Supported Decision-Making Service for Persons with Disabilities

Service Model

BIZCHUT

The Israel Human Rights Center
for People with Disabilitis

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Contents

Preface

In 2014, Bizchut launched a project funded by the European Union, entitled "My life in my hands – Article 12". The objective of the project was to promote the right of persons with disabilities to make decisions regarding their lives on the basis of supported decision-making. This was an added tier to our ongoing work on this issue. At first, Bizchut's work plan for the project seemed overambitious, but in retrospect, it was modest. Execution rarely surpasses planning, but it did in this case: between 2014-2016, we have given more than 90 lectures and training sessions on the issue to about 3,000 persons with disabilities, family members and professionals, including family court judges. We have established and advanced a coalition of 20 organizations to push for reform of the Guardianship Law and recognition for supported decision-making. We have produced information sheets, video clips, and reports on the need for developing alternatives to guardianship. We were partners in a historic move in the Knesset for the amendment of the law and recognition of supported decision-making as an alternative to guardianship. We ran the first pilot of its kind in Israel on supported decision-making, designed to help formulate a model for support. We helped individuals ask the courts to cancel guardianship and recognize alternatives. As a result of all this, and thanks to the work of other partners in this struggle, the past few years have been marked by growing support for the basic demand put forward by persons with disabilities to be recognized as equal citizens and as persons with full legal capacity. This growing trend of support has been observed among family members, government officials, organizations and professionals.

The model presented here is one of the major products of Bizchut's Article 12 Project. It is the culmination of hundreds of hours of support and accompaniment provided to persons with disabilities, and no fewer hours of thinking about how accompaniment and support should be given. Many important partners from both the government and civil society have helped formulate this model. Not all of them agreed with the conclusions and the proposed model, and it is specifically because of this that we highly appreciate their consent to play a major part in the learning and evaluation process. The model is solely Bizchut's, and we view it as a starting point that will undoubtedly go through many changes and transformations, as the reality of supported decision-making takes shape. Over the next two years, Bizchut plans to advance training for the role of 'decision-making supporter' based on this model.

This document is an English translation of an identical document published in 2016. It contains three parts: The first part, the background, provides a brief overview of the need to develop a supported decision-making service. The second part, the model, is the core of the document and includes many elements: the vision and guiding values, the support outline and ethical principles and dilemmas that arise around the issue of support. The third part includes annexes that provide additional information about various aspects of the model: a description of the pilot, an overview of the new law regarding supported decision-making and a discussion of the need to adjust the model to groups with particular characteristics. We have translated the relevant annexes to English as well.

Persons with disabilities and their family members have referred to the day that the amendment to the Legal Capacity and Guardianship Law passed as their Independence Day. We hope that these independence day celebrations break new ground and usher in a reality of support for choice, liberty and self-fulfilment for persons with disabilities.

I wish to thank all our partners on this special journey. In particular, I would like to extend my gratitude to the 22 pilot participants, who agreed to be the first to take the plunge, to the first class of eleven decision supporters in Israel, and finally, to the small and dedicated Bizchut team.
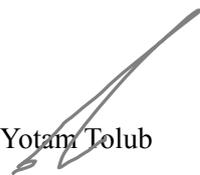
Yotam Tolub
Bizchut Executive Director

PART 1

Background for the model

A. Introduction

The right to receive support in decision-making touches on the most fundamental of human rights: the rights to liberty, autonomy and dignity. For persons with disabilities and older adults under guardianship, these rights are palpably and constantly limited. Recognition of the need to promote supported decision-making by persons with disabilities is on the rise, and in this section, we provide a brief background for this trend. We note that throughout this document, the term "persons with disabilities" mainly refers to persons with intellectual disabilities, psychosocial disabilities, persons on the autism spectrum and persons with complex disabilities.

The disability movement: Over the last 50 years, the approach toward disabilities in Israel and throughout the world has undergone a revolution. Under the influence of movements such as the movement for independent living; the People First movement; the deinstitutionalization movement; the human rights movement; and the development of the critical approach to disability; the relationship between persons with disabilities and society has been redefined: from a treatment-focused approach espousing supervision and protection, a new approach has evolved, emphasizing autonomy, self-determination and equality. The critical approach to disabilities whose principles were adopted by the Supreme Court (HCJ 6069/10 Machmali v. Israel Prison Service, May 5, 2014), holds society responsible for proactively removing the barriers which exclude persons with disabilities, and adapting itself to them through support, accommodations and accessibility. The Equal Rights for Persons with Disabilities Law, 5758-1998, reflects this paradigm shift in Israel.

Guardianship and legal capacity: As the reform in the policy towards persons with disabilities began to take hold, a fundamental question became more pertinent: How can the guardianship model be reconciled with the rights of persons with disabilities? More than 60,000 Israeli adults are under guardianship. Persons with intellectual disabilities are declared "wards" almost automatically according to recommendations of evaluation committees; service providers including bankers and physicians often raise doubts as to whether persons with disabilities have the legal capacity to make decisions regarding their lives; the prevalent opinion is that persons with moderate disabilities (autism, intellectual disabilities, psychosocial disabilities) should undergo a functionality test to prove their right to make decisions regarding their lives. Guardianship – a symbol of the different, inferior status of persons with disabilities – became a real stumbling block on the road to equality.

