval. When the requirement for an authorized signatory is imposed by court order, the court alone may cancel it and restore full control of the money to the person. Appendix B provides examples from Israeli court rulings that employed this measure.

In sum, this tool is a mechanism of co-decision-making, situated somewhere along the continuum between substituted decision-making by a guardian, and supported decision-making. A person's independence to make decisions regarding his/her assets is restricted, but the power is not fully delegated to another. In extreme cases in which individuals believe they need restrictions, this is the most proportionate restrictive tool we know. Nevertheless, it gives a great deal of power and influence to other people and therefore involves limitations on the person's autonomy and freedom.

**Advantages and disadvantages:**

The authorized signatory is not a partner in the account and therefore cannot independently make transactions and/or claim ownership over half the funds in the account.



The tool is restrictive, most certainly when it is court-ordered. In addition, many banks claim that due to their computerized systems, they will have trouble enforcing the requirement of a special combination of signatures.

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**c. Restrictions on withdrawals**

One of the primary concerns about harm in the banking sphere is that people might withdraw funds from the account irresponsibly. This can result in bank debts, the eradication of savings and inability to pay bills. There are several ways to restrict cash withdrawals. One of them is to limit the daily amount a customer can withdraw from the account. In banking systems where it is possible to withdraw the maximum daily amount from multiple ATMs (also known as ABMs or cash machines) before the computer system blocks further withdrawals, this measure will not be as effective for people who withdraw cash at the machine rather than in person at the branch.

It is also possible to require that all cash withdrawals by the customer be made through a bank teller, and provide the teller with instructions through notes in the bank's computer system. The notes can be tailored according to the individual circumstances. They may refer to the amount of money the customer may withdraw, the requirement to obtain the authorization of a third party for a withdrawal above a certain amount of money, or a requirement to inform another person about the withdrawal. Today, there are guardians who employ this method to grant people under their responsibility a certain amount of independence in managing their finances.

**Advantages and disadvantages:**

As long as such individuals do not have an ATM card, this is an effective tool to prevent them from emptying their bank accounts or rashly spending their monthly salaries or benefits.



Banks are reluctant to impose additional duties on their tellers and increase their responsibility towards customers. Therefore, not all banks will agree to this type of restriction. Furthermore, any restriction on a bank account is dependent upon the good will of the customer. The moment the customer changes his/her mind, the restriction must be canceled, unless it was imposed by court order.



### d. Additional restrictions on an account

Other than cash, there are three ways to withdraw funds from an account: by check, credit card, or preauthorized direct debit payments. It is possible to restrict the owner of an account in the use of all three of these means. Thus, for example, the bank can restrict the person's right to hold a checkbook (this is the default measure for debtors with limited means). Similarly, the bank can restrict credit card use, a measure we will discuss more extensively:

Several types of cards are issued by banks for use in financial dealings. These include a card that can only be used to receive information about the account; one that allows the holder to withdraw cash from an ATM; a debit card used as a payment method, subject to funds being available in the account; and a credit card that is a charge card. There are credit cards provided by the bank that are directly linked to the customer's bank account and non-bank credit cards, which can be paid by preauthorized direct debit from the bank account.

Various restrictions in the use of these cards can also provide effective protection from harm. For example, in banking systems that allow overdrafts, such as Israel's system, a "positive balance ATM card" would allow cash to be withdrawn only when there are funds in the account. Likewise, it is possible to restrict the daily withdrawal amount. In fact, it is possible to deny the use of a credit card altogether. A more proportional measure is to use a prepaid credit card. In this case, a certain amount of money is credited to the card by advance payment. In a prepaid credit card, expenditures are limited while card holders have full independence in how they spend the money.

In sum, it is possible to block or restrict the various pipelines by which funds leave a bank account. Like the alternative of restricting cash withdrawals, this option also raises the basic questions: who imposes the restrictions and who can cancel them?

#### Advantages and disadvantages:



Restricting withdrawals is an effective way to prevent uncontrolled spending.



The restrictions are specific to cards and in most cases will have to be one of a combination of measures.

### e. Investment

Individuals holding large sums of money can invest them in a long-term plan, thereby restricting their freedom to use the funds. At the same time, they can keep smaller amounts of money in their regular accounts. Often this is a preferred solution because it preserves the person's dignity, while providing financial security and preventing court proceedings. However, making a long term investment should factor in other considerations such as the effect on the value of the estate compared to other investment avenues.

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**Advantages and disadvantages:**

This is a restriction that people place on themselves using a universally employed measure. It has the added advantage of potentially producing future revenue in the form of interest on the investment.



As long as the money is closed in the account, it cannot be used. Therefore, this alternative is appropriate for investment funds and not for those required for daily needs.

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**f. Notarized power of attorney**

A notarized power of attorney makes it possible to grant a trusted person authority to conduct transactions in an account in accordance with the terms detailed in the power of attorney. This allows the trusted person to help track the account, conduct transactions on behalf of the account holder and implement the latter's decisions. Note the distinction between a specific, or notarized power of attorney which is the alternative discussed here and in which the person maintains legal capacity to make decisions, including to cancel the power of attorney; and a lasting power of attorney, in which the person to whom power is given acts in the other person's stead, leaving the latter with limited powers.

The question of people's capacity to sign a power of attorney may arise regarding this alternative. It should be noted that creating a power of attorney does not require the signatory to have a deep understanding of all of the areas falling under the authority of the recipient of the power of attorney, just as signing a power of attorney for a lawyer to submit a lawsuit does not require a person to be aware of all the details involved in the legal process and the lawsuit. Nevertheless, the signatory must have a minimal level of understanding of both the power of attorney and the areas it covers. In the case of people with significant intellectual disabilities, therefore, it may be difficult to make use of this tool.

In sum, a notarized power of attorney is another legal means of appointing a figure that provides support in financial affairs. The appointee can help people with disabilities clarify information and carry out decisions. The power of attorney can include restrictions on the powers of appointees, thus preventing them from exploiting the situation.

**Advantages and disadvantages:**

This alternative provides support that does not restrict the person with a disability in any way. Furthermore, it is in widespread use and familiar in the banking sphere.



The power of attorney affords great power to the appointee, who can make transactions in the person's bank account. In the absence of a trusted person, the device loses some of its appeal.

### g. Trust fund

A regular bank account can be turned into a trust fund managed by a trustee for a beneficiary. (For further discussion of trusts in the real estate context see the second alternative in Chapter 2.A.2 above.)

We know a successful example in Israel of a non-profit organization<sup>2</sup> which provides trusteeship services to people with disabilities. The service usually consists of a depositor (parent or property owner) and a beneficiary (the person with a disability). The organization provides services on a contractual basis, which includes management of the person's bank account and use of the funds in accordance with the consensual provisions of the contract. Because the organization is not-for-profit, the trusteeship services are provided at no cost. As long as the service is provided by reliable professionals or other trusted individuals at low cost, it is likely to effectively serve people who need assistance in managing their bank accounts.<sup>3</sup>

#### Advantages and disadvantages:



This solution is specific and flexible and does not require the involvement of the court.



If the property is registered in the name of the trustee, the trust fund can reduce the person's right to control the property. Furthermore, the solution is expensive because it requires payment of a fee to an attorney to draw up the agreement and, in many cases, monthly payments to the manager of the trust fund (unless there is an entity – such as a non-profit organization – which provides the service at no cost).

To summarize, a trust fund is a common and universal legal tool that can accommodate various programs and operational mechanisms. Because it is flexible, it is also neutral: poor use of it could lead to the loss of rights, whereas sensible use may achieve an appropriate balance between the authority of the trustee and the independence of the beneficiary.

### h. Informal trusteeship for income support and social benefits

In many countries an 'informal trusteeship' exists through which a limited form of substituted decision-making is created for the receipt of government income support. That is, in order to ensure that the person's rent and essential bills are paid, an individual is appointed to receive the government funds and manage it for the person. This vehicle was created to avoid the need for full guardianship but also to protect against potential harm.<sup>4</sup>

<sup>2</sup> See website: <http://www.neemanim.org.il/page.aspx?id=89&sid=14>

<sup>3</sup> For a summary regarding the use of trusts for people with disabilities see Canadian report: <http://www.lco-cdo.org/rdsp-discussion-paper.pdf>, pg. 70-76.

<sup>4</sup> In October 2013, The Law Commission of Ontario, released a report which addressed alternatives to guardianship in the context of the Canadian Registered Disability Savings Plan (RDSP). See pg. 76-82 that address informal trusteeships in Canada, Australia and U.S.A: <http://www.lco-cdo.org/rdsp-discussion-paper.pdf>.



**Advantages and disadvantages:**

This solution is specific and does not limit the person's capacity.



The solution distances a person from managing what is often his/her most important source of income. Furthermore, it is often used disproportionately even when the person is capable of managing his/her affairs with support.

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**6. Summary: banking**

Bank accounts are the nerve center of people's financial life. Their financial being depends upon their bank accounts, and everything connected to these accounts. Therefore, denial of the right to manage their accounts severely undermines their right to make decisions and manage their assets as they see fit. The list of alternatives included in this chapter may help find solutions to fit the particular needs of each individual. People who need support and guidance can get them by signing a notarized power of attorney or appointing a trustee; people who need to limit their financial activity may have to make use of restrictions on holding a credit card or checkbook or add an authorized signatory to their bank account. Although not all the measures listed here are currently recognized by the banks, we believe that by adopting one or more of them, we can find solutions to every concern about harm in this area. Appointing a guardian for in order to protect from financial harm in the area of banking is excessive and therefore unacceptable.

## C. Contracts

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### 1. Introduction

A contract is a legal and binding agreement between two parties based on a meeting of interests. Contracts, large and small, are an important part of our daily lives, used for purchasing products, buying bus tickets, signing direct withdrawal forms in return for receiving a service, paying for a cellphone in installments, renting or buying an apartment, etc. Contracts do not relate only to financial matters. For example, every surgical procedure requires the patient's consent, usually by signature, which constitutes a contractual agreement between the patient and the health service provider. In most countries, contract law is broadly developed and regulated in legislation and case law. As this is a common legal practice, all legal systems define in detail the conditions for creating a contractual agreement, and the manner in which it may be cancelled.

### 2. Concern regarding harm

People with disabilities, like all people, engage in contractual agreements for a wide variety of purposes. However, the claim is often made that they are especially vulnerable to harm in this area. During discussions with persons with disabilities, family members and professionals, a number of examples were raised. These included situations in which people agree to a preauthorized direct debit that they cannot afford, repeatedly purchase the same product, or purchase an expensive appliance which they cannot pay for. Concern was also raised that people might be pressured into signing on as guarantors, agreeing to a preauthorized direct debit to pay for someone else's expenses or taking on high-interest loans for others.

In this regard, two major arguments are raised for appointing a guardian. One argument is that guardianship is the only way to protect people with disabilities from getting themselves into debt by being sides to harmful contracts. Another argument arises from the often-encountered refusal by the other party to sign the contract with a person with a disability, questioning the person's understanding of the nature of the transaction and demanding that a guardian be appointed instead. This often occurs with regard to medical contracts or complex contracts with serious financial implications, such as signing a lease. The second argument is often raised regardless of the person's true level of understanding or the contract's level of complexity. For example, we encountered a situation in which a dentist refused to carry out a surgical procedure on a person with a communication disability even though the patient clearly understood the nature of the treatment. It was equally clear that the dentist did not correctly assess the patient's level of comprehension. Oftentimes the duty to accommodate services is not respected, which impacts the person's ability to understand the contract.

People who are declared to lack legal capacity cannot sign contracts. Usually this means that contracts they will sign can be cancelled without the need for complex legal processes. Denying legal capacity severely affects the right to independence and autonomy in the contractual sphere, since every contract that concerns the affected individuals must be signed by a guardian from the

time they are declared as lacking legal capacity. Even if such persons are allowed to engage in everyday contractual transactions, like grocery shopping, every major decision will require the signature of the guardian.

Finally, we must be aware that some problems cannot be solved by law. Nevertheless, the lack of a good solution does not mean that we must adopt one that denies human rights, such as appointing a guardian. It might be preferable to leave some loopholes which expose people to a risk of harm (until additional solutions are devised) than to sweepingly deny their right to legal capacity. According to Israeli law, the appointment of a guardian does not negate the legal capacity of the individual. Only in rare cases does the court deny legal capacity and declare the individual incompetent. This means that the overwhelming majority of the 40,000 people in Israel who are under a guardianship order continue to maintain legal capacity. Indeed, this leaves an opening for exploitation of people with disabilities or harmful mistakes by them. Yet though there is a certain recurrence of such incidents, it is not a widespread phenomenon and none of the decision-makers in Israel (from the Ministry of Justice, through the Ministry of Social Affairs, to the courts and social workers) are calling for the negation of legal capacity to provide protection in this area. Recently the Ministry of Justice even initiated an amendment to the law that eliminates the possibility of declaring an individual entirely incompetent. Therefore, alongside efforts to offer alternatives in the area of contracts, it should be recognized that even without good alternatives, there is no justification for negating a person's legal capacity.

### 3. Alternatives to guardianship in contracts:

Before examining the alternatives to the appointment of a guardian in the contractual context, we wish to clarify some characteristics unique to this sphere that should be kept in mind. Most of the alternatives we will discuss might involve litigation, such as the procedure to cancel a contract after it is signed. This involves lengthy procedures, most of them expensive and generally against powerful forces like cell phone companies and electrical appliance chain stores. In our search, we did not find an efficient and inexpensive solution that affords protection with regards to contracts. As detailed below, this area requires, above all, theoretical development and legislative change. Furthermore, the alternatives we shall suggest are based entirely on the Israeli legal system. Advocates and activists elsewhere should conduct thorough examination in their own countries among attorneys and senior academics proficient in local law regarding existing mechanisms that make it possible to be released from a contract or that offer protection from exploitation.

#### a. Void contracts

One of the basic conditions for creating a contract is the existence of *animus contrahendi* on the part of both parties, i.e. voluntary mutual intent to enter into a binding contract at the time of signing. If it is proven that voluntary intent was not present on the part of one of the parties, the contract is void. In every system of law, there are different tests for the existence of intent. Usually, this is not a purely subjective question; in Israel the test established for intent is whether a reasonable person examining the parties at the time of entering into the contract would have thought that there was intent on the part of both parties. For example, an individual (with or without disabilities) who is signed on as a guarantor may claim that since he or she was given a general explanation in non-legal terms and insufficient time to read the document in detail, there was no *animus contrahendi*.

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It is clear, then, that one may make use of *animus contrahendi* to declare a contract void when someone with a disability signed it without understanding it; however, the claim might be problematic, because it feeds into an implicit assumption that persons with disabilities do not understand contracts. This assumption undermines the entire move to eliminate guardians and recognize legal capacity for all.

Finally, it should be noted that there are additional conditions for a contract to be legally binding. These include the requirement that the contract be specific (that is, include all essential details), lawful, and, in certain cases, drawn up in writing. If these conditions have not been met, the contract can also be declared void.

To summarize, legal procedures often exist for terminating a contractual relationship which one of the parties did not understand at the time of signing. Nevertheless, the burden of proof usually lies with the individual who wants to declare the contract void. This fact, along with the expensive and complex legal proceedings required and the power imbalance between the individual and the other party makes it difficult to use this option.

### Advantages and disadvantages:



The more complex and visible to the eye the disability, the easier it will be to prove that there was no *animus contrahendi* (if indeed this meeting of minds was absent).



Many times the problem with harmful contracts is not the lack of intent but the exercise of poor judgment. In these cases the contract may not be declared void under the claim of “lack of intent.” Furthermore, the burden of proof is usually on the individual making the claim. This means the individual must apply to a court of law and enter into expensive and lengthy litigation.

## b. Voidable contracts

### *What is a voidable contract?*

The preceding alternative dealt with situations in which a contract is found to be void because it does not meet basic conditions for a legally binding contract. The following alternative deals with situations in which the contract did come into being – in other words, did become binding – but one of the parties wants to cancel it. Contract law recognizes situations in which one party is entitled to cancel the contract and thereby cancel the contractual relationship.

### *Under what circumstances does a contract become voidable?*

We will address two fundamental situations in which a contract may be cancelled.

**The first situation** occurs when one party violates its commitment. For example, if an individual received a damaged product or received it after an unreasonably long time, s/he may notify the other party that s/he is cancelling the contract. Cancellation must be made very soon after the violation, the notification must be unambiguous and the reasons for it must be stated.

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**The second situation** is when there has been a flaw in the making of the contract. There are several different kinds of flaws. The first is an error on the part of the signatory. For example, an individual who thought s/he was receiving a newspaper subscription at a reduced price and discovers only after the fact that s/he must pay a much higher price. Another defect is referred to as misrepresentation, that is, when the signatory's mistake happened due to misrepresentation by the other party. This is a more serious problem, because it involves inappropriate behavior on the part of the seller – e.g., a false representation regarding the transaction. In this way, for example, one may cancel a contract that has been signed with a seller who promised a genuine iPhone but delivered a fake one. A third situation is when an individual signs a contract due to exploitation by the other party. In this regard, taking advantage of a mental or emotional weakness is likely to be considered exploitation, all the more so when the terms of the transaction itself are worse than they normally are. An example of this would be the deliberate exploitation of a person by persuading him/her to buy several cellular phones. Finally, the most serious situation is one of duress, in which an individual is forced to sign a contract against his/her will.

When a person proves there was a defect in the contract, the possibility arises of canceling it. Cancellation may be partial, involving only the correction of the flaw; or absolute, in which case all the money will be returned to the buyer. Even if both parties agree to the cancellation, the other party may request compensation for damage that would result from the cancellation. To the degree that the flaw that caused the cancellation was the result of an error on the part of the party seeking cancellation of the contract rather than misrepresentation by the other party, the latter's claim for compensation is stronger.

### Conclusion

To conclude, as in the case of the first alternative, declaring a contract void, here, too, contract law allows for the cancellation of contracts on grounds of lack of understanding and of exploitation of one party by the other. That said, one of the reasons for contract law is to create certainty. In circumstances where recognition of the right to cancel contracts is likely to lead to uncertainty about whether to undertake transactions in the first place, there will be less protection for those who enter them.

#### Advantages and disadvantages:



Defects in the writing and signing of a contract, especially misrepresentation or exploitation, account for many cases in which people have signed contracts without understanding all their implications. The opportunity to cancel a contract is a legal tool well-suited to many situations in which persons, because of their disabilities, did not understand the nature of the document they signed.



Here, too, the burden of proof is usually on the individual claiming the defect. This entails a long and expensive proceeding which many people are unable to undertake.

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### c. Protections under consumer law

Many countries are developing legislation specifically devoted to consumerism. Consumer contracts are ones in which one party is a private entity that buys a property, product or service for personal needs (i.e., not for business), and the other party is a commercial entity. Thus, a lease between two private individuals would not be considered a consumer agreement, but a lease from an apartment hotel would be, since the latter rents out apartments as part of its business. The purpose of consumer laws is to afford additional protection beyond the general protection afforded by contract law, in order to bridge the inherent power gap between the private consumer and commercial entities.

Intelligent use of consumer protection laws affords much more effective protection than contract law for a number of reasons: First, protections in consumer law are usually based on simple and clear rules, unlike contract law protections, which are more subject to legal interpretation. Second, there is usually a simple judicial procedure for conducting proceedings against a commercial entity that violates the rights of the consumer. Third, in many countries there are organizations which assist citizens to exercise their consumer rights. There are different kinds of consumer protections, and each country has its own arrangement. In Israel, for example, an individual can cancel a transaction if it is not carried out in the presence of the seller (e.g. a sale via internet or telephone), or if it did not occur at the place of business (e.g. in the customer's home.)

For our purposes, one of the most relevant rights regarding consumer protection laws is the right to reconsider. According to the law, it is often possible to return a product purchased in a consumer transaction within a specified time, because the buyer has had a change of heart. There are conditions that must be met in order to cancel the transaction – for example, the product must not have been used and must be returned within the time determined by law. Products below a certain price cannot be returned. The advantage of this protection is that the buyer does not have to prove that there has been a misunderstanding, exploitation, or an act of deliberate misrepresentation in order to return the item. Essentially, the buyer does not have to prove anything, and the change of heart does not have to be based on any rational explanation. Let us take, for example, individuals (with or without a disability) who purchase subscriptions to a fitness center. They are entitled to change their minds and ask to cancel the subscription, whether it is because they personally had a change of heart or because they were persuaded by others to cancel it.

In sum, we see great potential in consumer laws to resolve difficulties that arise regarding contractual relations. Several constituencies will benefit from increasing protections in this sphere, including elderly people, who are often vulnerable to financial exploitation. Develop additional protective measures in the framework of consumer laws should be considered to increase their effectiveness, such as fast tracks for investigating consumer claims.

#### Advantages and disadvantages:



The protections afforded by consumer protection laws are broader than those in contract law, and usually more convenient to use, as they can be easily proved and do not require litigation.



This alternative does not provide a solution for cases in which an individual has already used the product or service, or when the contract is not for consumer purposes, but, for example, an agreement to serve as a guarantor or an agreement between two private entities.

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### d. Development of efficient procedures for cancelling contracts

Another protection worth considering is the establishment of a special litigation procedure that allows for an effective, inexpensive and expeditious appeal to cancel a contract. In Israel, for example, one may file a claim for small amounts in a small claims court. This is a court in which litigants represent themselves rather than use lawyers, and it is designed to be accessible to people who are not legally trained. Family courts in Israel, which are responsible for appointing guardians, sometimes decide to cancel contracts by virtue of the Israeli Law of Legal Capacity and Guardianship. The complex procedure that exists today for cancelling contracts entails expensive and prolonged legal proceedings; if it were possible to shift to a quick and simple procedure, individual cases that demand intervention could be dealt with more effectively, thus obviating the need for the sweeping and draconian measure of appointing a guardian who would then be in charge of all aspects of a person's life. An efficient procedure for cancelling contracts is also more appropriate in cases of exploitation because it focuses on penalizing those who exploit, rather than 'punishing' those being exploited by diminishing their legal capacity. There is a price to pay, however, in expanding grounds or procedures for cancelling contracts. A solution will have to be found for the damage done to the principle of certainty in contracts and the concern that service providers might refuse to enter into contracts with persons with disabilities for fear that the contracts will be cancelled.

#### Advantages and disadvantages:

-  The proposal to promote an accessible procedure for cancelling contracts does not require changing substantive law. It primarily involves defining the procedure and allocating resources for its implementation. This is a change that would assist many population groups without requiring new thinking about the rules of contracts.
-  Even though changes are procedural, they will require comprehensive modifications in legislation. Decision-makers will have to recognize that making these modifications and allocating the necessary resources for implementation are preferable to the appointment of a guardian.

### e. Changing substantive law

The following option addresses harm caused mainly by undertaking installment payments. However, since this option limits the range of decisions a person can make, it should be approached carefully. Transactions based on preauthorized direct debit, credit cards, or installment payments all require bank approval. We might therefore, consider a change in legislation that would allow the court to register an alert in an individual's bank account that would impact his/her ability to execute non-routine transactions. For example, the alert could inform the bank that an additional signature is required to complete the transaction. This would mean that before a transaction by credit card or preauthorized direct debit can be completed, the seller would have to check whether the customer had a special alert attached to his/her account (just as it is customary today for the

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seller to check with the credit card company that the transaction is approved). If there is an alert registered in the bank account (which might, for example, call for an additional signature or the approval of the transaction by a second person over the phone), the alert will appear on the seller's computer monitor. Should the seller ignore it, the customer has the right to cancel the contract immediately. A less restrictive mechanism could be attaching an alert to a bank account with a requirement to notify a relative or friend the person agrees to in advance. It is even possible to require that the transaction only enter into force after a certain amount of time so that the account-holder and his relative or friend can discuss the matter and consider cancelling it if necessary.

### Advantages and disadvantages:



Most countries will have to consider legislative changes in order to provide a good solution in the realm of contracts. Such amendments will have to address the circumstances discussed above and formulate effective protections that respect the freedom of the individual. To the extent that the legislative change is universal and does not apply only to persons with disabilities, it will increase its compliance with the principles of Article 12.



Making changes in substantive law is no simple matter. It requires expertise in the field and is likely to attract opposition from banks and businesses which are characteristically averse to complicating procedures. Furthermore, some of the suggestions mentioned above include restrictive elements. Thus, their success may lead to a situation whereby instead of affording more freedom, they will restrict the financial freedom for those released from guardianship.

## 4. Summary: contracts

The field of contracts is in need of new and creative thinking in order to achieve proportionate protections. The greater the coordination between bank information systems, credit card companies, service providers and courts, the easier it will be to develop specific and effective protections. Until all this happens, we will have to make do with contract and consumer laws. Between the two, consumer law is clearly preferable and is the one that should be developed. The alternatives which currently exist in contract law and the litigation within existing institutions are irrelevant to most people because they are expensive, prolonged and intimidating. Of the three areas discussed – real estate, banking and contracts – we believe the questions related to contracts raised in this chapter require the most thought: How can people free themselves from preauthorized direct debit transactions in their account, and when should the possibility of release be used? How can people be protected from repeated consumer commitments that are harmful to them? How can the role of the advisor and supportive figure be enhanced to have an influence in real time and not just after the fact? These are all questions that must be given new answers - answers premised on a future without guardians and with full legal capacity for all.

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## Chapter 3

# Dilemmas in the Development of Alternatives to Guardianship

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The discussion of alternatives to guardianship is no trivial matter. Any such discussion must enter the gray areas between free choice and coercion, between promoting human rights and maintaining discrimination, between revolutionary change and semantic change. We could point to the five sections of Article 12 of the Convention, demand full equality and the revocation of all guardianship arrangements and completely avoid studying alternatives. However, in doing so, we would be failing to meet our obligations, which are twofold: first, to engage in real questions vexing people in different countries, some of whom would be happy to adopt the provisions of Article 12 but are deeply concerned about the potential consequences of its implementation, and second, to take responsibility for the issue and not abandon the field to other policy-makers. Indeed, the questions at the heart of this report are already being discussed and will be discussed again and again as long as implementation of Article 12 moves from theory to practice. Many people who do not recognize the inherent right to legal capacity may fulfill significant roles in determining policy. If we do not have satisfactory answers that demonstrate full understanding of the complexity of the issue, human rights organizations that engage in this field may become irrelevant.

This chapter is entirely dedicated to dilemmas that arise from a consideration of the alternatives presented above. The purpose of this chapter is not to propose answers, but to present the various sides of each dilemma. In fact, this report need not be construed as authoritative in terms of deciding how to resolve these dilemmas; there may be different solutions in different countries for different people.

Finally, this chapter should be read in the context of the entire report. It is based on the belief in the ability of people with all kinds of disabilities to be masters of their own lives, in the right of people with disabilities to receive assistance and support so that they may exercise their legal capacity, and in the great respect we should accord to the autonomy and freedom of every individual.

## A. The fine line between restriction and coercion

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We must discern between restriction and coercion. Most of the alternatives presented in this report include an element of restriction, but one that is self-imposed. Thus, for example, a person may choose to restrict his/her ability to conduct a transaction involving an asset in order to cope with pressure from family members to have the asset transferred to them. As such, these alternatives are no different from the restrictions that many people place upon themselves – for example, taking out a loan or mortgage, restricting spending on mobile phone calls to a monthly amount, avoiding use of a credit card, opening a joint bank account requiring two signatures, etc.

However, it is clear that our discussion of alternatives will also have to confront the issue of coercion: are there conditions in which it is possible to impose some restrictions on a person? Does Article 12 of the CRPD forbid any such restriction, even when it is specific, temporary, or proportionate? From a moral standpoint, are there situations in which it is right to impose restrictions on people to protect their interests, whether they have disabilities or not?

As stated above, this report does not attempt to determine the answers to these ethical and moral questions. Readers will have to work them out for themselves. Furthermore, these answers will change from one society to another and be influenced by the worldviews of each culture. Implementation of Article 12 cannot disregard each society's moral outlook, which influences all of its members, not just those with disabilities. Thus, for example, there are countries in which life is considered more valuable than autonomy, and therefore legal mechanisms exist in these countries to enforce life-saving medical treatment (for all people, regardless of whether or not they have a disability). But there are other countries where the opposite is true. It is the same when it comes to the financial sphere. There are countries in which the fundamental worldview regarding the free market leads to imposing heavy legal restrictions upon people who cannot meet their financial obligations. These restrictions include prohibiting those in debt from holding credit cards or leaving the country. In other countries, on the other hand, social rights based on the right to live with dignity offer people a minimum of protection. In such context, for example, collecting debts from government benefits may be prohibited. There are societies in which decisions are made by a collective or by the head of the family and individual autonomy is more limited. Thus, the discussion on imposing restrictions will be heavily influenced by the social context.

Finally, we would like to point out that the discussion of “coercion” in this context is delicate. A person may “choose” to be restricted, but this decision is made in the context of a threat by the welfare authorities that otherwise, a guardian will be appointed. In such cases, the person is being offered a pseudo-choice. This practice is familiar from that of coerced psychiatric hospitalization: often, psychiatrists “recommend” that patients sign a voluntary hospitalization agreement, which offers a thin layer of rights such as holiday leave, in order to avoid being issued a forced hospitalization order and the loss of these rights. On the one hand, when considering alternatives to guardianship, one must take into account the issue of forced choice. On the other hand, the very existence of a slippery slope leading from voluntary restriction to coercion does not necessarily justify rejection of any form of “voluntary restriction.” We must assess whether placing suitable procedural and substantive guarantees can prevent sliding from one to the other.

## B. Does restriction constitute deprivation of legal capacity?

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What is unacceptable in the various kinds of guardianship arrangements is above all the revocation of a person's legal capacity and its transfer to someone else. The various alternatives presented in this report are meant to ensure that people with disabilities continue to enjoy legal capacity, but this capacity includes certain restrictions on their ability to make certain decisions. These restrictions themselves impinge on their legal capacity. One of the questions left unanswered in this report is at what point the restrictions on decision-making become so harsh as to effectively constitute substantive negation of legal capacity.

It is not easy to assess the harshness of the restriction. Take, for example, a decision to limit someone's banking activities because of constant debt. When alternatives to guardianship are offered, the same person might be able to choose between the following two restrictions: (1) Any transaction in the account above a certain amount will require a second signature. (2) A cap will be placed on the amount of money the person may withdraw each month. The first restriction is more severe than the second in that it grants discretion to a third party to intervene in the management of the account. The second restriction is more severe than the first in that it places a barrier of a monthly withdrawal limit, which there is no way to circumvent. Despite the difficulties in ranking the restrictions and the alternatives, we have attempted in the previous chapter of the report to discuss the advantages and disadvantages of each alternative, including the nature of the restriction, in order to facilitate discussion of the legitimacy of each.

## C. How much weight should be given to concerns about harm?

Taking the view that there are situations in which it is correct to restrict a person's financial activity, and sometimes even to forcibly impose such a restriction (and as stated above, this report does not take a position one way or the other) does not exempt us from the need to define the anticipated harm that would justify such a restriction. In fact, there are many types of behaviors that include harmful aspects, and care must be taken not to reach a situation where restrictions and protections are espoused against each and every type of harm. Thus, for example, a person with a psychosocial disability, who has never been under guardianship and participated in a study prior to the writing of this report, said that each month, he withdrew an amount much larger than his income, but had enough savings to meet his excessive expenditures. This person noted that if a court had to make a decision about him according to accepted law today, it might decide, much to his displeasure, to appoint him a guardian.

Often, the very discussion about harm to a certain person is discriminatory because it arises only because of the disability. There is a difference between a general concern regarding harm, often ascribed to any person with a disability, and a concrete fear based on events in the life of a specific

person. Furthermore, the question of the likelihood of harm is often subjective and therefore must be examined based on the premise that all people have the right to use their money as they wish, and that the right to legal capacity includes the right to make mistakes. Thus, for example, a guardian may think that spending money on a matriculation exam prep course for a person with an intellectual disability is a waste of money, while the person may think the decision is important and justified. By the same token, a person's decision to invite friends to a restaurant or a night out at his/her expense may be perceived as strangers exploiting the person's naiveté, while the person believes it to be a wise use of funds that makes him/her happy.

Assessing harm must also include harm to the person's independence, autonomy and freedom resulting from the denial of capacity. Often, these losses are not taken into account, or given little weight compared to financial harm of one kind or another. It would not be a generalization to say that most people, with or without disabilities, would prefer to lose some of their money to preserve their independence and freedom.

Finally, there must be a proportional relationship between the fear of harm and the measures taken in order to protect against such harm. Thus, for example, most of us would choose not to use a "hermetically sealed protection suit" which would prevent all harm but restrict all our actions; instead, we prefer specific protection measures which leave most of the control over our lives in our own hands.

## D. Procedural aspects of developing alternatives

Alongside the substantive aspects of alternatives to guardianship in financial affairs, we must also consider procedural ones. Both the substance of the decision to use an alternative, and the manner in which it is made, must stand the test of the CRPD's Article 12. The procedural question can be split in two: first, is it the people with disabilities, themselves, who chose the restriction? Is a particular procedure required to approve the restriction (for example, must those wishing to add someone to their bank accounts be interviewed by a bank employee to confirm that the decision is voluntary)? Secondly, if we have decided that there are situations in which a restriction may be imposed upon a person, we must determine what the proper procedure should be. For example, who makes the decision? How can we ensure the person's right to be heard, to be represented, to appeal, etc.?

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## E. The dilemma of the small steps

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Promoting alternatives to guardianship must be done carefully and after serious consideration. Even after it is clear what the proposed alternatives to guardianship are, it is still not clear whether it is right to advance them. One of these dilemmas shall be termed here “the small steps dilemma.” In many countries today, law is binary – either a guardian is appointed and the person loses legal capacity, or full legal capacity is recognized without restriction. The obligation placed on each country to adjust local law to Article 12 of the CRPD is expected to lead to substantive changes in many laws. In circumstances where the possibilities are binary, there is a greater chance that in order to meet the requirements of Article 12, guardianship arrangements will be revoked entirely. In such situations, presenting a range of alternatives to guardianship that create various degrees of restriction may be harmful. Thus, for example, the director of a housing system for people with psychosocial disabilities who was interviewed for the purpose of this report noted that today she avoids asking for guardianship for many residents because she considers it too severe a restriction. However, if there were a possibility of appointing an authorized signatory for the bank account of a resident in order to prevent him/her from over-spending, she would apply it, since, in her opinion, it is a more proportionate restriction. In other words, the freedom of people with disabilities may be harmed by the advancement of more moderate forms of restriction. This poses a dilemma between allowing the all-or-nothing solution (guardianship arrangements which severely undermine the right to legal capacity or no guardianship at all) or the introduction of small steps (proportional restrictions). This dilemma requires further discussion. If the struggle for the abolition of guardianship requires the addition of more moderate restrictions, does it not exchange one kind of discriminatory tool – widely viewed as problematic – for a different discriminatory tool that will be perceived as legitimate and enlightened?

---

We do not believe that the many reservations raised in this chapter undo the need for a thorough examination of alternatives to revoking legal capacity and deciding whether or not to use one or more of them. Being aware of and examining the alternatives, according to the issues detailed in this chapter, may help the worldwide effort to adjust national laws to Article 12 and restore legal capacity to all people.



## Chapter 4

# Conclusion

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Article 12 of the CRPD is based on a radical change – acknowledging every person’s right to legal capacity. This requires a dramatic change in current domestic laws. It requires the restoration of legal capacity and the development of supported decision-making as well as accommodations and informal support. These changes must be implemented in all areas of life, including financial affairs.

We believe that the first step in terms of financial affairs should be strengthening and supporting the capacity to make decisions. This includes training third parties to accommodate their services to suit a wide variety of clients (with and without disabilities) and supporting people in decision-making. However this report is based on the arguable assumption that there are people who may be exposed to significant harm if no protections are in place beyond support. We have therefore attempted to highlight dilemmas concerning the use of alternatives aimed at protection, and to specify the alternatives themselves.

In the second part of this report we sought to examine whether tools already exist through general law which could serve as alternatives to guardianship and afford protection without denying legal capacity.



**In real estate**, some effective and simple tools were discussed which protect a person’s property without diminishing his or her legal capacity and without impacting other aspects of life.



**In banking**, we discussed a wide variety of tools that can prevent unchecked withdrawal of funds from an account and financial exploitation of an individual. The banks, however, are not fully on board with using these tools. Banks are reluctant to deal with customers whose disabilities influence their judgment and comprehension. In these situations, banks encourage the appointment of a guardian and are hesitant to adopt the solutions raised in this report. Therefore, our conclusion is that the development of alternatives in the field of banking will require regulating the responsibility of banks and establishing the procedure for placing restrictions on an account at the customer’s request. The development of international guidelines with the help of financial experts and disability rights experts would be very useful towards prompting change in various countries.





**In contracts**, we demonstrated the large gap between the existing legal framework and the need to offer protection from exploitation and from undesirable transactions. Although contract law generally includes protections and remedies for transactions that were signed without understanding or intent, the procedure for voiding a contract is often expensive and complicated. Of the three spheres discussed, the need to develop new and specially-tailored tools is strongest in the sphere of contracts.

In sum, there are a number of proportionate and effective tools that are not currently considered as alternatives when the issue of guardianship arises. There are several reasons why these tools are not used: lack of awareness of their existence, insufficient weight given to the principles of freedom and autonomy, a disconnect between experts in the field of legal capacity and experts in the field of finance and a preference for sweeping and binary solutions. However, the more these tools are utilized and the more their practical uses are examined, the more likely it is that they will become substantive and useful alternatives.

• • •

In recent years, the disability rights community has sparked a lively discussion about the importance of Article 12 and the need to push for its implementation. The keen interest in the development of supported decision-making is the first and most important step in the implementation of Article 12 (see Appendix C). While the development of supported decision-making continues, the use of the alternatives proposed in this report should also be considered, accompanied by a study of how each country's legal system impacts the availability of the various alternatives.

A few centuries ago, the legal capacity of deaf people, foreign nationals, slaves and other marginalized groups was not recognized. Less than a century ago, married women were denied full legal capacity. In much less than a century, it will be hard to believe that many people with disabilities were denied legal capacity as a default. The CRPD reflects this aspiration. Today, it is up to us to put Article 12 into practice.

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# Appendices



## Appendix A

### Writing this report

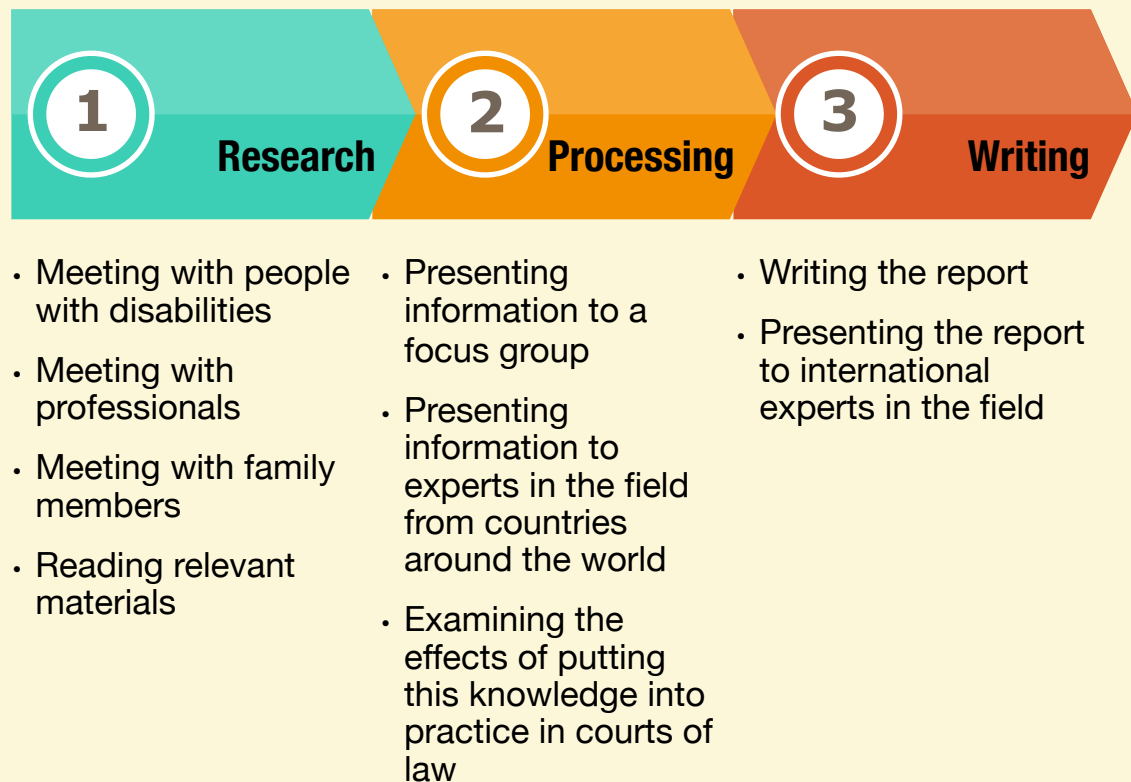
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This report was written by Attorney Yotam Tolub of Bizchut – The Israel Human Rights Center for People with Disabilities, under the guidance of Ms. Tirza Leibowitz, the legal advisor for disability rights at the Open Society Foundations' Human Rights Initiative.