Article 12: In 2012, the State of Israel ratified the UN Convention on the Rights of Persons with Disabilities (hereinafter: the CRPD). Article 12 of the Convention and its official UN interpretation stress that guardianship involves a violation of the right of all persons to full legal capacity in all areas of life. Article 12 in fact advocates a transition from a substitute decision-making model to a supported decision-making model which would enable persons to make decisions regarding their lives. Over the past decade many countries have adopted, in legislation and in services, different models of support and assistance as an alternative to guardianship, and some have even abolished the institution of guardianship altogether. At the same time, assistive services for independent living in the community and person-centered services, developed in the West, help limit the use of guardianship.

In view of these trends, Bizchut – The Israel Human Rights Center for People with Disabilities (hereinafter: Bizchut) has undertaken to develop an applied model, which would transform the principles enunciated in Article 12 into provisions in Israeli law and a practical model of supported decision-making for persons with disabilities.

Article 12 of the UN Convention on the Rights of Persons with Disabilities

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. "

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B. Challenges to full fulfilment of legal capacity of persons with disabilities

Article 12 of the CRPD seeks to restore autonomy, legal capacity and independence to persons with disabilities. To understand the depth of the challenge we wish to point at a host of difficulties confronted by persons with disabilities wishing to realize their legal capacity, particularly in Israel:

1. **Denial of independence and choice:** Many persons with disabilities are denied choice and independence in the management of their lives. This is manifested in the fact that decisions regarding both larger plans for life and daily routine, are made for them by others. Independence and choice are fundamental rights: studies point at the importance of independence, autonomy, choice and control over one's life in the definition of a person's quality of life.

2. **The challenge of self-determination:** Self-determination, namely self-managed and autonomous activity carried out consciously and out of choice – became a leading principle in the vast majority of services for persons with disabilities in the western world. Many persons with disabilities need the mediation and assistance of a supporter to realize the right to self-determination. In the absence of such a supporter, the environment often determines what a person's life would look like, rather than the person themselves.

3. **Lack of sufficient support:** Persons with and without disabilities may have difficulty managing their lives. Property management, choosing living accommodations or employment, medical care – may all present challenges. However, supported decision-making and the realization of decisions are not a recognized service in Israel. Difficulties in making decisions independently observed in persons with disabilities and older adults are often regarded as proof of the need to appoint a guardian, as opposed to highlighting the obligation of society to offer support.

4. **Professionalization in the area of disabilities:** Today, many professionals are involved in making decisions regarding the lives of persons with disabilities. As an example, the evaluation committee that determines the types of services a person with disabilities would be entitled to receive is composed of five members of different professions. Consequently, many evaluations do not give decisive weight (if any) to the person's wishes, but rather to institutional considerations (limited supply of services, budget considerations, etc.). In fact, the system of services currently available to persons with disabilities offers no independent party tasked with helping them to access rights and make decisions according to their wishes.

5. **Violation of human rights and stigma:** Persons with disabilities cope daily with discrimination due to their disability and with severe social stigmas, for instance by service providers in private or public bodies (bank clerks, physicians). Persons with disabilities also routinely interact with care, rehabilitation, and welfare agencies, which are often believed to over prioritize protection considerations. Given this background, there is increased need to provide individuals with the support and assistance needed to access their rights and insist on their will.

6. **The role of family members:** The implicit premise of the state is that parents of persons with disabilities or their family members should manage their affairs. In fact, of the 60,000 persons under guardianship, in about 85% of the cases the guardian is a family member or a close acquaintance, while the rest are under external guardianship. Imposing the responsibility to manage a person's life on a family member takes a heavy toll: there are high attrition rates among parents, who often report feelings of bearing a heavy burden they must carry throughout their lives, as well as tremendous anxiety over what might happen after they die. In addition, in a situation of parent or family guardianship, the line between the person's considerations and the parents' is blurred, and the person's dependency on their family is intensified together with their perception of being incapable and lacking independence.

7. **Criticism against the institution of guardianship:** The Supreme Court has held that guardianship *per se* curtails human rights and that its use should be limited. Beyond the inherent violation of rights, the institution of guardianship in Israel has come under heavy criticism in recent years: three State Comptroller reports (2004, 2011, 2012); the case of Yardena Nilman, a guardian convicted of stealing money from people under her guardianship; the closing down of the Dorei Dorot Guardianship Corporation; the General Guardian report regarding irregularities in the Sheffer Association; and many complaints from the field point at the heavy price people may pay just because they have been put under guardianship. Between 85%-90% of all guardianship appointments cover both person and property and proportionate alternatives are scarcely used. In addition to the need for better oversight, the use of guardianship itself should be re-examined along with the promotion of alternative mechanisms that leave people in control of their own lives, without impinging on their legal capacity.

It is against the backdrop of these challenges, which feature in the lives of persons with disabilities the world over, that many countries have come to realize the need to develop the independent and unique function of supporter.

C. Model development – background

The model presented in this document is based on ample knowledge accumulated by Bizchut in recent years. Specifically, the model is based on:

1. **Article 12 pilot:** In 2014-2015, Bizchut conducted a pilot project in which support in decision-making was provided to 22 participants who had been defined by professionals or by the court system as persons who should be appointed a guardian. The model presented here was developed as a basis for providing support to these persons and underwent many changes based on the experience accumulated in the pilot. For more on the pilot see Schedule A.

2. **Studying world developments:** Bizchut is active on the international scene and maintains ongoing relations with many of the experts conducting supported decision-making pilots. Some of the countries where developments have been studied include Sweden, Bulgaria, Canada, the United States and the Czech Republic. In addition, meetings were held with experienced experts from Australia, Ireland and England.

3. **Reciprocal learning from colleagues in Israel:** Bizchut is active in a coalition of 20 organizations that recognize the need to promote supported decision-making and pursue the realization of Article12 in Israel. In this context, the work of the Ministry of Justice Legal Aid Department is noteworthy as it has made inroads into obtaining court recognition for supported decision-making as an alternative to guardianship.

4. **Legal advocacy:** Throughout the years, Bizchut provided assistance to dozens of persons wishing to free themselves from guardianship and use alternatives. Among others, Bizchut provided legal representation in the first case in Israel in which the court recognized supported decision-making as an alternative to guardianship (the precedent of Dana Carmon in Guardianship file 50389-02-13 (Haifa) Attorney General v. A.). The legal and community assistance provided by Bizchut in these cases contributed to the formulation of the model.

> **Pilot participant:**
>
> 👍 When I saw that I was like the supporter, that I was her equal, that I'm also a human being, I saw the way she treated me, so nicely, without being judgmental, she didn't judge me and she never made fun of me… Suddenly I saw that she too had problems, that she also had money concerns.

D. The decision-making process

The decision-making process is usually described as consisting of the following stages: identifying the decision-making juncture; gathering information and data regarding the situation; identifying the options available; evaluating the meaning, advantages and disadvantages of the options; considering them, choosing and making a decision; and immediately thereafter implementing the decision and assessing it.

Studies from the last three decades point at the gap between normative models and descriptive models of decision-making: normative models outline the ideal decision-making process which would lead to the realization of the person's goals; the normative model is usually rational, consisting of statistical calculations, feasibility evaluations and the chronology of the decision-making stages. Descriptive models on the other hand, look at the actual decision-making process: they describe the person's blind spots in the process, the impact of the decision-making conditions on the quality of the process (risk, uncertainty, as well as information overload and choice overload), the impact of the decision-maker's emotions, the role of intuition, etc. At the same time, the importance of support and assistance is increasingly recognized as a means to facilitate and strengthen decision-making among diverse groups: employees in large companies, patients in health systems, military officers and beneficiaries of welfare services. Recognition of the fact that people form part of a wide net of connections and dependencies and that they make decisions with the support and assistance of their confidants is also on the rise. Meanwhile, multiple tools have been developed to strengthen abilities and skills in the areas of decision-making, choice and self-determination among persons with disabilities. The work model presented below relies in part on the assumption that the decision-making process is neither rational nor chronological and attempts to develop support and accommodations for some of the elements of this process.

E. Support by confidant versus support services

One of the main unresolved questions in the supported decision-making field is whether support should be given primarily by confidants (family and friends), in a legally regulated formulation, or whether it should be a professional service developed and funded by the state. On the one hand, some argue that support should not become a governmental service due to concerns that government intervention would distort support and turn it into a care service driven by the 'person's best interests' criteria rather than their wishes. Others argue that support should not be provided by family members to avoid conflicts of interest; independence is often sought from parents or family and therefore parents should not act as the main supporting agent in the process. Another argument is that some people have no close support system or relationships of trust, and that an external support service should be developed at least for them.

Bizchut takes the middle ground. We believe legislation should recognize both tracks – supported decision-making by confidants and as a state-funded public service, given mainly through civil society service providers. In view of our position, we believe that training and support programs should be developed to help family members and confidants act as decision-making supporters, concomitantly with a state-funded service that would offers external, professional support. The following model, which is also relevant to confidants and family members, focuses on the second option of developing a supported decision-making service. Bizchut's Article 12 Pilot which was premised on this model, was unique in the international context as it was the first pilot which sought to develop professional support rather than frame the support provided by family members.

PART 2

Supported Decision-Making Service Model

A. The Vision

Persons with disabilities eighteen and over will have the right and freedom to make their own decisions, and for that purpose they will be entitled to receive supported decision-making services.

B. Guiding values and principles

1 Will and Preferences   **2** Liberty   **3** Pluralism   **4** Adaptive Support
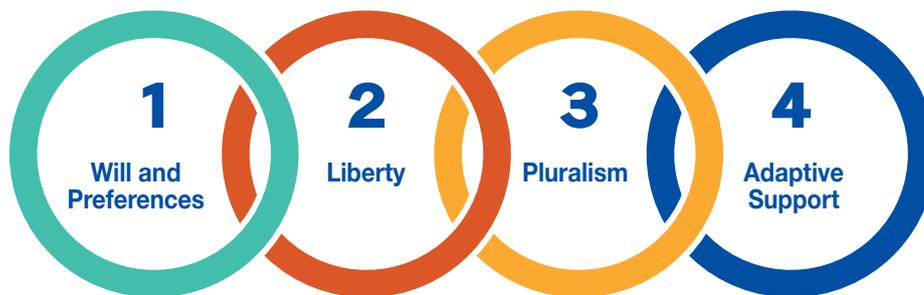
1. **Will and Preferences:** All persons have wishes and preferences which can be detected. All persons have the right to live their lives according to their wishes and preferences.