The promotion of alternatives to legal guardianship in financial affairs requires a separate learning process in each country. The goal of this appendix is to present the methodology used in the research and writing of this report, with the hope that this will be helpful to those interested in embarking on similar studies.

This report was written in three stages:





## 1. The research stage

The research stage began a few years ago when Bizchut started to engage in the right to legal capacity and to handle personal inquiries regarding this right. In the course of a few years, we were exposed to the stories of persons under guardianship and witnessed the many injustices they suffered. At the same time, through handling these personal inquiries we also came to understand the many difficulties faced by these persons' families and friends – difficulties which often lead to the appointment of a guardian. Family members and professionals described financial crises encountered by people with disabilities and their families due to problematic financial decisions; physical damage due to many years of neglect; and helplessness against a system that demands the appointment of a guardian as a pre-condition for the provision of services.

After several years of handling personal inquiries, which included legal representation in court, we began developing alternatives to guardianship. One of the most significant issues was the fear of harm and damage. While we were able to find measures to prevent personal and medical harm with relative ease, we encountered many difficulties when it came to finances. The financial issue was repeatedly mentioned in international forums attended by field organizations from various countries as the Achilles' heel of the Article 12 revolution.

We realized there was a need for a study that would focus on the financial aspects of alternatives to guardianship, and this topic became the purpose of our study.

Prior to writing this report, research was conducted over several months in order to gain a better understanding of the issue of alternatives to guardianship in financial affairs. During these months, we held many discussions and met with dozens of people with disabilities. The goal of the conversations was to understand the difficulties people with disabilities face in their financial transactions and the limitations placed on these transactions after a guardian is appointed. Some of these cases and their legal progression are described in Appendix B. At the same time, we held a number of meetings with parents of people with intellectual and/or psychosocial disabilities. During these encounters, the parents emphasized their concern about financial harm and their doubts about the actual implementation of Article 12 of the Convention. These cases brought to light by the parents were in our minds as we searched for alternatives.

In addition, over the last few years we have held several meetings with professionals who engage in various aspects of guardianship. We met with representatives of the Israeli Ministry of Social Welfare and Social Services who are in charge of guardianship appointments; we met with family court judges; Ministry of Justice staff who engage in legislative amendments on the issue; members of the Israeli parliament; psychiatrists and neurologists who sign the medical opinions used in guardianship appointment procedures; welfare officers and social workers; and others, both in the field of intellectual disabilities and the field of psychosocial disabilities.

We met with representatives of the three major guardianship entities in Israel as part of advocacy activities by people with disabilities vis-à-vis these entities. These three bodies represent the conservative view that guardianship is the most effective solution in many cases where harm is feared.

We then met with activists in the non-profit sector who engage in issues that overlap with those of this report. Among others, we met with the CEO of Neemanim, an Israeli organization which provides free trusteeship services to people with disabilities. This organization, founded by parents,



is based on a UK model (which also exists in the US) in which parents deposit a considerable sum of money to benefit their descendants after the death of the parents. The organization serves as a trustee for the money and is responsible for spending it on a treatment and rehabilitation program in accordance with the parents' wishes. Though the service is meant to act as a substitute for the parents, it may also be used by people with disabilities who seek assistance in managing their own money through a trust.

We also met with representatives of Yedid, an organization which provides legal assistance to people who have fallen into debt. We learned from them that many of the financial difficulties faced by people with disabilities can be addressed by representation from this type of organization, without appointing a guardian. However questions were raised regarding the accommodations needed in order to adjust general legal-aid services to people with psychosocial and intellectual disabilities.

We met with the CEO and legal advisor of the Association of Law in the Service of the Elderly, an Israeli organization working to minimize the use of guardianship for the elderly. Despite the difference in target audience, we found fertile ground for cooperation in advancing alternatives to guardianship. In the financial field, one of the salient tools which this organization promotes is a lasting power of attorney. This allows a person to provide power of attorney to another so that the latter can make financial decisions on the former's behalf, even when s/he does not have legal capacity. This tool is very relevant to people with Alzheimer's or degenerative conditions.

Lastly, we met with the CEO of Paamonim, an Israeli organization which provides personal guidance to families experiencing financial difficulties. This organization specializes in providing tools to people who have fallen into debt and have difficulties managing their finances. Here, we once again saw that the problems guardianship attempts to solve have other solutions that better preserve people's autonomy and dignity.

At the same time, we held a series of meetings and interviews with experts in each of the three fields at the center of this report – real estate, banking and contracts.

- Real Estate – We interviewed two lawyers with expertise in real estate law.
- Banking – We met with the legal advisors of two major Israeli banks. We also held a special meeting on this issue with the Association of Banks in Israel and with representatives of the legal departments of five major Israeli banks. In addition, we interviewed managers of two bank branches and a junior staff member at a bank. During these meetings, we observed a large gap between the stated policy of the banks' legal departments and the largely flexible practice at the branches. This observation is highlighted in the report.
- Contracts – We met with three academic lecturers with expertise in the fields of contract law, commercial law and guardianship.

During these meetings, there was a clear tension between the professionals' desire to support the rights of people with disabilities and their reservations about revoking the institution of guardianship. This was most prominent with regards to banking, with banks repeatedly claiming that without legislative change, they could not assume the risks involved in developing alternatives to guardianship.

At the end of the research stage, we consolidated the main findings in this report.

## 2. The processing stage

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Toward the end of the first stage, we put together a focus group with the purpose of presenting it with our findings and hearing the participants' reactions. The focus group met with experts in order to create a dialogue between the target population and experts. The focus group had eight members (four men and four women): three people with psychosocial disabilities, one person with intellectual and communication disabilities, a parent of a person with a psychosocial disability, a parent of two sons with communication disabilities, a rehabilitative social worker in the field of mental health, and an external guardian. The group held two meetings in which it met with two experts: a lawyer who specializes in real estate law and a lecturer in contract and commercial law. The meetings were transcribed to assist in analyzing the issues discussed.

At the same time, the report's findings were presented to activists for the rights of people with disabilities in several countries:

- **Bulgaria:** In Bulgaria, several organizations are pushing for a change in the country's legal capacity law following ratification of the Convention, through the promotion of the supported decision-making model. The findings of this report were presented to representatives of three Bulgarian NGOs: the Bulgarian Center for Non-Profit Law, a human rights organization working to implement the Convention; the Bulgarian Association for Persons with Intellectual Disabilities, an organization of parents of people with intellectual disabilities; and the National Organization of Mental Health Services Users (NPPZU), an organization of people with psychosocial disabilities. The findings were also presented to a senior official at the Bulgarian Ministry of Justice.
- **Armenia:** In Armenia, the Helsinki Citizens' Assembly Vanadzor focuses on the rights of people with psychosocial disabilities and their right to rehabilitation services within the community. The organization monitors psychiatric institutions, as a part of which it also addresses the right to legal capacity and human rights violations that result from the appointment of a guardian. The report's findings were presented to the organization's staff who conduct the monitoring, as part of training they received regarding the right to housing in the community and the right to full legal capacity.
- **Czech Republic:** In the Czech Republic, work is being carried out to promote the supported decision-making model as an alternative to guardianship and to incorporate Article 12 of the Convention into Czech law. The findings of this report were presented to activists in the field: staff from Inclusion Czech Republic, the umbrella organization of families of people with intellectual disabilities; the staff of Quip, a non-profit which promotes the rights of people with disabilities with an emphasis on people with intellectual disabilities; and representatives of Liga, a human rights organization active in the Czech Republic.
- **Sweden:** As part of the research process, a three-day conference was held with staff of PO-Skåne in Sweden. During the meeting, the supported decision-making model was discussed, as well as questions regarding possible avenues for intervention the management of the financial affairs of people with psychosocial disabilities (see Appendix C).
- **Kenya:** Some of the report's findings were presented via Skype to Ms. Elizabeth Kamundia, who wrote a report for the Kenya National Commission on Human Rights about the implementation of Article 12.

- **China:** Meetings with a Chinese human rights organizations promoting legal capacity for people with psycho-social disabilities helped us understand the broad use of substitute decision-making in financial and medical issues in China, irrespective of the appointment of guardians.

The presentation of the report's findings formed the basis for an extensive discussion about the relevancy of the findings in different countries and about the dilemmas the discussion of alternatives evokes.

Lastly, Bizchut has begun using the knowledge gained while working on this report in the legal aid it offers to people who wish to be released from guardianship. Practical use of the various alternatives has helped us clarify the advantages and disadvantages of these alternatives and how practical they are. Appendix B will expand on the issue with a discussion of several individual cases.

### 3. The writing stage

After investigating the issue, consolidating the large amount of information collected, and writing the report, the report was presented to a number of experts for comments and additional local examples. Attorney Elizabeth Kamundia made important comments about the relevancy of the proposals included in the report to Kenya. Attorney Lana Kerzner, a Canadian expert on Article 12, thoroughly reviewed the report and her comments have been invaluable in improving accuracy and adjusting the report to international audiences.

In conclusion, work on this report had value in and of itself. Aside from the knowledge gained and presented in the report, the process included raising awareness about the issue among people with disabilities, family members and decision-makers; gaining a deeper familiarity with the difficulties faced by people with disabilities in this area; forming an advocacy group; winning several legal cases; and consolidating international dialogue on the issue, while honing in on practicalities.

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## Appendix B

# Individual cases and example court rulings

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### Case 1

A woman with an intellectual disability was appointed a guardian by her brother because of the way she handled money. Among other things, she lost much of her savings on gambling. The woman complained bitterly about the guardian, an external body that provides guardianship services for a fee. She turned for help to Bizchut, which took the matter to court and presented an alternative plan. The court accepted the plan, whose main points are detailed herein. The guardianship was cancelled and the woman regained her legal capacity and autonomy in most areas of life. She received an accountant's support in decisions over property, for a fee. Some restrictions were imposed on her bank account and on her ability to sell assets she would own in future. One year after the ruling was handed down, the woman has more freedom of action, decides for herself how to spend her money and, at her own initiative, has also begun saving money for various goals she wants to achieve.

### Case 2

An army veteran suffering from a head injury sustained in war, who receives a large government stipend, repeatedly plunged into debt. The debts were caused, among other factors, by pressure from people close to him to pay for their expenses. As a result, the possibility of appointing his sister as his guardian was considered. The man turned to Bizchut, which led to an alternative plan being presented to the court. The plan included a requirement for the sister to co-sign any withdrawal over a certain amount each month. The plan, which was approved by the court, provided a solution for the debts he had been accumulating and obviated the need for a guardian.

### Case 3

This is the most significant ruling ever handed down in Israel regarding alternatives to guardianship. The case involves a woman with a psycho-social disability who, during periods of manic attacks, spent large sums of money. In response to a request by the woman's family, the family court decided to appoint a guardian for her. The woman appealed the decision. The appellate instance accepted the appeal and ruled that appointing a guardian should be avoided as long as it is possible to find alternative measures such as restricting the account or registering a caveat on the asset.

### Case 4

This case involves a woman with a disability who was due to receive a large sum of money in damages. Consequently, a procedure was launched to appoint a guardian for her on the grounds that she was incapable of managing her own property and there was concern that members of her family would exploit her. The court instructed that the guardian be removed and the damages awarded to the woman deposited in two separate accounts. One account was to be closed for a long period and accessed only with the court's permission, and another, open account, was to be used by the woman for her daily needs.



## Case 1:

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**In the Haifa Family Court**

Guardianship Case 50389/02/13

In the matter of:

**The Attorney General**

Represented by his legal counsel, Advocates E. Sagi and/or S. Aloni-Zrachia and/or R. Hess-Bachar and/or M. Kaplan and/or R. Houlie-Esawi and/or R. Salman Srur and/or N. Nasseraldeen Nashef

Of the Legal Adviser's Office, Ministry of Welfare and Social Services

5 Hassan Shoukry Street, Haifa, tel: 04-8619126/7/8; fax: 04-8619193

**The Petitioner****VERSUS****1. Respondent 1**

I.D. no. [\_\_\_\_\_]

Represented by her legal counsel, Advocate Yotam Tolub of "Bizchut" – The Israel Human Rights Center for People with Disabilities

at fax no. 02-6521219

**2. The Fund for Treatment of Wards of the State**

of 41 Hechalutz Street, Haifa

at fax no. 8671958

**3. Respondent 3**

I.D. no. [\_\_\_\_\_]

Represented by his legal counsel Advocate HersHKovitz

at fax no. 077-5444804

**4. Respondent 4**

I.D. no. [\_\_\_\_\_]

Of [\_\_\_\_\_]

**The Respondents****Abbreviated Judgment**

In the proceeding being conducted before me and in all matters relating to the motion of Respondent 1 (I.D. no. [\_\_\_\_\_]) (hereinafter, "Respondent 1") to cancel the guardianship, I hereby order as follows:

1. After having heard the parties and being convinced that Respondent 1 is able to take care of and handle her affairs, while obtaining assistance and support on her property affairs from the accountant, Mr. Yehuda Lavie, and after having reviewed the social worker's report on procedure, on June 2, 2013 I decided to cancel the appointment of the guardian – the Fund for Treatment of Wards of the State – as guardian over Respondent 1's person and property and to allow Respondent 1 to conduct her personal affairs independently and to



conduct her property affairs with the assistance and support of Mr. Yehuda Lavie.

2. I approve the financial plan submitted to the court file on behalf of Respondent 1 and the list of needs and expenses set forth therein.
3. I authorize Mr. Yehuda Lavie (CPA) I.D. no. \_\_\_\_\_ to accompany and support Respondent 1 in making financial decisions. In this context, and only in this context, his functions and powers shall be as follows:
  - A. To assist Respondent 1 in collecting and obtaining from any person or entity any information required for the purpose of making any decision she wishes to make.
  - B. To assist Respondent 1 in understanding the information which concerns a decision she needs to make, and all that this entails.
  - C. To assist Respondent 1 in presenting her decisions before any person or entity or presenting them on her behalf, according to her decision.
  - D. To assist Respondent 1 in implementing her decisions.
  - E. To represent her before any entity or body where necessary.
4. In carrying out his function and in light of Respondent 1's consent, Mr. Lavie may receive any relevant information or document in connection with Respondent 1's financial affairs from any public, private or governmental entity.
5. Likewise, I order as follows:
  - A. All Respondent 1's monies shall be managed in the account opened for her at Bank Leumi, branch \_\_\_\_, account no. \_\_\_\_\_.
  - B. A caveat shall be recorded in the aforesaid account that Respondent 1 may independently withdraw from her account each week a sum not exceeding NIS 300.
  - C. It shall be recorded in the aforesaid account that no credit shall be granted in the account and that any transaction over NIS 300 requires Mr. Lavie's approval.
  - C. Checkbooks and credit cards shall not be provided for this account.
  - D. Mr. Yehuda Lavie shall organize and establish these rules in the Respondent 1's bank records.
6. Respondent 1 shall submit to the court file by means of her legal counsel a document confirming that the above caveats were recorded in the bank account.



7. Likewise, I order that any arrangement between Respondent 1 and her brothers concerning the distribution of the estate shall be subject to the approval of the court.
8. Upon arrangement of registration of Respondent 1's rights over the apartments in the estate, whose details are as follows:
  - 1) Parcel 101, \_\_\_\_\_.
  - 2) Parcel 10, \_\_\_\_\_.
  - 3) Parcel 22 \_\_\_\_\_.

Caveats shall be registered at the Land Registration Office by Mr. Yehuda Lavie on the undertaking to refrain from conducting any transaction, within the meaning of Section 126 of the Land Law, 5729-1969. Deletion of the caveats shall be carried out only under a court order. Respecting the apartments which are not registered at the Land Registration Office, the equivalent transactions shall be performed according to the place of registration.

9. Respondent 1 shall submit to the court file by means of her legal counsel a document confirming that the caveats were registered as set forth above proximate in time to performance of registration of the caveats.
10. Any change or cancellation of the provisions of this abbreviated judgment shall be carried out only by court order.

Handed down today, August 22, 2013  
16 Ellul, 5773

( - )  
[stamp – Esperanza Alon, Judge]

Esperanza Alon, Judge (1)  
[circular stamp – Haifa Family Court  
[Emblem of the State of Israel]  
18]

## Case 2:

Guardianship Case 18541-05-12

In the Petach Tikva Family Court

[ ]  
 Represented by his legal counsel, Advocate Yotam Tolub  
 Whose address for the purpose of service of process is:  
 Bizchut, POB 34510, Jerusalem, 91000  
 Telephone: 02-6521308; fax: 02-6521219

Petitioner

V E R S U S

1. [ ]
2. The Custodian General of the Tel Aviv District
3. Ministry of Social Affairs and Social Services, Tel Aviv  
 22 Jerusalem Boulevard, Jaffa, 68022  
 Telephone: 03-5138200; fax: 03-5138222

Respondent**Abbreviated Judgment**

After the hearing of December 17, 2012 in this motion, it is held as follows:

1. Any transaction in the account of the Petitioner, Mr. [ ] in favor of a third party will require the signature of his sister, Ms. [ ].
2. Any withdrawal of funds from the Petitioner's account of over NIS1,000 a month will require the signature of his sister, Ms. [ ].
3. Deletion of these restrictions will be carried out only by court order.
4. The abbreviated judgment shall be brought to the attention of the branch of the bank at which his account is being managed.

Handed down today: January 21, 2013

[square stamp]

Petach Tikva Courts  
 Magistrates and District  
 January 23, 2013

January 31, 2013

Decision

Case 18541-05-12

Judge Yocheved Greenwald-Rand

The abbreviated judgment is signed and  
 certified

Petach Tikva Family Court  
 I Certify  
 That this copy is a true and  
 correct copy of the original  
 Feb. 4, 2013  
 Date

[circular stamp-  
 Petach Tikva Family Court  
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 chief clerk

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## Case 3:

Family Appeal (Jerusalem) 815/05

Plonit v. Attorney General

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### The Law Courts

Jerusalem District Court

Family Appeal 815/05

Before: The Hon. Judge Yosef Shapira

Nov. 30, 2005

In the matter of:

**Plonit**

Represented by her legal counsel, Adv. A. Schindler

**The Appellant**

VERSUS

**The Attorney General**Represented by her legal counsel, the Ministry of  
Social Welfare, Adv. A. Ishai**The Respondent**

### Judgment

Before me is an appeal on the judgment of the Family Court in Jerusalem (the Hon. Deputy President **P. Marcus**) in Family Case 5070/05 in which a guardian was appointed over the Appellant's property.

### Background

1. The Appellant is a 69-year old woman described as suffering from bipolar affective disorder. In manic episodes she behaves with impaired judgment and restlessness and in depressive episodes she is indifferent, apathetic and disinterested in her surroundings.

The Petitioner has six children and an additional son committed suicide while serving in the IDF. Two of the Petitioner's sons live with her at home while one of them is a ward of court and "Generations Fund" is his guardian. According to the court of first instance, we are dealing with a conflicted family which has been known to the Family Court for over three and a half years.

The Ministry of Labor and Social Welfare, by means of the Attorney General (hereinafter, the "Ministry of Social Welfare" or the "Respondent") filed a motion for the appointment of a guardian for the Appellant's property.

Presented before the Court were two opinions, the one which was filed on behalf of the Ministry of Social Welfare determined that a guardian should be appointed for the Appellant, in light of the complex relationship between the family members, and the second which was filed on behalf of the Appellant, determined that there was no need for such an appointment and that we were dealing with a woman whose functioning and judgment were generally functional. According to the second opinion, the Appellant's condition does not justify denying those freedoms incidental to the appointment of a guardian.