2. **Liberty:** All persons have the right to liberty and self-determination; the right to organize their lives according to their wishes and preferences, with adequate support if necessary.

3. **Pluralism:** There is more than one right way to live life and make life decisions. Therefore, there are no objective or professional criteria according to which decisions about a person's life should be made.

4. **Adaptive Support:** The right of persons with disabilities to independence, autonomy and full legal capacity often depends on receiving adaptive support for the realization of a person's needs and wishes. The need for support is not an indication of incapacity but rather of society's obligation to provide accommodations which would facilitate the realization of the will.

C. Target audience

A considerably large target audience can benefit from supported decision-making services. The following are some guidelines for identifying this target audience (whether the support is given by family members or by external support professionals):

1. **Persons under guardianship:** Any person to whom a guardian has been appointed or who is considered for a guardianship appointment may be a candidate for receiving supported decision-making services. The amendment to the Israeli Legal Capacity and Guardianship Law (see Schedule D) emphasizes that the court should consider the option of appointing a decision-making supporter prior to appointing a guardian. However, the appointment of a supporter concurrently with a guardian was repeatedly proven in the pilot to be ineffectual: the supporter cannot really help the person pursue their wishes when every choice is subject to the guardian's approval, and the supporter's work releases the guardian from their responsibility toward the supported person. Therefore, it must be clear that the supporter should substitute the guardian and that once a supporter is appointed, guardianship in areas in which support is provided should be revoked.

2. **A person's will and motivation:** The more motivated a person is to make their own decisions about their life and live autonomously through support – the greater the chances the support process will be effective and significant.

3. **Age:** The CRPD is premised on the concept that every adult has the right to full legal capacity; Israeli law is also based on the same premise. Therefore, every person over eighteen years of age can enjoy supported decision-making services at any age. However, age is a significant variable as far as the nature of the support is concerned: where younger persons are concerned (mainly 18-21), who still attend special education institutions, decision–making support usually focuses on providing tools and practicing decision-making processes; with older persons, the process tends to be less educational and provides more practical support in day-to-day challenges.

4. **Disability:** Several segments of the population of persons with disabilities that can benefit supported decision-making services may be identified: people with psychosocial disabilities, people with intellectual disabilities, people on the autism spectrum and people with other disabilities (rare diseases, complex learning disabilities) coping with difficulties in various stages of the decision-making process.

Guardian and relative of pilot participant:

> Too many cooks spoil the broth. Efrat has an emotional therapist, a coordinator and counselors at the housing program, someone from Bizchut, someone from employment and us. Nobody knows what the others are doing and she manipulates us: 'My Bizchut supported told me I could do whatever I want…' It's too confusing.

On a conservative estimate, supported decision-making services as an alternative for guardianship can be relevant at least to a significant number of people among the 60,000 persons living under guardianship in Israel. In fact, the number is much higher as it also includes persons without guardianship who need assistance and support to realize their will.

Reference should also be made to a population which was not included in the pilot and which is not the focus of this report – older adults: older adults living with dementia and their family members who must often cope with the issue of their legal capacity and the need to have a guardian appointed. It is very important to develop adaptive supported decision-making services and additional alternatives to guardianship (such as a lasting power of attorney) for this population. The Ministry of Justice Legal Aid Department and Yad Riva Association plan to conduct a supported decision-making pilot for older adults. Schedule G to this report, which was written by Prof. Israel (Issi) Doron, discusses the adaptation of the model proposed herein to older adults.

D. Description of the service

The supported decision-making service (hereinafter: the decision-making supporters or the service) is based on a personal supporter assisting the person to realize his legal capacity by promoting his wills and preferences. The supporter provides guidance, support and assistance in making decisions in all areas of life and the support continues for as long as the person wishes to receive it and needs it. The service includes practical training and guidance of the supporters.

E. Elements of the supporter role

The profile of persons who have been found suited for the role of supporter includes two foundational elements, one formulated as a desired element and one as undesired:

1. **A supporter need not be a care professional:** Most persons with disabilities have many care professionals involved in their lives. The purpose of the support is to ensure that the supporter does not represent the professional establishment but rather the interests of the individual, from his or her perspective. It has been found that not only was there no need to assign people with professional experience in providing care to persons with disabilities to the role of supporter, but rather that it was advantageous to assign people who are external to the professional establishment and do not bring a care-based approach into their interactions with persons with disabilities. Consequently, there is also no need to require any academic education as a minimum condition.

2. **Relevant experience:** Any experience supporters have had in their personal or professional lives that reinforces each of the following three elements in the supporter's role has been identified as advantageous:

   a. **Worldview and values:** The worldview underlying the role of the supporter is that every person has the right to make decisions about their life based on their wishes and preferences. Consequently, it is imperative that supporters subscribe to this worldview and believe in the supported person and their ability to make decisions about their life. Supporters should be aware of the proclivity of professionals working with persons with disabilities toward paternalism and over-protection.

They should be cognizant of their obligation to regard the person to whom support is provided as their equal.

b. Interpersonal skills and the ability to create trust: Support is based on the supporter's ability to establish a rapport with the supported person that is based on trust and remains on target. Therefore, supporters should have good communication and listening skills. In this context, supporter openness to the fact that people live their lives in different ways and that there are different ways to pursue goals, should be emphasized. It is also important to emphasize supporters' ability to stand back, let the process focus on the person receiving the service, and let them lead it as best they can.

c. Maturity: The role of the decision-making supporter requires the ability to cope with complex life situations, tension that may arise between the person and the community – including the supporter themselves – and with the very participation in an innovative process, which is not self-evident in Israeli society today. Hence, the role of supporter requires considerable maturity, and we are therefore of the opinion that 25 should be established as the minimum age at which a person will be eligible to act as a supporter.

In conclusion, supporter suitability should be examined first and foremost based on interviews and personal impression, according to the above guidelines.
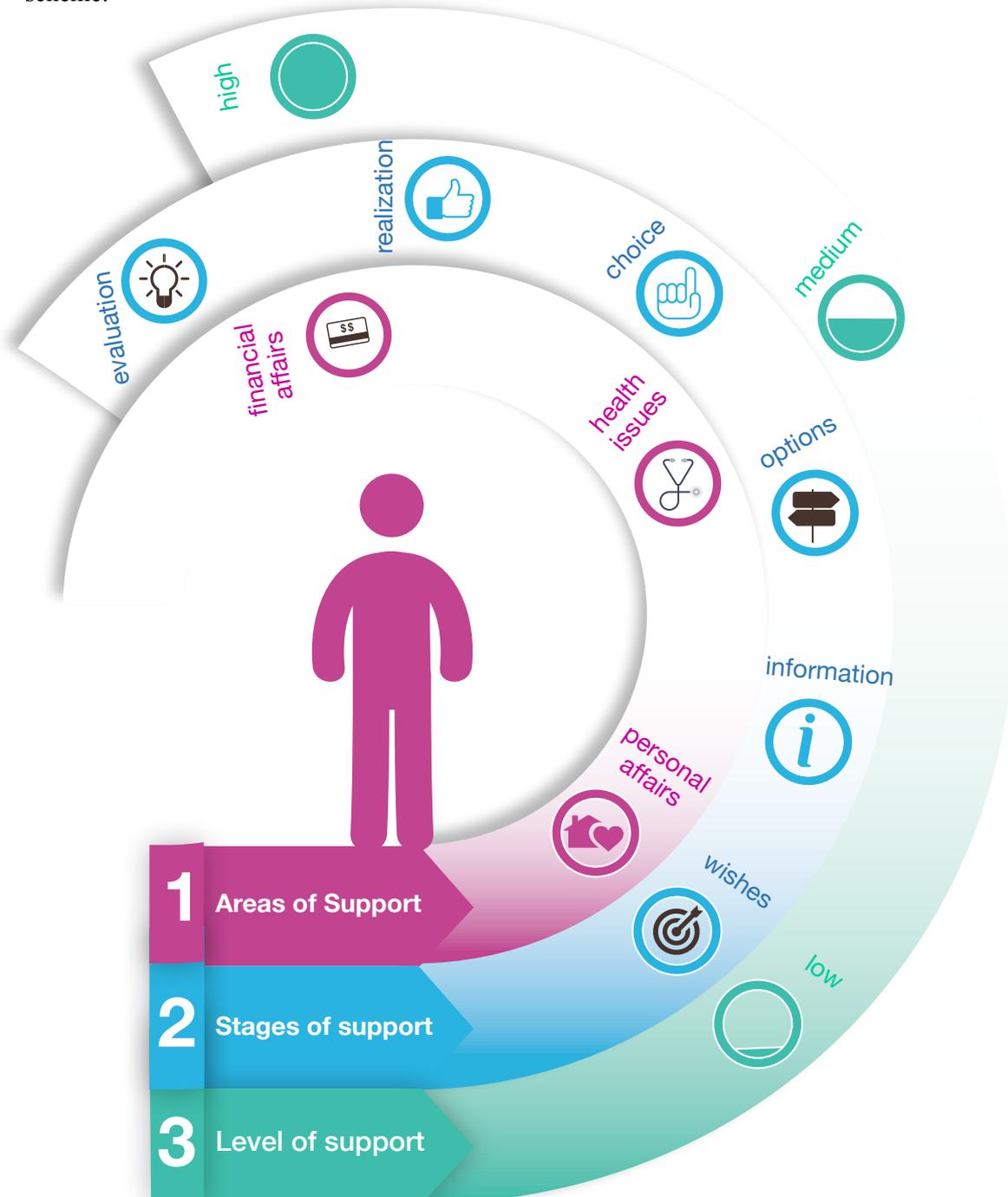
F. Support scheme

The support scheme is based on a combination of three dimensions:

1. Areas of support

2. Stages of support

3. Levels of support

We elaborate on each dimension separately and follow with several examples for the support scheme:

1 Areas of support

Areas of support may be numerous and diverse. Sometimes a person knows in which areas they wish to receive decision-making support, and sometimes it is part of the supporter's role to help the person identify these areas. Areas of support should be prioritized according to the person's wishes, the limitations in the scope of the support and the issues which are important to the supported person. The following is a partial list of issues that preoccupy any person and may be the area of support. As emphasized below, some of these issues – for instance housing and employment – have regulated support services. One of the supporter's roles is to help the supported person access and use available support sources. The person may choose not to use the available services and instead attempt to advocate for themselves. In this case, the supporter's role is to explain the ramifications of this choice, its advantages and disadvantages, rather than substitute the services available with respect to this issue. The following chart demonstrates the range of issues that may be included in the support.