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### **The Appellant's Arguments**

2. The Appellant opposes the appointment of a guardian, as she has opposed since the commencement of the proceeding and contends that her condition does not justify such a significant violation of her freedom, dignity and sensitivities. Furthermore, the Appellant contends that she goes and gets the treatments and therapies needed and fully cooperates with the treatment providers, so that it is even possible to almost completely prevent the periods when the disease intensifies and there is a problem with her judgment.

The Appellant also contends that the appointment of a guardian will seriously harm her relationship with her children, a relationship which despite its complexity is important to her and to them and in which she invests greatly.

A further contention which the Appellant raised is that the court of first instance did not consider determining alternative measures instead of the appointment of a guardian, measures which could have reduced the damage to her. This was despite the fact that this route had been proposed in the opinion filed by the Appellant herself.

The Appellant contends with respect to the opinions which were presented before the court that since these are contradictory opinions which were filed by both parties, the court should have appointed an expert on its behalf before taking such an extreme measure.

To conclude, the Appellant contends that if it is determined that a guardian should be appointed for her, as the court of first instance determined, then a guardian suited to the specific circumstances should be appointed and not the Fund for Treatment of Wards of the State which, according to her, prevents a relationship between a ward of court and the members of his family.

### **The Respondent's Arguments**

3. The Respondent's contentions were specified in his response to the motion for a stay of performance which was filed by the Appellant, and were also heard in the hearing which took place on November 22, 2005.

According to the Respondent, it was determined in the medical certificate which was filed with the court of first instance that a guardian should be appointed for the property in the present case. Furthermore, in light of pressures and influences which could be exerted by any of the members of the family if a guardian was appointed, the court of first instance was correct when it decided that an external guardian would be appointed for her. In light of this, the decision of the court of first instance should remain in effect.

The Respondent contends regarding the relationship between the opinions, that the medical certificate is from the psychiatrist who has been treating the Appellant since 1998, while on the other hand, the opinion filed by the Appellant is an opinion from a psychiatrist who has not known the Appellant for very long.

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Likewise, the Respondent contends that contrary to what the Appellant herself says, who contended that she functions fully and independently, her son's guardian reported that the house is not clean.

### **Deliberation**

#### **Appointment of Guardian**

4. The court of first instance did not specify on which section it relied in its decision to appoint a guardian for the Appellant. As a general rule, a guardian may be appointed under sections 28, 33 and 68(a) of the Capacity and Guardianship Law, 5722-1962 (hereinafter, the "Law").

Section 28 provides:

**"Upon the death of one parent, the guardianship of the minor shall vest in the surviving parent; however, the Court may, in addition to that parent, appoint a guardian for the minor either generally or in respect of matters to be specified by the Court. The same shall apply where one of the parents has been declared legally incompetent or is incapable of carrying out his duties under this chapter or the Court has determined, in an argued decision, that the parent has refrained, without reasonable cause, from carrying out all or part of his aforesaid duties or has been deprived by the Court of his guardianship of the minor or where one of the parents is not known or is not married to the other parent and has not recognized the minor as his child."**

This section is part of chapter two of the Law, which deals with the relationship between parents and their minor children and which is concerned with the appointment of an additional guardian in the place of the natural parent of the child, in the circumstances specified in the section. In the present case we are dealing with the case of a ward of court and not a minor, thus this section should not be regarded as a possible source under which the guardian was appointed.

Section 33(a) of the Law enumerates a list of alternatives in which a guardian is appointed by the court. The sole alternative among those provided in the section, which could possibly apply to the present case is alternative (4), which provides as follows:

**"(a) The Court may appoint a guardian –**

**...**

**(4) For any other person who permanently or temporarily, is unable to look after all or any of his affairs, there being no person authorized and willing to do so on his behalf;"**

The Supreme Court held that an appointment under this section is designed for the purpose of managing the affairs of a ward of court and that an examination should be

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made of whether a factual basis was laid before the court from which it follows that this is a person who is unable to look after his affairs and there is nobody else willing to do so (see, Civil Appeal 445/81 **Elizabeth (Malin) Seabrook v. Salcia Zucker and 2 Others**, 37(3) PD 440; Civil Appeal 1233/94 **Dr. Deborah Cohen v. Attorney General**, *Takdin Elyon* (4)95, 217 (hereinafter, the "Deborah Cohen Judgment"); LCA 3232/04 **Ploni v. Plonim**, *Takdin Elyon* (2)2005, 1685).

The third source for appointment of a guardian is section 68(a) of the Law, which deals with the determination of protective measures and grants the court a general power for this purpose:

**"(a) The Court may, at any time, on application of the Attorney General or his representative or of an interested party or of its own motion, take temporary or permanent measures which seem to it appropriate for protecting the interests of a minor, a legally incompetent person, or a ward either by appointing a temporary guardian or a guardian *ad litem* or otherwise. The Court may also do so on application of the minor, the legally incompetent person or the ward himself."**

This section grants the court general power, which may be exercised in any manner, whose purpose is to protect a legally incompetent person, a minor or ward of court (see, Miscellaneous Civil Motion (Jerusalem) 1237/98 **Plonit v. Almonit et al**, *Takdin Mishpacha* (1)99, 46). Among the options available to the court is also the option of appointing a guardian.

### The Relationship Between the Sections

5. The Appellant was not declared a ward prior to the handing down of the judgment of the court of first instance and it seems that calling her a ward in the body of the judgment derived in consequence of the appointment of a guardian under section 33. In light of this, it is highly doubtful if it is possible to appoint a guardian under section 68 before the declaration of the Appellant as a ward of court.

Notwithstanding this, if it is said that it is possible to appoint a guardian in the present case also under section 68(a), it is necessary to examine whether or not this appointment is contingent on the fulfillment of the conditions in section 33. In the case of a guardian appointed under the provisions of section 28 of the Law, it is determined that section 68(a) provides a response also where the conditions determined in the specific section have not been fulfilled (see, LCA (Haifa) 759/00 **Plonit et al v. Ploni et al**, *Takdin Mechozi* (4)2000, 112). On the other hand, where the relationship between section 68(a) and section 33 is examined, the provisions of section 33 may actually prevail. Section 33 sets forth the cases in which a guardian will be appointed and also incorporates appointment under section 28.

Since this is an appointment under law, this list should be regarded as a closed list and hence the alternative of appointment of a guardian under section 68(a) should be subordinate to the fulfillment of one of the alternatives stipulated in section 33.



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6. As a general rule, the dilemma which the court faces when considering a violation of basic rights which is likely to arise upon the appointment of a guardian and protection of the financial interests of an elderly person is not simple. In the aforesaid Deborah Cohen Judgment, it was stated as follows:

**"When exercising authority, the normative starting point is that it is a basic right of any person – including any elderly person – to protect his dignity, his privacy, his property and his personal autonomy. These rights which have always been central pillars in our system of law, are currently protected in the Basic Law: Human Dignity and Liberty" (*supra*, page 218).**

Before the Court decides on the appointment of a guardian it must examine whether there is no other route which could satisfy the purpose of protection of the affairs of the ward of court without this appointment. If any route is found, the Court must refrain as far as possible from appointing a guardian. Moreover, even if the Court sees fit to act to appoint a guardian, it must examine whether it is actually possible to appoint a person close to the ward and not a person or entity alien to him, who is anonymous as far as he is concerned and he is not interested in being subordinate to him (see, the Deborah Cohen Judgment, *supra*, at page 220). And *a fortiori* where the ward is a person whose judgment is not impaired and he is able to express an opinion on the matter.

#### **From the General to the Particular**

7. It is undisputed that in the Appellant's life there are periods when her illness temporarily intensifies and in these periods her judgment is likely to be impaired and she is likely to be taken advantage of by any of her family members. At these times she requires protection. This situation satisfies the first two conditions in alternative (4) of section 33.

However, it must be asked whether there is not indeed anyone that may be authorized to handle the Appellant's affairs and is also willing to do so. It should be added to this that in the present case this is not a woman with many assets but a woman who owns a residential apartment, half of an additional apartment and NIS 80,000, with over half of this amount being in her son's possession for her benefit. Furthermore, her monthly income is somewhere around NIS 13,000 a month. It seems from all the evidence that there is someone willing to handle her affairs and her son Meir has already been operating in this manner and is in possession of half her money, with her consent. Likewise, the Appellant expressed herself before me and I was impressed that this was a woman of unimpaired judgment, aware of the fact that there are times when her ability to judge is impaired and that she is interested at these times in being helped to avoid the performance of transactions with her assets.

Since there is someone willing to handle the Appellant's affairs, the conditions for appointment of a guardian under section 33(a)(4) are not satisfied. Furthermore, even if the conditions had been satisfied, the appointment of a guardian to permanently take control of the Appellant's assets is not a desirable solution balancing between her constitutional rights and the desire to protect her assets at the times when she requires this protection.



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Even preference of a threatening son over any other is a common phenomenon, and still this does not justify the appointment of a guardian for every aging person. In the present case this is not someone with many assets, as set forth above, and therefore the appointment of a guardian for the Appellant is not proportionate. However, cancelation of the appointment will be subject to restrictions approved also by the Appellant.

### **Result**

8. In light of the above, I accept the appeal and order the cancelation of the appointment of the guardian.

In order to protect the Appellant's assets I order that within 10 days of the date of receipt of the abbreviated judgment, Advocate Schindler shall register cautionary notes on her apartment and on her rights in half of the additional apartment, with the abbreviated judgment constituting an "undertaking to refrain from performing a transaction" within the meaning of section 126 of the Land Law, 5729-1969. Deletion of the cautionary note shall be carried out only by an order of the court. If the apartments are not registered at the Land Registry Office, then equivalent transactions shall be performed according to the place of registration.

In order to protect the Appellant's money, I order the following:

1. Any transaction in the account in favor of any third party will require the signature of an additional authorized signatory who shall be added to her account, at her election, subject to that stated in section 2 below.
2. Any withdrawal of monies from her account in excess of NIS 6,000 a month shall require the signature of an additional authorized signatory.

The abbreviated judgment shall be brought to the attention of all the Appellant's children and to the branch of the bank at which her account is managed.

There is no order for costs.

The bond shall be returned to the depositor.

**Handed down today, 28 Heshvan, 5766 (November 30, 2005) in the absence of the parties.**

**The court office shall send a copy of the judgment to the legal counsel of the parties.**

**May be published without identifying particulars.**

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Yosef Shapira 54678313-815/05

**Yosef Shapira – Judge**

This version of the document is subject to drafting and editing changes.

## Case 4:



**Tiberias Family Court**  
**Before the Hon. Deputy President Ethy Bouhadana**

[ ] *et al*  
 [ ] *et al*  
**Haifa and Northern District**  
**September 2, 2012**

...

**The parties, as well as all those persons present: it is agreed as follows:**

1. That Ms. [ ] no longer requires a guardian for the person and/or property, and the appointment of the Fund for Treatment of Wards of the State shall be canceled immediately.  
 The Fund for Treatment of Wards of the State shall be requested to file a final report to the Custodian General with a copy to Advocate [ ]. It is clarified that the report is audited by the Custodian General.  
 After the filing of the report, the balance available to the credit of Ms. [ ] will be directly transferred by the Fund to Ms. [ ]'s account.
2. Notwithstanding that stated in section 1 and to ensure that the compensation for the damage to be received by Ms. [ ] is indeed invested in order to guarantee her daily living as well as her future, Advocate [ ] is authorized to act in the following manner:
  - A. The compensation monies to be received shall be invested generally in three plans, the first long-term, the second short-term and the third to provide for ongoing needs.
  - B. Advocate [ ] shall submit a list to the Court within 7 days on the needs of [ ] and alongside these needs, all sources to provide such needs, including the national insurance benefit.  
 Within this same period, Advocate [ ] shall file together with the list of needs, bank proposals for investment of the monies.
  - C. It is agreed that the monies to be invested in the short-term plan shall not be wholly or partly withdrawn except with the leave of the Court in a motion to be filed, and a suitable note to be recorded in the account.
  - D. A proposal as set forth in sections B and C shall be sent directly to Advocate [ ] who will properly explain it to Ms. [ ], and within two days of the date of receipt thereof shall file his position with the Court.
  - E. It is agreed that Advocate [ ] is barred from transferring the compensation monies to Ms. [ ] or to anyone on her behalf until the investments have been entered as a judgment. However, to enable [ ]'s needs to be covered from the compensation

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**Tiberias Family Court**  
**Before the Hon. Deputy President Ethy Bouhadana**

[ ] *et al*  
 [ ] *et al*  
**Haifa and Northern District**  
**September 2, 2012**

monies until conclusion of the process, Advocate [ ] shall be authorized to transfer to an account in Ms. [ ]'s name only, the sum of NIS 50,000 only.

F. The Court is requested to enter the investment proposal and the manner of financing Ms. [ ]'s ongoing needs as a judgment.

3. It is requested to enter these consents as a decision.

### **DECISION**

The consents of the parties are entered as a decision.

In light of the consents to cancel the order appointing the Fund for Treatment of Wards of the State as guardian over the property of Ms. [ ] and these consents are based also on a medical opinion, I order the cancelation of the order given on March 4, 2010.

Advocate [ ] is barred from transferring the compensation monies awarded to Ms. [ ] until a judgment is entered on the manner of their investment, except for a sum of NIS 50,000 which Advocate [ ] is authorized to transfer into an account in Ms. [ ]'s name only, for the purpose of covering her needs, including a caregiver.

A copy of this decision shall be sent to the Fund for Treatment of Wards of the State and to the Custodian General in Haifa.

The file shall be brought for my review on September 13, 2012.

**Handed down and notified today, 15 Ellul, 5772, September 2, 2012 in the presence of those persons present.**

( - )

Ethy Bouhadana, Deputy President

## Appendix C

# A supported decision-making service in Sweden

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This appendix is based on a visit to Sweden which took place in April 2013. The purpose of this visit was to become acquainted with an NGO that has been working since 1995 to provide supported decision-making services to persons with psychosocial disabilities. The name of the organization is PO-Skåne: PO is an acronym for Personal Ombudsman, meaning a personal supporter, and Skåne (Scania) is the name of the region in which the organization works.

The trip to Sweden was carried out within the framework of writing this report, based on the understanding that the most meaningful alternative to legal guardianship is providing support services to the person with a disability. We chose this Swedish organization based on its long-established activity, its accumulated experience and the significance of its former chairperson, Mr. Maths Jespersen, in incorporating this support model into Article 12 of the Convention. This appendix will present the background to the development of this service, its guiding principles and the nature of its ongoing activity.

Between 1978 and 1995, Sweden underwent an accelerated process of deinstitutionalization vis-à-vis those with psychosocial health issues. During that period, the number of persons with psychosocial disabilities institutionalized in psychiatric hospitals and mental health facilities dropped from 38,000 to 6,500. However, many problems accompanied the process of departing from hospitals and reintegrating into the community. Despite the development of services in the community, many people found it difficult to integrate into life in their communities. This resulted in increased rates of homelessness, drug addiction and poverty, and the number of people found to be in near-total social isolation increased as well.

In the early 1990s, the Swedish government formed a committee to propose reform in the field of mental health. The committee's proposal placed responsibility for the treatment and rehabilitation of persons with psychosocial disabilities on local authorities (which are referred to as "communities" in Sweden). As a practical outcome of this reform, local authorities were required to develop rehabilitation services which dealt with housing, employment and recreation for persons with psychosocial disabilities. Moreover, the reform included a decision to establish a personal service to assist persons with disabilities in coordinating the different services provided to them and help them to actualize their independence in the community.

In 1995, the Swedish government issued a call for tenders to operate different personal support programs for a three-year pilot period. Out of hundreds of proposals, ten were selected, and the PO-Skåne service was one of them. This service is unique in two key areas: it is not directly



operated by local authorities, and it is managed by two NGOs – one for persons suffering from schizophrenia and the other composed of family members of persons with psychosocial disabilities. PO-Skåne commenced its pilot stage with two Personal Ombudsmen (POs). The service continued after the pilot stage and has expanded. Since the year 2000 PO-Skåne has been regularly providing full service in about ten local authorities through 15 POs who accompany some 250-300 clients. Half of the service is funded by the Swedish government and the other half by local authorities. As noted above, there are other bodies that operate similar support services in Sweden. All in all, there are currently some 300 POs throughout Sweden, providing services to approximately 6,500 persons with psychosocial disabilities.

This report is based, among other sources, on conversations and personal encounters with the founders of PO-Skåne, Messrs. Maths Jespersen and Harald Wilhemson, as well as with the current head of the organization, Ms. Ann-Christine Engdahl; five different POs; a former client of this service; and welfare officials from the local authorities.

## Who is the target population for this service?

Initially, the Swedish government designated this service for persons with psychosocial disabilities with a particularly low level of function, primarily individuals with schizophrenia or an active psychosis. Over the years, the target audience of the program was expanded, and today every person with a psychosocial disability is eligible to sign up for this service. So far, the service has not been extended to other populations, such as persons with intellectual disabilities, persons with autism, the elderly and others.

In order to receive the service, one does not need to prove the existence of a psychosocial disability, nor fill out any official paperwork. As will be detailed below, a person's decision to receive support and to contact the Personal Ombudsman are sufficient to enroll in the program.

## What is a PO?

The Personal Ombudsman (PO) provides support to the client and is committed to the client alone. The PO is not part of the official welfare and health system, nor is s/he part of the local authority in the case of PO-Skåne. The primary role of the PO is to provide support to the person in the following manner:

1. To help the client define his/her needs and wishes and the areas in which s/he requires assistance and support.
2. To support the client in fully realizing his/her rights and in utilizing the services available to him/her.
3. To provide professional and compassionate support.
4. To aid in the development of a support network for the client.

Each PO accompanies 15-20 clients on average. The professional backgrounds of POs are diverse: each holds a bachelor's degree, but among them are social workers, lawyers, graduates of the

humanities, nurses, financial advisers and others. They do not go through preliminary professional training; once they are inducted into the organization, they are accompanied by a veteran PO who guides them through a transition period.

According to the PO-Skåne staff, one of the most important changes a new PO must undergo is to unlearn the concept of “professional responsibility” that is common among people who work in social welfare and rehabilitation. That is, the PO’s role is not to harness the person to rehabilitation goals that are right for him/her. Instead, the PO must begin by listening to the person’s wishes and only then work on supporting him/her. Time and again, PO-Skåne’s members reiterated that the PO must possess dialogical skills and the ability to think creatively. Dialogue is the main tool which allows the PO to communicate with the client. Through dialogue, the client’s needs and wishes are elucidated, and through dialogue the trust necessary for such a process develops. A foundation of dialogue between the PO and the client allows him/her to become more independent.

Creativity is also a necessity for POs. Their responses cannot be limited to pre-existing courses of action; they must be able to create new paths of action suited to the client. According to POs from the organization, the position also requires good interpersonal communication skills, life experience that includes dealing with crises, and openness to the fact that there is more than one way to accomplish things.

## Principles of PO-Skåne’s work

Some principles guiding the organization’s work are enumerated here:

1. Placing the person in the center – The person knows what is best for him/her. Therefore, the starting point must always be the person’s knowledge, experience and abilities.
2. Relinquishing all power dynamics – The POs are not part of the official welfare system and therefore do not possess any power or authority over the clients with whom they work. This is also the reason why PO-Skåne does not have any permanent offices. The PO works from home and meets the client in a neutral location (coffee shops, public parks) or in the client’s place of residence.
3. Flexibility – POs work 40 hours a week, from home and in the field, without regular hours. It is often during the evening hours or on the weekend that their clients request their assistance.
4. Inverting the pyramid – The immense bureaucracy and the increase in the number of services have created a situation in which multiple bodies are responsible for caring for people with a psychosocial disabilities, each with regards to a specific aspect (social insurance, employment services, the local authority and welfare ministry workers, the healthcare system, etc.). Thus, when rehabilitation plans are created, each body develops its own plan of action. Even when the different bodies attempt to coordinate, the separate considerations of each service provider are afforded decisive weight in determining the substance of the plan. The result is that the person is not at the center of the plan and is often required to conform to the needs of the pre-existing programs. PO-Skåne’s service inverts this pyramid: it first determines what the client wants, and from there proceeds to examine how the various bodies and government agencies can smoothly integrate in order to make sure his/her needs are met.