Personal affairs

- Choosing living accommodations
- Employment
- Family relations
- Social relations
- Leisure activities
- Vacation
- Intimate relations
- Home maintenance
- Education
- Exhaustion of rights
- Personal disputes

Health Issues

- Preventive care
- Handling a medical problem
- Medication
- Hospitalization
- Dental care
- Health insurance
- Alternative medicine
- Fitness and nutrition

Financial Issues

- Budget balancing
- Benefit management
- Bank account management
- Property management
- Automatic payment management
- Debt management
- Inheritance
- Financial exploitation
- Investments
- Legal financial proceedings
- Exhaustion of proprietary rights

Examples from the pilot of the different support areas:

☑ **Choosing living accommodations** – a desire to move from a hostel or group home to independent supported living accommodations in the community.

☑ **Employment** – a desire to leave a protected employment factory or workplace.

☑ **Social relations** – a desire to expand the social circle.

☑ **Vacation** – a desire to take a vacation abroad.

☑ **Intimate relations** – a desire to find a partner, or a need to address difficulties around this issue.

☑ **Education** – a desire to enroll in professional training or academic programs or to learn to read.

☑ **Exhaustion of personal rights** – a desire to access all services offered to persons with disabilities by the National Insurance Institute, the local authority or various government ministries, including specific issues people wanted to pursue, such as a driver's license or name change in the Ministry of the Interior.

☑ **Health issues** – navigating the bureaucracy of the health care system, changing to another health fund, requesting to psychiatric treatment from the health fund as part of the Israeli mental health reform, dilemmas regarding medical procedures.

☑ **Budget balancing** – a desire for more independence with budget management and for a balance of expenses vs. income.

☑ **Debt management** – a desire to settle debts vis-à-vis the execution office or service provider.

☑ **Financial exploitation** – expressing concern over financial exploitation by a service provider or a private individual.

☑ **Wills** – a desire to draw-up a will.

☑ **Exhaustion of financial rights** – a desire to increase the National insurance Institution benefits or to arrange eligibility for rental support from the Ministry of Construction and Housing.

Pilot participant:

"I decided to switch health funds and I made a decision, just like that, without giving it much thought, that is, I was on the Internet and switched funds… without thinking about the consequences, for example, that it was inconvenient because there is no transportation to the new clinic… I called my supporter and she told me we should take a look at what's good and what's not so good. So I explained to her the transportation issue which I had forgotten to take into account and I also hadn't thought about the issue of having to start from the beginning again, which is very hard for me… and all kinds of things like that, so in the end I thought it would be better to cancel…"

External guardian of pilot participant:

"Responsibility was returned to her and now everything is stuck – all the medical documents which were required for her to receive an additional allowance. Over the past six months, I spoke to her about this and told her she was losing rights because she wasn't providing the documents. I can't submit the application. It's stuck with her".

2 Stages of support

The decision-making process consists of six stages: establishing **wishes**; gathering the relevant **information** for making choices and decisions; understanding the different **options** available including their advantages and disadvantages; making a **choice**; **implementing** the choice; and **evaluating** the choice made and the additional choices currently on the agenda. The support outline is affected by what stage of the decision-making process the person in question is in. We describe the support in each one of the stages:

A. Wishes

The support process is predicated on a person's wishes and preferences, and therefore it begins with exploring these wishes. At this stage, the person expresses a range of desires, great and small. This stage is crucial for building trust and marks a significant difference between a decision supporter and a care professional. The supporter may regard some of the desires as unrealistic or problematic, but their role is not to judge or to express their opinion about them, but rather to help the person realize their own desires, to present the difficulties and challenges in the process, and to propose ways to overcome them. At the same time, it is important to help the person clarify their wishes more thoroughly: is there another way of realizing the objective which should be identified (for instance, a desire to learn to read in order to successfully pass a test which may also be taken orally)? Is the desire their own or someone else's (for instance, a parent's desire for their child to attend an afternoon class)? This exploration is part of the decision-making learning process. One of the major challenges of support is that sometimes a person finds it difficult to identify their desires. The supporter's role is to help them identify their desires and become acquainted with the diverse options available to them.

Practical tools:

- Introductory and trust building meetings: many people cannot embark on the support process and identify a person's real desires without becoming better acquainted with them and their support environment, and without building trust with them. During the pilot, several desirable features were identified for meetings with the supporters:

- Meet the person in a location that is meaningful for them (workplace, childhood home).

- Develop clear and open communication based on respect, honesty and no judgment, both in verbal communications and in gestures and body language.

- Use the person's social circle of confidants or meeting individuals who play a significant role in the person's life.

- Build relationships through shared activities.

- Mutuality – the supporter should be ready to learn from the person and welcome mutual exposure.

Using existing models in a bid to identify the will:

The PATH (Planning Alternative Tomorrows with Hope) model assists a person to identify their wishes. The model consists of nine stages, focusing on a person's dreams and their transformation into achievable goals and it is mainly aimed at persons with intellectual disabilities. Another model, known as MAPS (Making Action Plans), was developed in the context of children with special needs but is also applicable to adults. The model is aimed at assisting a person to build a personal life story and to identify their wishes based on their life story, dreams and aspirations, fears, significant past choices, preferences, strengths and skills, resources available to the person, etc.

B. Information

Once the person's basic wishes are identified, updated and relevant information should be gathered concerning the available options, enabling them to weigh the advantages and disadvantages of each option towards making a specific decision. The supporter does not have to be a content expert and should not provide the information to the person, but rather help them access and understand it.

Practical tools:

- Rely on the supported person's knowledge.
- Suggest sources that can provide information.
- Hold joint meetings or conversations with professionals, service providers, experts, and (obviously) family members and friends.
- Explore ways to overcome internal impediments (language, communication difficulties) and external obstacles (bureaucracy) to accessing information.
- Illustrate the information to the person (using a chart, a drawing, other visual aids).
- Simplify and reorganize the information (important and unimportant, more or less relevant).
- Synchronize information obtained from different sources.

C. Options

A person almost always has more than one option. The decision-making process consists of identifying the different options and understanding the advantages and disadvantages of each one of them. This is the core of the support outline and it is its most sensitive stage, given that biased support can easily highlight the disadvantages of one option and the advantages of another in order to lead the person towards a certain choice. This is where the supporter's professionalism and personal ethics come into play: the supporter's role is to put themselves aside as much as possible and help the person identify the different options available to them. Still, there is value in the supporter taking a proactive approach at this stage, raising additional options which were not considered by the person and pointing out advantages and disadvantages which had not been taken into account. It is also important to encourage the person to consult with the people close to them to hear their opinion about the different options. At this point the supporter may face the dilemma of whether to share their personal position with the person (see Schedule A for discussion of the ethical dilemmas that came up during the pilot).

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Practical tools:

- Compare the options according to different parameters (pros/cons, advantages/disadvantages, practical/impractical, immediate/far-off.

- Demonstrate the options, for instance by simulation or experience.

- Break down a goal to several sub-assignments to make it easier for the person to understand the different options available to them.

- Assist the person to limit or expand the number of options available to them.

D. Choice

Choosing between the different options is a significant and constitutive moment in the process. The supporter's role at this stage is mainly to help the person reach a decision-making junction. Once the options have been presented including their advantages and disadvantages, the choice is the person's alone, and it is not purely rational. It also involves emotional considerations, inter-personal influences and intuition. The supporter's role at this stage is to conceptualize the choice for the person and help them prepare for the next stage, the implementation of the decision.

E. Implementation

Whether or not support in the implementation of the decision is part of the role of the decision-making supporter is a matter of debate. Bizchut's position is that the decision-making process is futile without support in the implementation of the decision. Therefore, Bizchut's model also includes the implementation element. Supporting the implementation consists of three aspects:

Examination of the ways to implement the decision: In certain areas, the state provides the person assistance in the implementation of their decisions (such as employment support). In certain areas assistance may be privately acquired and in certain areas assistance is either non-existent or insufficient. The supporter can help the person examine the different implementation options and decide how they would like to use them.

Exhaustion of rights: a considerable number of services are aimed at assisting a person to implement their choices: supported living accommodation, supported employment, legal aid, third-sector services for exhaustion of rights, etc. The supporter should help the person exhaust their rights using the currently available services according to their choices and decisions.

External guardian about a pilot participant:

It seems that Shira's requests are more focused than they used to be in the past. She does not call just for idle conversations, she requests realistic things.

Supporting the implementation of the decision: In view of the fact that the support services available to persons with disabilities are partial and lacking, the support of the supporter is often needed for the implementation of the decision. However, in many cases such support is partial and insufficient since it is time consuming, intensive and requires training which the supporter does not have. This is the case particularly in the employment and housing areas which require multiple, diverse support resources – for instance when the case concerns a person seeking independent living accommodations in the community. Hence, it should be emphasized that the development of supported decision-making services cannot replace the development of a personal support package.

Practical tools:

- Help the person build a practical plan for the implementation of the choice made.
- Accompany the person in the implementation process (writing a letter, completing a form, planning a meeting or any other act).
- Break down the implementation into stages, according to the person's ability.
- Help the person plan and conduct meetings attended by the person, the supporter and the relevant party for the implementation of the choice (service provider, parent, welfare department social worker).
- Advise the person on how to contact different agencies, including simulations and hands-on experiences.

F.   Evaluation

The last stage in the decision-making process involves self-evaluation of the decision made and its implementation. Despite the fact that it is referred to as the last stage, it actually runs through the entire process, which consists of constant re-evaluation of the circumstances, options, wishes and manner of implementation of the person's decision. At this stage, the person can change their mind, change direction or feel stronger and more reassured about their decision.