## The process

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The support process is composed of several stages:

1. Initial contact – Many people with disabilities contact the service after former clients recommend it to them. The process can also be initiated by relatives, professionals or the interested clients themselves who have read informational brochures or heard about the service. Contact is directly established with the local PO, whose information is disseminated on the organization's website and in their brochures.
2. Meeting to set expectations – The first meeting is designed to explicate the nature of the service to the client: what it includes and what it does not include. Based on this meeting, the client will decide whether s/he is interested in commencing the process of receiving support.
3. Defining wants and needs – The client presents his/her needs and wishes to the PO, and the PO is also free to add relevant suggestions if s/he deems this necessary. The client, though, is the one who ultimately decides what to include in his/her support plan. Sometimes a client may seek to achieve a goal that the PO perceives as misguided. In such a situation, the POs stated that they would share their opinion with the client but would also promise to support them in facing the consequences of their decisions. They further noted that progress along any given path – even if the client will later find it to be misguided – still helps him/her advance.
4. Drafting an agreement – The client and the PO draft an agreement together to outline their future activity. There is no fixed format for the agreement, and it is always subject to change. The agreement is composed in the client's words and in accordance with his/her wants and needs, which they define together through a shared dialogue. The agreement can be as detailed or general as the client wants and delineates the obligations of both parties.
5. Putting the agreement into practice – This stage can last anywhere from a few weeks to many months, depending on the nature of the objectives and on the client's availability to make progress on the plans.
6. Reviewing achievements and results – Every few meetings, the PO takes out the agreement. Together, the client and the PO examine how far along they are in their plan and what objectives still lie ahead of them.
7. Concluding the support process – The client determines when the process has ended. This can be done explicitly or by gradually reducing contact with the PO.

These stages are the external manifestation of the internal process which the client and the PO go through. This process includes building trust, generating motivation, encouraging action ("activation"), reviewing achievements, and bringing the support process to a close.

In the early days of PO-Skåne, the support process was significantly lengthier than it is today. It had no time constraints whatsoever and in practice lasted for several years. Today, even though the service still runs without time constraints, it rarely lasts more than a year and a half and generally runs for less time. The client is the one to terminate the support process. The termination is often the result of a "fading out" process, without any formal closure. The client can always reestablish contact, whereupon the support process will begin anew. Should the person request it, s/he may take a "timeout" from the support process, and if the person agrees to it in advance, the PO may re-contact them after a few months have passed.



## Areas of support with examples

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The support process may encompass several areas, in accordance with the client's wishes:

1. Caring for the client's basic needs. This can include finding housing, helping the person support his/herself financially, and protecting him/her from exploitation.
2. Providing support in receiving adequate medical treatment, which may include psychiatric care, general medical treatment and dental work.
3. Facilitating access to the full array of social welfare and rehabilitation services to which the person is entitled, if s/he so desires.
4. Managing financial affairs, such as debt repayment.
5. Connecting the person to formal and informal support networks in his/her community.
6. Helping the person restore or establish a social network that includes parents, descendants, extended family, and friends.
7. Assistance in finding a meaningful occupation, such as studying or working.

In most cases, the support process will not attempt to resolve all issues at once. It instead focuses on a few objectives that are important to the client and then gradually advances to new goals according to his/her pace. Many times, in the first stage the client focuses on finances and housing. The role of the Personal Ombudsman is to listen to the client and to adjust to the client's wants and needs. This approach is based on two understandings: firstly, that people will genuinely commit themselves to plans that are based on their wishes; and secondly, that rehabilitation must be founded upon the person's own wishes and not on the wishes of those around them. Most of the POs I met said that they dedicate half of their meeting time to general conversations and half to making progress towards concrete goals.

The following are examples of problems or wishes expressed by clients and the manner in which the POs addressed them:

1. **Objections to taking medications** – When a client resists taking medication, the PO might suggest joining him/her in a meeting with a psychiatrist in order to help him/her make an informed decision. The PO helps the person be an active partner in choosing a medication plan (if they do so), thereby further increasing the odds that that plan will succeed.
2. **Confronting psychosis** – One of the POs provided guidance to a person who claimed to possess divine knowledge about how to save humanity from horrific disasters. Until he received support from his PO, this person was forcefully institutionalized every time he raised this topic. The PO tried to think together with him about this matter and about his desire to save humanity. The PO suggested that he write a letter containing his detailed proposal to save humanity to an academic institution that deals with ecological and environmental matters. The client wrote down all of his suggestions and even received a thank-you letter from the institution. Instead of attempting to fight the issue, the PO tried to help the person live in peace with it.



3. **Irresponsible financial conduct** – One of the POs supported a person who insisted that he was the King of Sweden and that he owned several apartments, including the one in which he lived. He thus refused to pay rent to his landlords. The PO entered into dialogue with the person, and without objecting to the claim itself, pointed out the fact that this person had no legal documentation to prove his ownership. Consequently, without giving up his claim to the throne, he agreed to pay rent until he could produce documents proving otherwise.
4. **Small but significant support** – Each PO has a budget, which s/he can use as part of the support process. For example, one client told his PO that one of his greatest dreams is to sit in a coffee shop. The PO invited him for his first cup of coffee and fulfilled this simple dream. Another PO bought his client a CD for his birthday; the client said it was the first time in years that he had received a birthday present.
5. **Breaking the law** – One of the clients asked for help in filling out a form to receive a welfare benefit. He had filled out the form with false information. The PO informed him that he could not assist him in filing an illegal request with false information. Through the dialogue between the two, they agreed that if the person went ahead with filing the request, the PO would not assist him in this matter but would continue to assist him with the rest of his affairs.
6. **Suicide and life-threatening situations** – During the course of my research, POs brought up several dilemmas regarding suicide and intervention in life-threatening situations. In one instance, a client informed his PO that he intended to commit suicide and went as far as inviting the PO to his farewell party. The PO attended the party and did everything that he could to convince the client not to kill himself. When that effort failed, he brought in the client's psychiatrist, who issued an order for forced institutionalization. In another instance, a PO came to a client's house after the latter had not answered his calls for some time. When the client did not open the door, the PO called the police, concerned for his own safety. The police broke down the door and discovered that the client had fallen down the stairs and had been lying there for three days unable to move.
7. **Making friends** – One person told his PO that he had difficulties dealing with his loneliness and lack of friends. The PO offered to help him write letters to old friends with whom he had lost touch, in order to try to reestablish contact with them. Thanks to these letters, the client reconnected with two of his former friends.
8. **Reconnecting with relatives** – The connection between clients and their family members is often severed entirely, and at times comes with tremendous baggage. Due to the PO's involvement, the family can relinquish the role of caring for and treating their family member with psychosocial disabilities and return to simply being his/her relatives. This allows relatives who have distanced themselves to restore their contact with the person, and build on it from there.



## Legal aspects of the service

Since the PO service is a type of personal support, it does not require a legal definition or specific legal arrangements in order to operate. Because the support process entails contacting third-parties (welfare services, psychiatrists, local authorities), the client grants power of attorney to their PO. Despite the Swedish government's initial intention to embed the service in law, after reviewing several models, the service has never been written into law.

## Professional ethics

The ethical principle guiding the POs is that they are not working on their own behalf but rather on behalf of the client. PO-Skåne has ethical guidelines (the main principles of which are listed at the end of this appendix) which describe their commitment to confidentiality and promise that the POs will be completely loyal to their client and refrain from exerting any external influence on him/her. The ethical dilemmas of this role appear to be manifold. For example, concerning life-threatening situations: generally, most of the people I spoke to stated that in the case of a threat to life and limb they would act contrary to a client's wishes in order to protect the client's life. Here, too, the importance of dialogue was brought up. Thus, for example, over the course of the regular meetings, the POs often discuss with their clients the question of whether one should prevent a person from committing suicide by informing a psychiatrist, who would initiate a process of forced institutionalization. Maths Jespersen stated that he used to ask clients whom he supported not to tell him if they wish to commit suicide, as he would try to stop them. PO-Skåne further emphasized, with regards to the ethical aspect of their work, that POs are not required to act against their conscience and that they may tell a person that they cannot support him/her in a matter that runs contrary to their conscience.

## Other roles of the PO

Some 70% of the PO's time is dedicated to accompanying and supporting up to 20 clients. At the same time, the POs conduct several other activities: 6% of their time is designated to initial contact with people who have not yet decided whether they want support or not. Additional time is designated for staff meetings, administrative work, and consultations with other POs. The POs also play an important role in promoting social change based on their experience in the field. Several problems with the county's mental health services, for example, were identified through PO-Skåne's work: opening hours that were not suited to the needs of the relevant population; a lack of documentation of medical prescriptions by doctors in hospitals; the absence of a defined goal in the preexisting treatment plan; and a lack of response for the population during the evening hours. All of these issues and more were raised by POs during roundtable meetings attended by representatives of the local authority, the welfare agents and relevant service providers.

## Legal guardianship and the PO

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In the Swedish legal code, there are two tools related to a person's legal capacity that are worth understanding:

1. Partial guardianship (favalta) – This is the most severe restriction imposed on an individual, particularly with regards to financial affairs. A person under partial guardianship cannot sign contracts or manage a bank account, and all of the person's financial affairs are managed by his/her legal guardian (the person retains the right vote in elections, resist medical treatment and make decisions in personal matters). The guardian can be a relative or a person who provides this service as a secondary job (such as a social worker, a psychiatrist, a lawyer and so on) for a fee determined by the court.
2. Trusteeship (goodman) – The role of the trustee is to lend support to a person with a disability in his/her financial affairs. The trustee may assist the person in arranging for automatic direct withdrawals, managing a bank account or repaying debts. The trustee is not authorized to sign on the other person's behalf. A person with a trustee can continue to manage his/her bank account and enjoy full legal capacity, while receiving the help and financial guidance of the trustee. However, the goodman has the ability to restrict the person from performing certain financial transactions.

These two legal mechanisms (being a favalta or a goodman) require a court appointment. They fall under the supervision of the Public Guardian and are performed by private citizens. The majority of the PO-Skåne representatives that I spoke to do not feel that the service they provide is intended to replace the role of the guardian or trustee. They cited several reasons for this:

1. PO-Skåne's services are time-restricted, while these two positions are not. Many people require financial guidance and even financial limitations over a long period of time, which the PO cannot provide.
2. It is often necessary to impose restrictions on the person, yet the essence of the PO service is that it is based entirely on the person's wishes and on the POs lack of power or authority over the client.
3. The PO service carefully refrains from directly dealing with money, while a goodman or a partial guardian deals with financial affairs as per the legal definition of those two terms.

In fact, according to most of the members of the organization, the PO must assist the person in attaining the appointment of a goodman or even a legal guardian, should that person indeed require assistance or restrictions in financial affairs.

However, if the person wants to pursue something to which the guardian objects, the PO may assist the person in dealings with his/her guardian. This could be the case if a person wishes to live independently in the community contrary to the position of his mother, who was appointed as her son's legal guardian. With the person's consent, the PO can meet with the mother and try to convince her to respect her son's wish. If a person has criticism of his/her guardian's conduct, the PO can assist the person in exercising his/her rights, whether by contacting a supervising body or petitioning the court with a request to replace the guardian or to limit the scope of the guardian's appointment.

## Change generated due to PO-Skåne's service

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PO-Skåne's service has been active for thirteen years now. Its establishment was guided by several evaluation studies – one after three years and another after six years – which concluded that the service is highly effective in several respects. One study that followed 300 clients discovered that after two years of receiving support, the number of days the persons spent in psychiatric hospitalization dropped on average from sixty days to four on a per annum basis. Another study, which examined the financial effects of the service, concluded that it generates a savings rate of 1 to 17; that is, for every Swedish krona invested in developing support services, 17 kronor were saved on hospitalization, psychiatric treatment, lost workdays of family members and other expenditures. 70% of those receiving support services never get to a point in which they face psychiatric institutionalization. Medical evaluation for PO-Skåne's clients has become more accurate due to the involvement of POs with the medical establishment. Furthermore, local authorities have shown an increased sensitivity to the needs of this population thanks to the involvement of the POs.

## Conclusion

A supported decision-making service has been in existence in Sweden for over thirteen years. It was founded long before Article 12 of the Convention on the Rights of Persons with Disabilities was drafted, and it does not perceive itself as an alternative to legal guardianship. However, it serves as an important example of the feasibility of a supported decision-making service and the significant impact such a service can have on the lives of persons with psychosocial disabilities. At this point in time, we must further examine how such a service could be operated for persons with other disabilities, how it could deal with all areas of life (including financial ones), and how it could serve as an alternative to legal guardianship.

## Main ethical guidelines for employees of PO-Skåne

- You must, in your work, assume that the individual has knowledge, experience, ability and willingness to develop, change and lead their own lives. It is always the individual who determines their own life and actions and is responsible for them.
- You should be religiously and politically independent in your work. You have no right to influence the client based on your own beliefs or political opinions.
- You should display compassion and respect for the individual.
- You should always have a personal mandate from the client for courts, government agencies, healthcare providers and so on. The power of attorney must be drafted in accordance with PO-Skåne's confidentiality agreement.
- You are bound by the confidentiality of data.
- You must keep documents relating to the individual in such a way that they can not become

available to unauthorized persons. The individual should always have full access to all documentation relating to their case. With the completion of your service, all documents of the case should either be submitted to the client or destroyed.

- You may not use alcohol or other drugs in connection with your role.
- You should always stick to the facts and accomplish your mission in accordance with applicable laws and regulations.
- You must make a clear distinction between yourself as an individual and your professional role as the client's advocate.
- You should be cautious in receiving gifts from clients and their families.

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## Appendix D

# Perceptions of guardianship, autonomy, and supported decision-making by persons with intellectual disabilities, persons with psychiatric disabilities and parents of persons from both groups

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## 1. Background

The 2006 UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by Israel on September 10, 2012, is meant to promote, protect and ensure the full and equal enjoyment of human rights and basic liberties by persons with disabilities, and to ensure their dignity (Article 1). The basic rights of persons with disabilities, as described in the Convention, include dignified treatment, non-discrimination, full participation in society, equality of opportunity, accessibility and autonomy (Article 3).

This study focuses on the right to autonomy and independence, as expressed in the right of every person with disabilities to participate in society, to enjoy self-determination and to make decisions about his/her own life. Support for the value of autonomy is reflected in Article 12 of the Convention, which maintains that states must recognize persons with disabilities as having legal capacity equal to that of persons without disabilities, in all areas of life. In order to enable persons with disabilities to realize their legal capacity, Article 12 calls for the use of appropriate measures – primarily supported decision-making – in order to enable real choice.

Many persons with intellectual disabilities or psychiatric disabilities, both in Israel and throughout the world, have had their legal capacity revoked by the appointment of a guardian, despite their fundamental right to self-determination and autonomy. Guardianship is a legal mechanism by which a decision-maker is appointed in a person's stead, who, for intellectual or psychiatric reasons, has been deemed unable to handle his/her personal and/or financial affairs (Gibson, 2011). Article 33(a) of the Israeli Legal Capacity and Guardianship Law determines that a court of law is authorized to appoint a guardian and restrict a person's legal capacity in cases in which





the person “cannot, either permanently or temporarily, handle his/her affairs, in whole or in part, and there is no person qualified and willing to handle the affairs in his/her stead.” In practice, in many cases, the guardianship appointment is all-encompassing and systematic. For example, the diagnostic committee discussing the case of a person with intellectual disabilities usually automatically recommends that a guardian be appointed when the person reaches age 18 (Sa’ada, 2012). Similarly, the Israeli Ministry of Welfare and Social Services instructs that a guardian must be appointed for all persons with intellectual disabilities as a pre-requisite for their receiving housing services (Israeli Ministry of Welfare and Social Services, 2003).

The guardianship mechanism does not reconcile with a person’s right to self-determination and autonomy for several reasons. Today, the world is slowly coming to recognize the right of persons with intellectual or psychiatric disabilities to make decisions about their lives with assistance and guidance. Many studies have shown that this is indeed possible (Ferguson et al., 2010; Wong et al., 2000). Evidence of this possibility can be seen in the existence and activity of self-advocacy groups that encourage and assist persons with disabilities to express their needs and desires (Garcia-Iriarte et al., 2009). Similarly, in various countries (Britain and Canada, among others), support networks are being developed that are meant to assist persons with intellectual, communication, or psychiatric disabilities in making decisions about their lives.<sup>5</sup> In other words: it is possible, given the appropriate supports, to replace guardianship as it is implemented today, so that persons with disabilities can enjoy full legal capacity and make decisions over their own lives.

With the ratification of the CRPD, the question again arises of the suitability of the Israeli Legal Capacity and Guardianship Law in its current format, as well as the suitability of accepted practice in Israel, to the vision on which the Convention is based, and to Article 12 in particular. This is the basis for the present study, which conducts a preliminary mapping and evaluation of attitudes towards the institution of guardianship and its alternatives. The study’s value lies in its viewpoint, which is that of the major stakeholders: persons with intellectual disabilities and persons with psychiatric disabilities. At the same time, this study evaluates the attitudes of parents of persons in these two groups towards guardianship, independence and the alternatives being promoted today.

5 The following are examples of supported decision-making programs in different countries:  
<http://www.ont-autism.uoguelph.ca/STRATEGIES7.shtml>    <http://mdac.info/en/olivertalks/2013/05/21/building-inclusive-communities-through-circles-support>  
<http://www.iidc.indiana.edu/?pageId=411>  
<http://www.po-skane.org/ombudsman-for-psychiatric-patients-30.php>



## 2. Research methodology

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### A. Study participants and research procedure

The research is based on focus groups conducted with four groups of stakeholders: persons with psychiatric disabilities, persons with intellectual disabilities, parents of persons with psychiatric disabilities, and parents of persons with intellectual disabilities. Each group of stakeholders participated in a separate focus group. The criteria for inclusion in the study were a mild to moderate level of intellectual disability, allowing for verbal communication in the group, and knowledge of the Hebrew language. The participants were recruited through programs which provide services to persons with the aforementioned disabilities, including housing and employment programs, community mental health clinics, and organizations for parents of persons with psychiatric disabilities. Some of the parents are their children's guardians and some are not.

In total, 33 people participated in the study in seven focus groups. The specific breakdown was two focus groups of persons with intellectual disabilities (n=8), two focus groups of persons with psychiatric disabilities (n=9), one focus group of parents of persons with intellectual disabilities (n=8) and two focus groups of parents of persons with psychiatric disabilities (n=8).

Annex A and Annex B summarize the demographic data about the study's participants. Eleven women and six men with disabilities participated in the study, as well as ten mothers and six fathers. The age range of the adults with disabilities was between 19 and 64 (an average of 35.23, standard deviation=14.48) and the age range of the parents was between 46 and 87 (an average of 62.87, standard deviation=9.29). All of the persons with intellectual disabilities had a guardian and all the parents of persons with intellectual disabilities were their children's guardian (aside from one adult and his mother, the parents and adults in the groups were unrelated to one another). All of the persons with psychiatric disabilities were without guardians. Among parents of persons with psychiatric disabilities, two couples of parents (meaning four out of the eight) were their children's guardians, and four parents were not guardians.

### B. Research tools and data collection

Group interviews were conducted with the help of an interview guide, which included questions meant to examine the manner in which the institution of guardianship is implemented today in Israel. Each meeting included a short presentation of the subject matter and the participants' introducing themselves, followed by the discussion and a conclusion. The facilitators were two social workers who asked guiding questions and let each participant respond. The following topics were discussed in the groups: perceptions on guardianship; the nature of the relationship between the person with disabilities and those with whom s/he interacts; obstacles to acting and implementing decisions; familiarization with alternatives to guardianship (supported decision-making); and opinions about these alternatives.

### C. Data analysis

All of the focus groups were recorded and transcribed. Content analysis was used, which allowed for systematic coding of the content raised in the focus groups. Partially-focused methodology

was used; researchers built their analysis on criteria for four *a priori* themes, which they chose based on their knowledge and on literature in the field, while retaining maximum flexibility in examining the content raised in the focus groups. Four major themes were selected for particular focus during content analysis: 1. Perceptions of guardianship; 2. Perceptions of independence of persons with disabilities; 3. Decision-making in financial matters; 4. Perceptions regarding guidance and support (supported decision-making). Two researchers read the transcriptions repeatedly and identified quotations and major categories for each of the themes. This analysis was first conducted separately for each focus group and afterwards for all the groups together while identifying points of similarity and differences in the perceptions of persons with disabilities as opposed to parents, between the two groups of persons with disabilities and between the two groups of parents. The researchers discussed the differences evident from the encoding as well as their understanding of the categories and themes throughout the analysis process until they were in general agreement.

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### 3. Findings

In this chapter, we will present the primary findings from the dialogue regarding the participants' perceptions of the institution of guardianship and guardianship's impact on them, according to the four major themes, with supporting quotations included.

#### A. Perceptions of guardianship

The participant groups were differentiated by their perceptions of the reasons that lead to the appointment of guardians and also by their perceptions of the roles attributed to guardians. Some of the participants ascribed importance to the protection from harm as the primary responsibility of the guardian, while others noted that the guardian's role encompasses handling all of the person's affairs and needs. We will first present the perceptions of persons with disabilities and afterwards those of the parents.

Persons with intellectual disabilities did not completely understand the reason for which they had a guardian appointed. This lack of understanding was primarily due to the fact that in most cases, persons with intellectual disabilities do not receive any explanation on the guardianship appointment process, the reasons for the appointment, the responsibilities of the guardian, or their rights vis-à-vis the guardian. Often, persons with intellectual disabilities perceived guardianship as something an external party imposed upon them without having consulted them about their desire for a guardian or about the selection of the guardian, as evident from Yehuda's words:

*Yehuda: Now, because my mother went to... What is it called? To court, I don't know how this whole thing happened, how it started.*

*Facilitator: Your mother applied to the court?*

*Yehuda: I think so. Or the hostel did, or I don't know how it all started, the...*

*Facilitator: Do you know why this changed? What happened?*

*Yehuda: Maybe that's what they decided, all the... Or the counselors maybe decided, or the directors of the hostel, I don't know how...*

For most of the persons with intellectual disabilities, one of their parents was appointed guardian, and it is evident that these adults had a difficult time differentiating between the responsibilities of their parent and those of a guardian. For example, persons with intellectual disabilities thought that they must always listen to their parents by virtue of their being parents and not only due to their role as guardians. In addition, most of the persons with intellectual disabilities perceived their parents' guardianship as unlimited and involved in all areas of their lives. They provided examples of their parents' intervention in situations in which the person with disabilities might have been harmed, primarily in the financial field, as well as in situations in which they were not exposed to harm. The decisions in which the parents intervened spread across a wide spectrum, from clothing to employment to housing to relationships and weddings (some of the persons with disabilities were not interested in this type of intervention, as will be described in Chapter 3.B.).

The weight of the guardian's intervention was also expressed in the fact that most of the persons with intellectual disabilities felt that they needed and were even dependent on their guardian. In



this group, only one participant expressed a desire not to have a guardian, while the rest of the participants, including those who considered themselves capable of independence, felt that they needed a guardian. The majority of the participants perceived the guardian's decisions as for their benefit and two even expressed an uncompromising position that guardianship is always justified, and thought that there is no reason to appeal the guardian's authority or decisions. An example of this from the participants is their response to a vignette in which a mother who was appointed a guardian decided alone to transfer her son to a different workplace even though he was satisfied with his work. Five of the six people who responded attributed more weight to the mother's opinion and thought that the son should listen to his mother. Naveh, a young man with intellectual disabilities, explained, "I would intervene in this, I must intervene in this. The mother is the one who decides where to place her son, where to place, what's good for him." A more extreme example is Sophia's reaction. Despite the fact that she meets her guardian very infrequently (the guardian is from an outside organization), she, nevertheless said, "For me, Sarah [the guardian] decides, and I won't get mad. She is the guardian and she decides." However, when the facilitators explained to the participants that they have the right to express a range of views about guardianship, about half of the participants toned down their views and said that they desire to be permitted independence in making decisions in various aspects of life (this matter will be included in the discussion of the next theme).

Persons with psychosocial disabilities addressed the role of the guardian in a more limited manner as none of them have guardians. The primary emphasis of this group was the role of the guardian in preventing harm, particularly in financial matters (this issue will be discussed extensively below). This group was interested, not in guardians, but rather in a supporting figure for the purposes of advice and as a guiding hand, or as a figure to mediate with outside parties. For example, Isaac, one of the persons with psychosocial disabilities, said:

*If I was wasting my money endlessly, in this situation I would want a guardian or someone like that... I could give an example that I bought a tank top for 500 shekels [approximately US \$135], I have never worn it since. It's still in its plastic bag and I would have wanted my mother or someone to have been there with me and told me, "Isaac, 500 shekels? And besides, you'll never even wear it..." I really regret that I did this and didn't consult anyone else, like my mom for example.*

When the persons with psychiatric disabilities were asked who they would like to consult in a time of need, they wavered between the desire for the involvement of their parents or other family members and the involvement of an outside figure. One person with psychiatric disabilities, Guy, said that he would like support from his parents, "I would choose a family member, because with an outside figure... You don't really believe that you can trust him, or that he sees completely eye-to-eye with you." Two persons with psychiatric disabilities expressed a desire for external assistance from a friend, co-worker or supportive organization. Isaac explains, "I usually do not listen to my mother. I really prefer an outside person, even just a close friend or something, someone external, yes. Mom? No, because then I would give her hell."

A shared point for most of the persons with psychiatric disabilities and half of the participants with intellectual disabilities was the experience of the guardian's role as a restrictive, and even harmful, figure. Even though none of the persons with psychiatric disabilities had a guardian,

they addressed the attempts of others to influence their lives against their will, which became restrictive. Half of the persons with psychiatric disabilities described situations where a different person, such as a co-worker, doctor or other authority figure, applied sanctions or made decisions on their behalf, leading them to feel helplessness and anger. This is evident from the statements of one of the persons with psychiatric disabilities, Natalie:

*My wanting to move forward does not mean that I need to be punished. Maybe I need to be told off, you know, telling me off first of all, and not punishing me right away. It's a bit too many restrictions. Sometimes I think that people don't even relate to me because I have crossed the line too many times.*

When we go on to examining the positions on guardianship of the parents' group, a clear congruence emerges between the parents' opinions and those of the persons with disabilities. Parents of persons with intellectual disabilities saw guardianship as a direct continuation of their responsibilities as parents and of the care given to their children until age eighteen as natural guardians, without a court order. The blurred lines between parenthood and guardianship were clearly evident.

Moreover, in the group of parents of persons with intellectual disabilities, there were those who maintained that there is no need for appointing a guardian, because the responsibilities involved are their inherent rights as parents. Some of the parents in this group also expressed anger and offense that the State, in their view, requires them to be appointed to a role that they have always filled anyway and will continue to fill. At the same time, the majority of the parents were very concerned that the State or some other entity would take away their role as guardian, and this concern led them to take guardianship upon themselves. In light of the connection made between parenthood and guardianship, these parents were afraid to even imagine a situation in which their guardianship would cease. Similarly, these parents expressed great concern that there would not be a person who takes their child's affairs upon him/herself after the parents' death.

Whether the parents resented the obligation to be appointed guardian or whether they accepted the obligation with a certain amount of understanding, in practice all of the parents of persons with intellectual disabilities were appointed their child's guardian so that they could continue being involved in all aspects of their child's life. These parents added further obligations to the guardianship role, including protecting the child from harm as well as extensive involvement and supervision of most of the aspects of the child's life even in adulthood. Moran, mother of a person with intellectual disabilities:

*If, God forbid, there is some kind of external intervention that the parent or the guardian must decide to do or not, and sign, then we sign if we want to... Like surgery, not on us, or anything else, like purchasing something. We are guardians of everything from the toenail to the purchase of I don't know what. For his body, his property – everything connected to the same person.*

Parents of persons with intellectual disabilities emphasized the importance of their close supervision and oversight of their child and his/her daily routine as part of their obligations as guardians. As they explained,





*Tomer: Life-threatening dangers, from electrification, touching electricity, they aren't aware, he could go and do things... My son decided one day that he was fixing some light fixture in the house, he opened it, and I came back from some place and the power was out for the whole house, until I understood that he was trying to change a light bulb. It doesn't have, like, they don't have...*

*Facilitator: But, Tomer, in this situation, how did your being a guardian help you?*

*Tomer: Just an example, if I'm in a place that I can look at him all the time, yes, with a microscope at his daily routine, activities, at these things, it's completely different. Completely different.*

*Adi: You can tell him, "Go over there, do this..." and he'll do it, whatever you say.*

*Tomer: You can influence him in a second. For example, even in clothing, if he goes someplace very cold and didn't wear a jacket, he was wearing a short tank top, you need to intervene.*

*Bracha: But how is this part of guardianship? I don't understand.*

*Reuben: It is part of it.*

While parents' involvement in the lives of persons with intellectual disabilities is intensive and regulated by guardianship, involvement by parents of persons with psychiatric disabilities is much more limited. Whether they are appointed guardians or not, their involvement is usually limited to protecting their child from harm or at a time of crisis or extreme situation. All the parents of persons with psychiatric disabilities who were appointed their child's guardian filled the role with a heavy heart, only after reaching the conclusion, with the help of professionals, that the appointment was necessary and they had no other options. Yossi, a father of a person with psychiatric disabilities, was appointed guardian on personal matters only (and not guardian of the property) because there was a need for immediate intervention in dental care. Yossi relates that the line between intervention and non-intervention is not always clear, and that he dedicates a significant amount of thought to only intervening when needed:

*True, the line is very fine. Very, very fine, and it's all very sensitive and this problem is so complicated, it's endless. Very simply, it is endless and sometimes there is no answer and no solution and sometimes when I start to think about, for example, writing a will or guardianship, etc, I don't reach any solution. And sometimes I tell myself, I'm not reaching a solution? That's also a solution, I'll leave this alone.*

The blurred line between parenthood and guardianship was less prominent among the parents of persons with psychiatric disabilities. Two parents of persons with psychiatric disabilities who do not serve as guardians for their children and two who do felt that the service that they provide





to their children stems from their roles as parents and is no different in essence from the role that they would fill under a legal guardianship order. In contrast, a couple who are parents of a person with psychiatric disabilities, who do not serve as guardians, and a couple who do serve as guardians both preferred that the role of guardianship be filled by a third party, with preference for a person with familiarity with services and laws and with legal qualifications. Such a person, in their minds, can serve as a supporting bridge between the parents and the child, and can intervene in a time of crisis when the parent does not manage to help his/her child and the child rejects the parents' intervention. A parent of a woman with psychiatric disabilities expressed this well:

*When she is in a period of decline, she is not willing to listen to anyone, not to us first of all, and the whole world hates her because it's clear, it's black and white, the whole world is black and white, there are no colors in between. She can harm herself, cause herself harm, it's a moment of crisis and then the guardian needs to step in. Let's say there was a guardian, then we have no need to play the role of parents because she doesn't want us, and I can't say, "I do want to be your father," because I am not her father and Rivka is not her mother at this stage.*

Parents from both groups—intellectual disabilities and psychiatric disabilities—felt that guardianship would allow them to protect their children from potential harm. However, among parents of persons with intellectual disabilities, the concern about harm spread over a wider variety of fields—for example, the fear of small daily dangers such as wearing inappropriate clothing. While both parents' groups addressed potential financial and physical/medical harm, there was a difference between the types of concern. Parents of persons with intellectual disabilities were concerned that their children could be exploited by others, while parents of persons with psychiatric disabilities feared life-threatening dangers such as suicide. Quotations from two mothers will demonstrate these differences:

*I'll give an example, something that I have feared. We have a neighbor who tried all the time to convince Shlomo to go learn how to drive. If I was not his guardian, he might have given him money, "Teach me to drive." What would I have done... I'm saying, if he had sole judgment. If I was not his guardian, Shlomo could have gone and written him a check, Shlomo knows how to write a check. He could have written him a check, does that seem right to you? He could have given him 100 shekels [approximately US \$25], "Teach me to drive." (Bracha, mother of a man with intellectual disabilities)*

*Because he was hospitalized and isn't aware of the situation and how important it was to undergo those treatments [dental treatments], so we as parents, of course together with the doctor at Tel Hashomer [Hospital]'s judgment, who examined him at the oral and maxillofacial clinic for high-risk patients, and with this letter and consulting the doctor treating him, on his advice, we went with the guardianship of the person, and thank god, he underwent treatment. If we were not his guardians it would have been*

*impossible, he definitely would not have signed and not been aware, so we signed off on the anesthesia and they did the treatment. (Maya, mother of a man with psychiatric disabilities)*

The conclusion of the primary perceptions of the four groups (persons with intellectual disabilities, persons with psychiatric disabilities, parents of persons with intellectual disabilities and parents of persons with psychiatric disabilities) regarding the role of guardianship, is that it seems that person with intellectual disabilities feel dependent on and desire guardianship, while persons with psychiatric disabilities prefer only a supporting figure. Parents of persons with intellectual disabilities see guardianship as a continuation of their parental role, including intervention in all areas of life, while the parents of persons with psychiatric disabilities expressed a desire for much more limited involvement. The study also showed that the feelings of persons with intellectual disabilities and parents who are also guardians derive from two reasons: firstly, in most cases, the parent and guardian are in practice one figure, and there is continuity between the role of a person as a parent and as a guardian when the child reaches age 18; and secondly, parents of persons with intellectual disabilities have the perception that their guardianship is critical in order to advance their child in the full range of aspects of his/her life.

## B. Perceptions of independence

A major theme that came up in all focus groups was the participants' perceptions of the independence of persons with disabilities. Their perception of independence was for the most part dictated by their perceptions regarding persons with disabilities' ability to make independent decisions in various aspects of their lives. While persons with disabilities expressed largely similar opinions regarding their perceptions of independence, the large difference between the two parents' groups on this issue was prominent.

Persons with intellectual disabilities, and particularly persons with psychiatric disabilities, placed great importance on their independence and degree of control over decisions about their own lives. The difference between the two groups of persons with disabilities was the process that the participants had gone through during the focus group until they expressed the level of importance that they place on independence. Persons with intellectual disabilities at first refrained from talking about their desire or need for independence, and some even hesitated to answer questions connected to independence. Only at a later stage did they begin talking about the areas in which they valued their independence. For example, some of them spoke about the important roles that they fill in the housing program in which they live as an example of their ability to make decisions. On the other hand, the perception of the need for and high value placed on independence was already prominent in the early discussions with the focus group composed of persons with psychiatric disabilities. This may indicate that this group ascribes especially great importance to the value of independence. However, this appreciation for independence was stated alongside the conviction of members of this group that during times of crisis, independence must be waived and responsibility for decision-making transferred to a person who can be trusted. In addition, the majority of the participants with disabilities (all of the persons with psychiatric disabilities, and less decisively, also five of the persons with intellectual disabilities) explained that in the processes of decision-making about their lives, when the opinion of a different person contradicts theirs, they themselves decide and act according to their will. Moriah and Aliza expressed themselves along these lines:

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*I would have transferred from the factory, where I work now, to work closer to my father's house. I could do this. I prefer not to. Because I don't have to be closer to my house, I prefer to work at a place that's good for me, based on what my heart desires (Moriah, woman with intellectual disabilities).*

*I'm trying to remember, it was a long time ago. I know that there are decisions that maybe I could have made differently, but I don't think that someone else would have been more successful or even... I would not have listened to somebody else. At the end of the day, my decisions are my own and my responsibility and I have the responsibility. If I think about decisions I made when I was living at home, which were maybe made with too much help from my parents, the decisions weren't any better (Aliza, woman with psychiatric disabilities).*

Alongside the desire to be independent, persons with disabilities from the two groups (especially the persons with psychiatric disabilities) expressed anger when they felt that they were not the ones making decisions and in practice, the decisions were being made by another. This anger was directed not only against guardians, but also against any other person who the individual felt was intervening too much and undermining their independence:

*My counselor comes into the room. I like to organize my closet by myself, put away everything that needs to be put away – everything is organized. When I was at home, I did all of this by myself, I like organizing things, I don't like messes. I don't like when my clothes are dumped out, I want to organize things myself. On Tuesdays when I am here [visiting another hostel], she does what she wants. I don't like it when other people organize my closet (Renana, woman with intellectual disabilities).*

*My opinion is that you feel like you're... If you feel inside of you that forced institutionalized will do you no good and they force this thing on you anyway, in my opinion this can really harm you and make your psychological condition worse. And on an unrelated note, if there is a pill that you want or you don't want, that's a matter of awareness, internal awareness (Guy, man with psychiatric disabilities).*

Contrary to the widespread belief among persons with intellectual disabilities about the supreme importance of individual independence, a minority view was expressed by two women with intellectual disabilities. According to them, in some areas (primarily those regarding employment and banking), they fear independence. Even though these women also said that their independence is important to them in specific areas, they felt that the possibility of independence is too frightening. Therefore, they would prefer to give up their independence, in exchange for feelings of security that the decision is in another person's hands:

*Renana: Everything is written on the sheet of paper: the bank branch, bank number, and everything. That's what I get, my dad takes it and goes... He presses the number and then takes out the cash and with that, they buy me*

*what I need: clothes, shoes, whatever is needed.*

*Facilitator: And what do you think about this arrangement, that your parents are responsible for your money?*

*Renana: They don't give me the money, they buy things with their money, and split it up.*

*Facilitator: Now I will ask you a question, like I asked Yehuda, if you could imagine how you would want it to work with the money, what you would want...*

*Renana: The truth? To tell the truth, in things like this I can't manage alone. I can't, it's hard for me. I can't (Renana, woman with intellectual disabilities).*

A large difference was found between the two parents' groups regarding their views about their children's independence. In order to understand the views of the parents of persons with intellectual disabilities, their initial reactions must be separated from the opinions they expressed at later stages of the encounter. The initial responses, which were naturally automatic, were that capability is a static trait and that their children are not able to make decisions. In addition, it is unnecessary to teach the son or daughter skills in a field in which s/he is unable to apply judgment and which may place the child at risk in the future. It was clear that these parents place capability as a precondition for granting independence to their children. In most cases, the parents' basic assumption was that as long as their children do not display the ability to make decisions in some field or other, they should not be granted independence:

*But I want to explain something to you. Why do we accept guardianship? Because they don't have judgment, you see? They can't make decisions for themselves, they don't have the skills... He doesn't have judgment, I need someone else in his place to make decisions (Bracha, mother of a person with intellectual disabilities).*

Despite consensus on the topic of lack of capability, when one of the participants later explained that she involved her son in decision-making about his affairs, other parents also related instances where they involved their children in decision-making. This shows that the parents' views became somewhat more flexible over the course of the discussions. Some of the parents said that their children's capability is area-dependent; meaning, if the son or daughter displays capability in a certain area, it was important for the parents to be attentive to their desires, and in these instances the parents allowed them a certain level of independence. However, this involvement of the children was for the most part in simple and trivial decisions, was carried out carefully and was subject to the agreement of the parents. In most areas of life, the parents' desire that their children be independent clashed with their feelings about their children's lack of capability. A dissonance arose in which the parents involved their children in decisions regarding the children, but if the son or daughter's opinion was different than that of the parents, the parent pulled the child in the direction that was correct in the parent's perception. It became clear that the parents recognized the importance of their children experiencing the feeling of independence, but they did not think that it was right to give them real independence. This experience of independence was therefore



fictitious. Apparently, in complex or important decisions, the need to protect overcame the value of independence:

*I think we should let them use their judgment, listen to them, and even if their decision isn't good, direct them towards our decision, reach a compromise, because this gives them independence, it gives them confidence that they are considered and we don't disregard their opinion. Yes, we should consult with them but we should also push them a bit. If we think differently, then we pull them to our direction and show them that our way is better (Maayan, mother of a man with intellectual disabilities).*

In contrast, parents of persons with psychiatric disabilities held almost the opposite opinion. These parents very much want to see their children as mature and independent and therefore worked with the aim of respecting their independence in making decisions on their lives. These parents perceive capabilities as dynamic and variable in accordance with their child's psychiatric condition, such that the parents routinely considered their children as fully capable. The child's capability decreased in times of crisis and in situations in which the child refused to make decisions for him/herself or preferred to not take responsibility for his/her life. In these parents' view, if the child did not manage or displayed inability, it was their responsibility to intervene and make a decision in place of the child until s/he stabilized or displayed responsibility and capability in the situation. In such situations, the parents tended to limit their involvement to the situation at hand:

*I have no authorization to be a guardian, but I feel that there are situations in which I do need to make decisions for him, when he is having a breakdown and when he's not there at all, he's in a different world so he can't make decisions. There were many things in the hospital that he couldn't decide himself, so we decided, the doctors with me and with his father and with his siblings... Afterwards, after he woke up he said, "Why do you need to decide for me? What, I don't have an opinion? They need to decide for me? I'm an adult." But we told him, "You are having a breakdown, you're not here, we're not asking you right now." There's nothing to do about it, these are the rules when you're in the hospital, hostel or rehab, or any other place (Ayelet, mother of a man with psychiatric disabilities).*

When parents were forced to intervene in the child's decisions, they did it with a heavy heart and a feeling of pain about being forced to restrict their child. For example, Ayelet, the mother of a man with psychiatric disabilities, pointed out:

*So he said to me, "You won't make decisions for me," that's what he said to me. I say to him, "True, I don't make decisions for you, but this is the reality." He wants to be at home, "I feel safe at home," so what can I do? "So stay here." Today he went to work and from there to the hostel. But it's hard for us, it's hard to see his situation, it's hard for us, especially for my husband... He wants to decide for himself, but he says, "You make decisions for me all the time." I said to him, "Itamar, we don't decide for you. So ok, fine, be at home." But when he's at home he doesn't do anything, anything*





*at all. He goes to the porch at home, to the couch, he sits there staring into space, he does nothing. At the hostel, they make them get up for work, go to meetings, he can't get out of it. Here he gets out of it. And we also want him to be independent and explained that to him. We said to him, "You need to be independent, if you won't be independent now, we won't be here forever, and your sisters have lives of their own." We explain this to him, that he needs to deal with his problems alone and that's what will help him leave home."*

As stated, this pain about restricting children's independence was less present in the group of parents of persons with intellectual disabilities.

In sum, persons with disabilities, and especially persons with psychiatric disabilities attributed significant importance to independence and control of their lives. In this context, it is important to differentiate between real independence and a feeling of independence. Parents of persons with psychiatric disabilities attributed importance both to a feeling of independence and granting real independence. In contrast, the parents of persons with intellectual disabilities saw independence as a right that a person gains in accordance with the level of capability that s/he displays. These parents of persons with intellectual disabilities, recognized the importance of providing an experience or feeling of independence, but did not deem it right to provide independence in practice to their children.

### C. Decision-making in financial affairs

Because finances are crucial in the lives of persons with disabilities, we chose to focus on presenting the findings based on decision-making in financial matters. It was found that the participants' views regarding financial affairs were derived from their wider perspective on independence and personal capability. In financial matters, a close connection was also found between the participants' perceptions of capability and of independence. In contrast to other areas of life, finances evoke significant concern about harm to parents and other family members. As for the independence theme described above, differences in the participants' perceptions were assessed for each group separately. Among parents of persons with intellectual disabilities, and to a lesser extent also among persons with intellectual disabilities themselves, the consensus was that these persons lack the capability to manage their own financial affairs independently, even if provided with assistance and support. In contrast, persons with psychiatric disabilities, and to a lesser extent also some of the persons with intellectual disabilities, talked about their desire for independence alongside the need for a supporting and guiding figure. Parents of persons with psychiatric disabilities allowed their children freedom in financial affairs as an expression of granting independence, except in cases of real and tangible concern about financial harm that could severely impact the life of the child or those around him/her. We will expand on these perceptions later.

Amongst the participants with intellectual disabilities, four felt that their close surroundings do not allow them a degree of independence which accords with their desires and feelings of capability. These participants expressed anger about their guardians' decisions in financial affairs and even felt that their guardian restricts them. This led them, during the focus group, to express a desire for independence in financial affairs. However, these participants did not express this desire to their guardians and accepted the existing situation submissively. This is evident through the words of

Yehuda, who expressed dissatisfaction with the management of his financial affairs by others, but did not dare to think in terms of independence when asked to imagine a different reality:

*Yehuda: My mother is responsible for my money and not the hostel or my counselor. She takes care of me, brings me money. When I am stuck, then I need to call her all the time, sometimes she is at work, so I also need to wait a long time until she goes to the bank, withdraws the money, it also takes a long time. It's annoying and also... It's annoying mostly that you have to go the bank and until she withdraws the money that also takes time. I would also want her to bring me more pocket money, and then she brings me less all the time.*

*Facilitator: How would you want it to work? Can you imagine for yourself a different way of doing things?*

*Shay (interrupting): Also the same thing, when I bring her my salary, I need to call her so that she can come take the salary and also sign the check.*

Only when the facilitator attempted to probe more deeply into the issue did Yehuda express a desire to manage his bank account independently, even though he felt that it would not be permitted:

*Facilitator: How would you want it to work, if you could change things, what would you change in your guardianship?*

*Yehuda: For me to go to the bank and withdraw money alone. I don't know if that's possible.*

Two other participants had expressed their wishes to open bank accounts in their own names with the support of a guardian, but they were not permitted to do so. These participants also expressed an active opinion about the quality of the service that they receive from their guardians. Specifically, both felt that their guardians did not properly fulfill their responsibility in the financial field, and therefore both took action and succeeded in replacing the guardian. Lior, a woman with intellectual disabilities, describes the conduct of her guardian, who was a friend of her mother's:

*I did not agree that it should be a friend of my mother's, I did not agree. Because I was annoyed and I said to my mom, "I don't want your friend, because she doesn't do anything," and this and that, and I told her [the guardian], "I want to see details of the money in the account." She said it's not possible, ok, and after that I went with her [the guardian, the friend of her mother's] to open a bank account, in her name, in her name and address, and after all that you want to replace the guardian with your mother? You need to change everything [all the bank account details].... I like when people say things together, not alone, she went alone without asking me [to open the bank account].*

In contrast to the view described up until now, two women with intellectual disabilities expressed a lack of desire and also fear of participating in decision-making in financial affairs. They reported that they get a sense of security from the fact that decisions are made for them by other people.







*Renana: The manager of my apartment asked my counselor that at the end of each month, I need to get 150 [approximately US \$40]. This my father decides, I don't decide.*

*Facilitator: And how do you feel about the decision that your father made?*

*Renana: I'm comfortable with it.*

*Facilitator: You're comfortable with it?*

*Renana: Yes, I'm comfortable with it. What are you gonna do, that's the way it is.*

*Facilitator: You're comfortable with it, or that's the way it is? Those are two different answers. There's the answer, "I'm happy with it," and there's the answer, "there's no choice, that's the way it is." It's either you have no choice or you're happy with your father making decisions?*

*Renana: I'm happy that my father does it for me.*

It must be assumed that this perception of independence is influenced to a certain extent from the views of parents of persons with intellectual disabilities. In their eyes, decision-making in financial affairs is not possible for their children. According to all of the parents of persons with intellectual disabilities, a person with intellectual disabilities is not able to manage his/her financial affairs independently. In addition, financial information shouldn't be shared with him/her and s/he should not be involved in decision-making processes in this area in order to prevent harm to him/her or the family. This state of affairs is reflected in the discussions of mothers of persons with intellectual disabilities in response to one mother's statement that she taught her son to write checks:

*Nava: But if you don't trust him, why do you need to teach him that? The Mastercard, the Visa, or anything.*

*Moran: His naiveté will cost you.*

*Maayan: He'll take your credit card from you.*

*Nava: If you're asking me, I wouldn't teach my son anything that he can't do. You know why? Because I am causing him and myself more problems that I can't solve.*

Even though the persons with psychiatric disabilities were similar to a portion of the persons with intellectual disabilities in that they expressed a desire for guidance from a supporting figure in financial affairs, the points of departure were different for the two groups. While the majority of the persons with intellectual disabilities discussed their desire for independence, with acceptance of the existing situations which does not permit them independence, the persons with psychiatric disabilities did not doubt that they should be the ones managing their money. However, because sometimes the decisions of members of this group regarding use of their money are made with momentary lapses in judgment, they were happy to accept consultation or assistance in managing their bank accounts. The following is an example, through the eyes of Roni and Guy:



*We consult with the organization Paamonim [which provides guidance in financial management]. We are taken care of by them now, so even for buying a shirt I need to consult with them, even small things. I supposedly can make decisions for myself but not really... Really, all decisions are hard for me to make, at work, buying something at the grocery store, I have - - - It's hard for me to make decisions. It's not that I need a guardian, I'm not in that kind of situation, but it's hard for me to make decisions. Especially in the realm of finance, it seems that we really need someone to watch over us a bit, for now at least, even though I feel that there is a kind of progress, that we are becoming a bit more responsible. I learned from reality (Roni, woman with psychiatric disabilities).*

*Guy: I think that in all areas I get by on my own, but managing my bank account is a bit of a problem. My mom is my power of attorney and I only withdraw money from the bank once a week, so I feel that I'm not fully in control.*

*Facilitator: Is this your decision? How did this decision about this specific day happen, is it you who decided that once a week you want to withdraw money, or did someone decide for you?*

*Guy: Yes, I decided once a week, so I won't take out too much money. People help me here --- I take some of the money for me and some of the money I leave here, so they can help me manage better.*

Like the individuals with psychiatric disabilities, and unlike the parents of persons with intellectual disabilities, parents of persons with psychiatric disabilities talked a lot about managing bank accounts as an important and necessary way to strengthen their children's feelings of independence and therefore attempted to encourage and support independence in this area as much as possible. In instances in which parents felt that their children were not making the right decisions, they acted in one of two ways: If they felt that their children's poor decisions would not harm them or others much, they preferred to honor the decisions and allow their children independence. This can be seen in the words of Yossi, a father of two persons with psychiatric disabilities, who serves along with his wife as a guardian on personal affairs of his son, but not for his son's property:

*Facilitator: Regarding the situation of your two children, why did you not seek to be appointed guardians of their property?*

*Yossi: [If] I appoint myself guardian of property, this means that I am responsible for his bank account. How do I trust him at all? I need to show him that I trust him, that he is capable of going to the bank, managing his account, even if partially, withdrawing money, asking the banker questions.*

In contrast, if parents of persons with psychiatric disabilities felt that there was too great a risk for financial harm or negative effects on the person's support frameworks, they intervened actively and effectively in order to prevent or repair the harm. As opposed to the parents of persons with intellectual disabilities, who intervened ahead of time in an attempt to prevent any possibility of

harmful financial mistakes, parents of persons with psychiatric disabilities talked about intervention as a response to an event that already took place, or a response to the child displaying difficulties in the field. Boaz and Shlomit, parents of a person with psychiatric disabilities, spoke in this vein:

*Listen, we had a restriction when our son simply went to a lawyer, paid him some 24,000 [approximately US \$6,800] ... just like that, for all kinds of patents that he supposedly invented, for the lawyer to represent him... He is clever, but you can trick him. He's smart, but not in a practical way... Afterwards, how do you call it, from the internet? A Nigerian scam, also another 30,000 [approximately US \$8,500] and something shekels, he tried to transfer, he saved some, somehow got it back... I got back some of the money from London, because I am familiar with money transfers... In short, we just did it [appointing a guardian] because we had no choice, just so he wouldn't get himself into trouble... He thought he would be a millionaire --- and all kinds of things like that. It's really not easy --- we're exhausted.*

Ronit, mother of a woman with psychiatric disabilities, related that she acted in a different manner in order to prevent her daughter from causing financial harm. In her opinion, active intervention, such as that in the previous example, will cause her daughter to feel that she is not trusted and will anger her. Therefore, the mother preferred to assist her daughter secretly:

*She is not capable of managing her money. She wasted a lot a lot a lot of money in the beginning, which we had saved for her, for an apartment, for everything. So today because of the girl --- maybe if it wasn't for our granddaughter she would have managed better alone, if she lived alone, but she has a daughter so we fund everything really. She doesn't know everything, she thinks that she works for someone who employs her, but we pay him... It's good how we arrange it now, she's very careful about money, she knows that it all goes to vegan, vegetarian, organic and all that stuff. It's a good thing, it's food and also rent. I split it with her. She thinks that she also pays, but it's all... It's something that I know that she can't do and something that we must do for our granddaughter, to give her the feeling that she is independent and that her daughter sees that her mother is an independent woman who manages, who knows, who buys things, and cooks, and manages the household... But I know that she can't manage the --- She doesn't make enough money to get by. It's a big deal, it's a bit painful.*

In sum, few persons with intellectual disabilities expressed a strong desire to prevent the intervention of a guardian in their decisions in financial matters. Of those, those who did prefer to be granted independence in finances did not express this desire to their guardians. This finding can be understood in light of the parents' views which do not permit independence for the adults with disabilities in financial matters because they believe that their children are unable to manage on their own. In contrast, both the persons with psychiatric disabilities and their parents greatly valued independence in financial matters and recognized the need for intervention only in situations in which there is a risk of real financial harm.







## D. Perceptions of support and guidance

In the findings presented thus far, the central role played by support and guidance in the lives of persons with disabilities stands out. The findings indicate that there exist a variety of interpretations regarding the needs of persons with disabilities: from decision-making at the hands of an external agent (“substituted decision-making”), through decision-making with the assistance of external sources of support (“supported decision-making”), all the way to independent decision-making without the involvement of any other person.

The discussion regarding support and guidance amongst those with intellectual disabilities was complex, and resulted in ambiguous findings. Firstly, participants with intellectual disabilities had difficulty understanding the difference between substituted decision-making and supported decision-making, which affected the possibility of expressing an opinion on the need for support and guidance services. Secondly, because all participants with intellectual disabilities had guardians, they were accustomed to a situation in which another individual makes decisions for them or has the last word in the decision-making process. They struggled to imagine a hypothetical situation in which they fulfilled the role of decision-maker. The complexity of this topic was also expressed in the participants with intellectual disabilities’ great ambivalence about their desire to make decisions for themselves versus their wish for someone else to do so for them; they changed their opinions on this matter many times over the course of the focus group. Initially they sided with the mechanism of substituted decision-making and expressed happiness that there was someone else to take the responsibility of deciding for them, and did not doubt decisions made for them at the hands of a guardian. Since persons with intellectual disabilities often sought the facilitator’s answers, the facilitators tried to encourage the participants to discuss the positive and negative aspects of guardianships and of supported decision-making. Following persistent encouragement on the part of the facilitators to express a variety of opinions, a total of four participants opted to change their position and side with supported decision-making and expressed a slightly more active and critical position vis-à-vis substituted decision-making. These participants were happy when decisions made by someone close to them (for example, a family member or a staff member acting as guardian) suited their wants and needs. However, when decisions went against their wishes they reported frustration, and two of the female participants also replaced their guardians when they felt that their guardian was doing them only harm. Thus, for example, when Lior felt that her guardian (who was a friend of her mother) did not care enough for her needs, she fought to replace her for a guardian who would act as a partner in decision-making and would take interest in her well-being on a regular basis. Despite her reservations about her new guardian (her mother), Lior did not want to give up on having a guardian in her life:

*She [her mother] cares about me. When I’m sick she comes, brings me something to drink and eat, buys me clothes. When she [the guardian] was my mom’s friend, she didn’t care. I like the...I don’t like it when people like my friend, who is a guardian for herself [meaning that she has no guardian], this isn’t worth it. Why isn’t it worth it? Being your own guardian isn’t worth it. Because they put money inside your account and it’s impossible for her (Lior, a woman with intellectual disabilities).*

Two other women persisted in their view that they cannot get by on their own and therefore still wanted another person to make important decisions on their behalf.



The parents of persons with intellectual disabilities responded dismissively about the possibility of replacing the institution of guardianship with supported decision-making, and gave two reasons for their reluctance. Firstly, because they considered their son or daughter incapable, they felt that it was incumbent on them to be the central factor in decision-making. Parents from this group were shocked by the idea that the State of Israel asked to promote alternatives to the institution of guardianship and even responded with great anger to the facilitators' attempts to explore with them the advantages and disadvantages of an alternative model. In their view, the supported decision-making mechanism will completely neutralize their influence on their children. At the same time, as they see it, the use of supported decision-making would only produce a semantic change in light of their children's inability to make decisions even while receiving support. Reuven, the father of a person with intellectual disabilities, expressed himself in this vein:

*I think that this [supported decision-making] is definitely a mistake; it's not possible to give up on the institution of guardianship. You could call it by another name, it doesn't matter, they can't make decisions on their own. Plus you need someone to make decisions instead of them, and it's best that it will be someone who cares and has good judgment. It's true that you need to listen to them and really hear them, but at the end of the day the decision belongs to the guardian.*

Another justification brought up by the parents in their opposition to developing alternatives to guardianship was that Israeli society is not open and accessible enough to allow for supported decision-making. As they see it, stigma in Israel towards persons with intellectual disabilities and, by extension, their level of self-confidence, would not allow the idea of supported decision-making to function in practice.

*I have no problem with liberalism, I have no problem with getting rid of the term guardian, but, once again: this needs to be examined and confirmed, whether we're in this situation. I don't think that the State of Israel is at that point yet, I think that other countries, maybe they are at that point. I am also aware of things that are very different from the way they are in Israel, I go around the world a lot. In the United States and in Europe it's totally different from here in Israel, the entire institution of people who are dependent is totally different, the mechanism behind it. That population does know how to accept the other and does know how to regulate these issues with all sorts of laws, in a country that does offer the protections like you said. Because at the end of the day my fear, I'm talking about myself, is the protection of the dependent person from all sorts of things which they are susceptible to, from harassment, from things which I have the right to and which, for now, they gave me the right to decide for him about some things, good or bad, for better or for worse. (Tomer, father to a person with intellectual disabilities)*

Unlike those with intellectual disabilities, persons with psychiatric disabilities and their parents brought up the need to further implement the supported decision-making approach before the

facilitators of the study even mentioned this possibility. Individuals with psychiatric disabilities related to the need for guidance and assistance in making decisions and were even curious to know how they could get a supporting figure for themselves. They explained that independence and support do not contradict each other, and that support allows them to exist more independently. They attributed great importance to the support they receive from those around them in most areas of life, and explained that this support helps them advance and is good for them as long as the final decision remains in their hands. Persons with psychiatric disabilities positively experienced support from persons whom they trust and with whom they are in close contact. They often demonstrated how different supportive figures, such as family, friends and treatment staff, fill an important role in providing assistance in decision-making:

*I would maybe want someone to come with me to the psychiatrist, because sometimes I feel as much as I explain myself, she doesn't fully understand and doesn't match me with the medicines that I really, hours of medicine or...I think that she doesn't totally...maybe it's that she needs an additional opinion from someone who knows me. From this perspective, I think that maybe I would want it. (Guy, a man with psychiatric disabilities)*

An additional example is four women with psychiatric disabilities who participated in a support group, who explained that group support and facilitation expanded their level of confidence, in the group and in moments of decision-making. They did not, however, always accept the group's opinion and sometimes decided to act differently. Three individuals with psychiatric disabilities expressed doubts about the broad use of the supported decision-making mechanism, and felt that in the case of a life-threatening situation (a dangerous medical issue or a psychotic state) it would be preferable for someone else, and not them, to make the decision regarding their institutionalization.

The parents of persons with psychiatric disabilities demonstrated the manner in which they support their children today. These parents saw themselves as supporting figures in the decision-making process during normal times. They differentiated between periods of calm and periods of crisis during which they observed a need to make decisions on behalf of the person with psychiatric disabilities in order to prevent harm. The parents of persons with psychiatric disabilities who are not guardians felt that today they already use the supported decision-making method. Even parents who were appointed guardians for their adult children only did so in order to constitute a legal authority to act on their son or daughter's behalf in specific areas that demand external intervention, rather than in a sweeping and comprehensive manner. These parents continued to serve as supporting figures in other areas of life in which their children were independent and not exposed to any potential harm.

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## 4. Discussion

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This study examined the attitudes of persons with intellectual disability and persons with psychiatric disabilities and parents towards the institution of guardianship, towards the independence of the person with disabilities, and towards alternatives to guardianship (specifically towards supported decision-making). This chapter will discuss the findings that were presented. The discussion will focus on a number of topics: firstly, on the differing perceptions of the various study groups towards the institution of guardianships and towards supported decision-making. Secondly, it will discuss the confusion regarding the boundary between the role of the parent and that of the guardian amongst parents of persons with intellectual disabilities. Thirdly, the views of the participants regarding supported decision-making will be considered. Fourth, we will look at attitudes regarding independence and autonomy of persons with disabilities. Fifth, the transition from childhood to adulthood will be presented as an important phase in education about adulthood and independence. And finally, we will raise suggestions for the implementation of this study's findings.

### A. Differences in perceptions of guardianship and supported decision-making

The main finding of this study was that, despite the divergent perceptions of the various stakeholder groups, many participants – and especially those with psychiatric disabilities, the parents of persons with psychiatric disabilities, and some of the participants with intellectual disabilities – expressed their desire to transition to the supported decision-making model. In this spirit, participants with psychiatric disabilities emphasized their desire and their right to be independent in making decisions about their lives; the parents of persons with psychiatric disabilities aspired to be a support and an aid to their children and to encourage expressions of independence as much as possible, with the exception that they be able to intervene during moments of crisis. Moreover, the parents of persons with psychiatric disabilities also preferred that in cases which necessitated involvement and decision-making for their son or daughter, this involvement be carried out by an authorized external third party and not by the parents themselves. Some of the persons with intellectual disabilities also expressed a desire for support in decision-making, though they worried that this would not be practical for them. Other persons with intellectual disabilities emphasized that they prefer that another individual (a guardian) make decisions for them in certain cases, because they are not capable of making independent decisions regarding their lives. In contrast with the majority of persons with intellectual disabilities, parents of those with intellectual disabilities expressed unequivocally their opinion that it was critical for them to serve as a guardian for their children in order to maintain their involvement in every area of their children's lives.

In this chapter, we offer a number of possibilities to account for the discrepancies in findings for the two different groups of persons with disabilities. Firstly, one must relate to the difference between intellectual disability and psychiatric disability. For both types of disabilities, there exist a wide range of abilities and functioning. Along with this, while a person with psychiatric disabilities deals with issues of functioning, those with intellectual disabilities have difficulties which lead to different problems in their functioning. For example, even though persons with psychiatric disabilities have difficulty expressing their thoughts when experiencing psychosis or thought disorder, they generally have relatively clear understandings of things and are capable of communicating their wishes. For persons with intellectual disabilities, however, the ability to



communicate is often inferior (Ditchman, Werner, Sokol, Jones, Elg & Corrigan, 2013). Intellectual disabilities are also characterized by difficulties in executive functioning, i.e., the cognitive steps which are responsible for an individual's ability to organize his/her thoughts, to order priorities, to manage time, and to make decisions (Meltzer, 2007). Even though a person with intellectual disabilities is capable of learning skills and can progress in various areas, the disability itself accompanies him/her for a lifetime (Developmental Disabilities Assistance and Bill of Rights Act, 2000). In contrast, psychiatric disabilities are frequently characterized by episodic lapses and deterioration, after which the individual returns to a similar level of functioning (APA, 2000).

Secondly, it may be that the differing perceptions and attitudes of parents of persons with intellectual disabilities and those of parents of persons with psychiatric disabilities, as well as the attitudes of professionals and the wider society, lead to a different process of socialization for the two different disabled groups. This socialization is influenced by the question of the phase of life in which the disability begins to influence the functioning of the person. An intellectual disability becomes evident in the first years of life and influences the development of the child. The parents are familiar with their child's objective difficulties, and must deal with parenting a child with a disability from the first days of the child's life (Muggli, Collins & Marraffa, 2000). Professionals and others in society convey the message to the parents that their child's reduced capabilities will be with him/her for a lifetime. The societal discourse surrounding reduced capabilities is internalized by parents, and is in turn passed on to persons with intellectual disabilities by their parents and other key figures in society, including by professionals at school and daycare, by those who deal with housing, and indirectly via the policies of the Ministry of Welfare. Studies indicate that there is a correlation between the perception of the parent and others regarding the capability of the individual, on the one hand, and the autonomy and independence actually developed by the individual on the other (Huang & Lee, 2010; Gordon & Rinaldi, 2010).

The socialization processes of persons with intellectual disabilities and persons with psychiatric disabilities are different, because psychiatric disabilities are manifested later in life in the majority of cases. Despite studies which found that people who began to suffer from schizophrenia displayed a lower degree of autonomy than their peers even before the outbreak of the illness (Reichenberg, Rabinowitz, Weiser, Mark, Kaplan & Davidson, 2000), most types of mental illness manifest themselves around the ages of 20-25 (Sadock & Sadock, 2007). Therefore, one can assume that in light of healthy functioning in their early years and during adolescence, the parents of children with psychiatric disabilities afford them a certain degree of independence, and accordingly persons with psychiatric disabilities are raised with the expectation that they will demonstrate a growing level of independence as they mature.

We propose a third important hypothesis that may explain the differing perceptions between persons with intellectual disabilities and persons with psychiatric disabilities about the possibility of realizing their own autonomy through supported decision-making: this difference is primarily the result of social construction. The existing gap results from differences in attitudes and perceptions amongst parents and in society, and it is clear that we should understand social construction as holding critical importance in the different attitudes of the main stakeholders. This social construction places persons with intellectual disabilities on a lower rung. Society approaches individuals with intellectual disabilities in a paternalistic manner, and the ability of these individuals to oppose this paternalism and to demand their rights is less than that of a person with psychiatric disabilities. The recognition of the right and ability of persons with intellectual disabilities to manage their own affairs without a guardian but with support is therefore much lower.





This attitude is pervasive, and it influences the opinions of person with intellectual disabilities who feel that their guardian is the one who ought to make decisions regarding their lives. In contrast to this stands the high level of awareness for the need for support as an alternative to guardianship amongst persons with psychiatric disabilities and their parents. An example of the role of social constructions in shaping the differences between the two groups under discussion is Inclusion Czech Republic, an NGO formerly known as SPMP<sup>6</sup>. This organization is the representative organization for parents of persons with intellectual disabilities in the Czech Republic and is one of the leading organizations in the implementation of Article 12 of Convention on the Rights of Persons with Disabilities and in using alternatives to guardianship to ensure the full legal capacity of the individual.

In conclusion, although there are objective differences between intellectual disability and psychiatric disabilities, the objective disabilities are only a starting point. The view that persons with intellectual disabilities in Israel need to be under guardianship is primarily due to social constructions, not the objective characteristics of these disabilities or because of the limits of public resources in Israel compared with other countries like Canada. Thus in the Czech Republic, which has limited public resources, the official position of parents of persons with intellectual disabilities is that their children do not need to be under guardianship and that support services must be developed for them while respecting their legal capacity.

## B. Blurring the boundary between parenthood and guardianship amongst parents of persons with intellectual disabilities

This study's findings indicate that most participants did not have enough information about guardianship (knowledge of the roles, authorities, and boundaries, as well as the rights of the person under guardianship). Parents of persons with intellectual disabilities tended to blur the boundaries surrounding the institution of guardianship by attaching parental roles they played before their children reached the age of 18. This blurring of boundaries thus led to a situation in which the natural candidate for the role of guardian for a person with intellectual disabilities was the parent. In contrast, amongst parents of persons with psychiatric disabilities there was no blurring of boundaries, and they also preferred for the role of guardian to be reserved for an outside person in order to differentiate between the formally authorized role of the guardian and the role of the parent.

Even though the parents are considered natural guardians by virtue of their intimate acquaintance with their children, the confusion about the boundary between the role of parent and the role of the guardian has many implications, some of which are not desirable. Firstly, fulfilling both of the roles at the same time is difficult. Secondly, the parent-guardian continues to relate to their child as incapable, and his/her status thus remains similar to that of a child well into adulthood. Thirdly, because the position of the guardian is directly related to the role normally fulfilled by the parent, parents of persons with intellectual disabilities greatly fear for the future of their children after their parents' death. This fear is even stronger when there is no sibling or relative capable of taking on this role. Fourth, the blurring of lines may actually lead to limiting the legal capacity of the individual with intellectual disabilities. In other words: extensive involvement by parents in daily decision-making naturally leads individuals with disabilities to turn automatically to their parents, at the cost of not experiencing independence. Fifth, the characteristics of guardianship,

6 <http://www.spmpr.cz/en/introduction>

which include restrictions, coerced decisions, and enforced control, naturally harm the intimacy and closeness between the parent and their adult child.

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### C. Attitudes towards supported decision-making

As stated previously, three out of the four studied groups (persons with psychiatric disabilities, their parents, and some of the persons with intellectual disabilities) expressed a need for supported decision-making. In contrast to these groups, the parents of persons with intellectual disabilities opposed the use of the supported decision-making model, which they saw as a liberal model that would not afford full protection to their children. These parents also had difficulty understanding the difference between this model and guardianship. From their perspective, this would be a merely semantic change, inasmuch as they would continue to fulfill the roles that they had fulfilled previously. All of the participants asked many questions about the way in which the model would be implemented. These findings indicate the need to provide full information about the status of guardianship and about supported decision-making to persons with disabilities and their parents. This should be accompanied by information explaining that the transition to the supported decision-making model can assist those from these two groups of disabled persons in realizing their right to autonomy and self-determination (Werner, 2012).

### D. The role of independence and attitudes towards independence

Despite persons with disabilities' desire to be independent, we found that parents of persons with intellectual disabilities felt that it is important to encourage a sense of independence, but rarely did so in practice. Conversely, parents of persons with psychiatric disabilities recognized the importance of combining these two components – giving a sense of independence and encouraging actual independence. Persons with psychiatric disabilities saw themselves as independent, and their parents were found to be more willing to see their children as independent individuals capable of making decisions about their lives. In light of the strong desire to be independent and out of respect for this desire, persons with psychiatric disabilities and their parents positively received the involvement of a third party in the process of decision-making only when the person with disabilities or his/her parent felt that the child was not capable of making a decision about a specific matter during times of crisis. In contrast, even if some of the persons with intellectual disabilities greatly valued independence, most of them emphasized that it is sometimes hard for them to make decisions without assistance. Similarly, parents of persons with intellectual disabilities want to encourage a sense of independence in their children, yet in many cases, the parents tried to guide their children to decisions which already seemed correct to them. In other words: these parents do indeed recognize the importance of giving a sense of independence and experiencing independence, but in practice the worry about potential harm to their adult sons or daughters and the desire to protect them overcame the desire to give them independence.

The differences in attitudes between the two groups of parents were especially pronounced in their discussions of the connection between independence and capability. Here, the study found that the attitudes of persons with intellectual disabilities regarding their own independence were strongly linked to the *a priori* attitudes of others, including their parents, about their level of capability. To the extent that parents considered their children less capable than others, they afforded their children a lesser degree of autonomy and were much more involved in their decisions. This attitude led parents to give their children fewer opportunities to make their own decisions and



fewer opportunities to implement supported decision-making. As an outcome of this process, many persons with intellectual disabilities saw themselves as less able to make decisions on their own. Even when persons with intellectual disabilities felt that they were able to manage their own affairs independently in every area of life, this feeling was accompanied by ambivalence and an urge to continue and maintain the role of the guardian. In contrast to these parents, the parents of persons with psychiatric disabilities placed greater emphasis on independence; they only perceived their children as incapable in specific circumstances in which their child appeared to be struggling. Even in instances of incapability amongst those with psychiatric disabilities, there still prevailed an acknowledgment of the importance of providing support and guidance, and these two options were preferred to the appointment of a guardian.

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## E. The transition to adulthood and educating towards independence

The findings discussed above indicate the tremendous importance of educating towards independence from the earliest stages of development, in order for persons with disabilities to be able to develop an attitude of competence and independence. Theories of self-determination emphasize that the foundations of one's self-determination are built at a young age. Even at that stage, support by socialization agents whose role includes enhancing a child's motivation towards self-determination is centrally important (Deci & Ryan, 2000; Soenens & Vansteenkiste, 2005). Socialization agents have a decisive ability to help children with disabilities develop as capable people who can make their own choices in adult life (Ryan & Solky, 1996). Parents and professionals in society at large (especially those who work in education, housing, and medicine) are responsible for fostering in young children the skills necessary for self-determination. Further, it is important to foster the skills needed to make choices from a young age, so that children can develop the ability to set priorities, to choose what they like and dislike and what they want and do not want. All of this is necessary in order to prevent a learned powerlessness carrying over into adulthood (Liso, 2010). Constructive dialogue on the issue of self-determination encourages a person to see him/herself as an adult with a self-determined identity, and who asserts his/her rights as an adult member of the larger community (Clement, 1996).

The important role of parents, educators, professionals, and members of society in educating towards self-determination is magnified several times over during the period in which persons with disabilities transition to adulthood at the age of 18. In adulthood the legal responsibility of parents comes to an end, and young adults receive control over the activities and decisions in their lives. These adults are free to choose their areas of interest and live their lives according to their own wishes and attitudes (Murphy, Clegg & Almach, 2011). Studies have shown that persons with intellectual disabilities are not always aware of the transition from adolescence to adulthood (Mill, Mayes & McConnell, 2009). The appointment of a guardian for persons with disabilities often confuses this transition and establishes the individual as a child and the parent as the one who manages his/her life. However, professionals who work with persons with intellectual disabilities during the transition to adulthood emphasize that these persons have both the desire and the ability to express their own wishes, although bringing these wishes to light and understanding them is difficult and requires skill and creativity on the part of the parent and the professional. In other words: one can encourage a person with disabilities to achieve adulthood and independence by giving him/her the appropriate tools in accordance with his/her ability. It is important to create an open, suitable environment to affirm the individual's wishes, and to provide the ability to genuinely choose from among different possibilities (Murphy et al., 2011).

## F. Recommendations for implementing this study's conclusions

In accordance with the findings of this study, we will present practical recommendations for promoting the fundamental right to autonomy and self-determination for persons with disabilities:

1. It is important to recognize the differences between human beings and to move away from generalizations based on type of disability. In making decisions about guardianship and supported decision-making, we must move away from the classical medical model which rests primarily on the opinion of clinical medicine. Instead, we should examine the individual's abilities alongside his/her support system and developing skills. That is to say, we must identify the individual needs of every person with disabilities by considering the level of support s/he needs and the areas in which this support is necessary. This approach accords with the person-centered planning approach, which helps supporting figures to see the individual as having ambitions, desires, and the ability to define him/herself on all matters that relate to his/her future (Whitney-Thomas & Timmons, 1998). In this spirit, we should direct support in decision-making according to the individual's opinions regarding his/her well-being, and not according to the opinions of those around him/her, as occurs in the substituted decision-making model. Furthermore, we should move away from objective diagnoses and from sweeping policies which require the appointment of a guardian, and should work instead to explore the individual abilities of every person. Along these lines, it is important to recognize the abilities of persons with intellectual disabilities are not static, but instead as developing with increased independence and support.
2. In order to reduce the gap between providing a feeling of independence and actually recognizing the value of true independence, we must refine the understandings held by parents, professionals, and others so that they can differentiate between these two elements, and we must emphasize the primary importance of the latter. In practice, merely providing a feeling of independence is not enough to lead to full independence, and obscures the fact that decisions are actually made by others and not by the person with disabilities.
3. It is important to focus on providing support, assistance, and guidance to parents, because many parents (mainly parents of persons with intellectual disabilities) expressed concerns about and opposition to implementing the supported decision-making model and eliminating legal guardianship. This study exposed the degree to which parents' attitudes significantly impact those of their children. A genuine change in the field of guardianship and real promotion of persons with disabilities' right to be independent and autonomous will not be possible without parents choosing to be partners in this change. In order to achieve cooperation on the part of the parents, it is thus crucial that they become aware that the supported decision-making model is for the benefit of their children. We should create an open dialogue with the parents that will allow them to investigate the source of their opposition and give expression to their concerns. It is important to explain how it is possible to protect their children from exploitation and harm, which are the parents' primary concerns. It is also important that parents understand that the values of autonomy and self-determination must be weighed against the desire to care for and protect their children; that is to say, there may be situations in which it is preferable to opt for protection and care. An irresponsible implementation of the right to self-determination, without first examining an individual's ability to think critically, is liable to expose vulnerable people to harm as a result of choices they might make with little understanding of their consequences. (Murphy et al., 2011).

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4. In the spirit of the socialization hypothesis above, persons with intellectual disabilities should be encouraged to gain skills and independence starting in childhood. Many studies (including Wong, Clare, Holland, Watson & Gunn, 2000) report on the areas of life in which an individual with intellectual disabilities is capable of gaining new skills and discovering, with outside support, their ability to function independently. Without training and without education about independence, it becomes difficult for an individual to develop these abilities. Adults with disabilities should be provided with knowledge and with legal recognition of their right to manage their own lives. While the appointment of a guardian strengthens the process of socialization which seals the individual in a clearly incapable role, legal recognition of the individual's right to manage his/her affairs encourages a discourse of independence. The interventions aimed at developing independence ought to be implemented in the education system, alongside training parents to give their children empowering support on the road to independence.
5. In light of parents' concerns that capability and independence are unrealistic due to mainstream societal attitudes, it is very important to work towards changing the general perceptions of the public. This is because society's attitudes and the attitudes of professionals reinforce the attitudes of parents and the individual. To this end, we must impart the values of the UN Convention – equality, inclusivity, non-discrimination – to schools and service providers (such as banks, lawyers, and commercial entities).
6. Because some the participants in this study were clear proponents of the supported decision-making model, a pilot should be conducted which offers this type of service. Models must be developed in accordance with the needs of the various disability groups and with the personal needs of individuals. For example, supported decision-making services for persons with intellectual disabilities could focus on increasing the individual's awareness of his/her right to independence and self-realization. Open dialogue and education can bring about a transition whereby the individual moves from a state of dependence towards a reality in which s/he adapts to the role of an adult bearing the full right to make his/her own choices. For persons with psychiatric disabilities, the focus should be placed on practical education and training in preparation for their making decisions independently. Persons with psychiatric disabilities would learn to differentiate between areas in which they do not need help and outside involvement, and areas in which they do need another's assistance. The individual should also be prepared to learn how to ask for and utilize this type of assistance. Professionals and family members should be trained to adapt the supported decision-making model to the needs of the population requiring their assistance.

We are hopeful that the implementation of these recommendations will advance and improve the status of persons with disabilities in society. The implementation of the supported decision-making approach will help realize the right of persons with disabilities to make their own decisions about their lives, and will help Article 12 of the UN Convention on the Rights of Persons with Disabilities become a reality.

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## Annex 1: Table of demographic data for the groups of parents of persons with intellectual disabilities and psychiatric disabilities

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Group	Sex	Age	Child's residence	Child's age	Additional guardian-ship	Number of years serving as guardian
Group 1: Parents of persons with intellectual disabilities	Man	48	Hostel	22	Mother	4
	Woman	46	Hostel	22	Mother	4
	Man	65	Apartment in community	30	Mother and sister	10
	Man	72	Hostel	38	Sister	18
	Woman	59	Parents' home	26	Father	6
	Woman	61	One at home and two in a hostel	28, 34, 38	Father	10
	Woman	59	Hostel	26	Father	7
	Woman	60	Apartment in community	24	Brother	3
Groups 2: Parents of persons with psychiatric disabilities	Woman	66	Apartment	42	No guardian	
	Man	70	Rental apartment	33	No guardian	
	Woman	87	Rental apartment	55	No guardian	
	Woman	59	Hostel	34	No guardian	
Group 3: Parents of persons with psychiatric disabilities	Woman	64	Apartment in community	29	Parents	3 months
	Man	64				
	Woman	63	Apartments in community	Son: 39	Parents (only for the son)	Two months (only for the son)
	Man	63		Daughter: 30		

## Annex 2: Demographic data table on the groups of persons with intellectual disabilities and psychiatric disabilities

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Group	Sex	Age	Residence	Guardianship
Group 1: Persons with intellectual disabilities	Woman	38	Hostel	General guardian
	Man	42	Apartment in community	Mother and brother
	Woman	30	Apartment in community	Parents
	Man	25	Hostel	Parents
Group 2: Persons with intellectual disabilities	Woman	25.5	Supporting community	Parents
	Woman	25.5	Supporting community	Parents
	Woman	39	Supporting community	General guardian
	Man	47	Supporting community	General guardian
Group 3: Persons with psychiatric disabilities	Woman	45	Independent apartment	None
	Woman	64	Independent apartment	None
	Woman	51	Independent apartment	None
	Woman	61	Independent apartment	None
Group 4: Persons with psychiatric disabilities	Man	21	Supporting community	None
	Man	20.5	Hostel	None
	Man	19.5	Hostel	None
	Woman	23	Hostel	None
	Woman	24	Hostel	None

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