The transition between the different stages has its own dynamics: So, for example, the process, in and of itself, can evoke new or 'dormant' desires for the person, leading to an additional support process. In addition, understanding the different options available to them may cause the person to go back and gather additional information, in a bid to explore all options. Hence, the transition between the different support stages is not necessarily linear, repetitive and consistent but can rather be spiral and even staggered.

3 Level of support

Throughout the stages listed above, the person and the supporter are required to make decisions about the level of support, namely, how intensive and how active it is. In this context, several scenarios are possible – the person wishes to act independently despite the supporter's opinion that they will not be able to succeed alone or the person requests more intensive support than the supporter thinks they need. As part of the effort to avoid paternalism, there needs to be dialogue between the person and the supporter, acknowledging that asking for help and support is natural and legitimate, as is the desire to try to proceed independently. The person and the supporter should decide whether the support will be given mainly in the form of consultation and behind-the-scenes assistance (for instance, by providing assistance with writing a letter or understanding information), or whether it also requires the supporter's presence and involvement in the different decision-making stages vis-à-vis the different figures in the person's life (for instance, taking part in meetings or telephone conversations, escorting the person to National Insurance Institution appointments, conducting joint conversations with the parents).

Summary of the support outline

The combination of the area of support, stages of support and level of support creates the supported decision-making outline, as demonstrated below through the different processes that took place in the pilot:

Example 1: ▶ area: **property – drawing up a will**

▶ stage: **all stages**

▶ level of support: **medium**

A pilot participant expressed a clear desire to draw up a will. The issue in question was how to pursue this and how to obtain legal aid for this purpose. The process began with exploring the wishes and understanding the available options – drawing up a will independently or approaching legal aid to obtain the services of a lawyer who would assist to draw up the will. After a decision was made to proceed with the second option, we broke down the execution into different stages: obtaining a psychiatric certificate concerning the participant's capacity to draw up a will, contacting legal aid and completing forms to secure representation. The participant did not require much help vis-à-vis the psychiatrist but needed mediation in her communications with legal aid.

Example 2: ▶ area: **living accommodations**
– moving into independent living accommodations

▶ stage: **implementation**

▶ level of support: **medium**

A pilot participant expressed a clear desire to move to independent living accommodations in the community. A short examination revealed that a supported housing service providing assistance throughout the transition process into independent living accommodations was set to open in Jerusalem. The support was mainly given to the participant in sourcing information, applying for the service and assisting the participant to convince his family members to support the transition. After the pilot ended, the participant moved to independent living accommodations under the auspices of the supported housing services.

Example 3:   ▶ area: **property – independent money management**

   ▶ stage: **all stages**

   ▶ level of support: **medium**

A pilot participant expressed a desire to be more independent and less dependent on his family members. Throughout the year it became apparent that he wanted to manage his disability benefits and employment income by himself with the assistance of his family members – instead of having the latter manage the funds for him. For this purpose, he had to have a better understanding his earnings and expenses and reach an understanding with his parents which would balance his will for independence and their desire to prevent him from making mistakes. As the process progressed, an application to revoke the family's guardianship over his property had to be filed with the court and the welfare worker had to be convinced to give a supporting recommendation. The support was provided along all stages on a medium level, as it was sufficient to break down the goal into stages – which the participant executed independently with the supporter's specific intervention in the more complex junctures.

Example 4:   ▶ area: **all areas (property, living conditions, health)**

   ▶ stage: **will**

   ▶ level of support: **intensive**

A pilot participant requested her supporter to help her cope with many difficulties in her life: debt accumulated by her guardian with the municipality, difficulties with her treating physician, her desire to revoke the guardianship, etc. Throughout the entire year, the support process remained in the first stage of exploring participant's will: whenever she expressed a wish and its implementation process was initiated – the participant chose to re-open the discussion about this wish and the ways to implement it. The entire process required intensive support in all of its initial stages of support (identifying the wishes, sourcing information, understanding the options) due to participant's difficulties.

Example 5:   ▶ area: **examination of finances**

   ▶ stage: **all stages**

   ▶ level of support: **high**

A pilot participant requested assistance in managing her property. She was not familiar with her financial situation and consequently felt paralyzed with respect to financial decisions she had to make such as heating during the winter. The first stage was to identify her wishes, which revealed that she did not want other people to make decisions for her, but did want someone to help her understand her financial situation. At the second stage, with the assistance of her supporter, she gathered information about her financial situation by going over the printouts of her checking account and credit card bills and studying the bills she received by mail. Thereafter, an annual table of earnings versus expenses was created, facilitating the understanding of her financial situation and serving as a tool for making specific decisions (such as buying a new printer). The support throughout the process was intensive, but after it was completed and everything was properly organized, low intensity support was sufficient, needed only once every few months.

G. Support duration

The supported decision-making service is differential by nature since it varies according to the different characteristics and needs of the person who receives the service: young people starting out their lives may need support for a certain designated period of time after which they would be able to establish their ability to make decisions without supported decision-making services. Others, such as persons with intellectual disabilities, may need support throughout their lives. Persons with fluctuating functionality (such as persons with psychosocial disabilities) may need support at varying levels of intensity. Therefore, the duration of the service and its intensity should be tailored to each and every person, acknowledging the fact that many people may need support for their entire lives.

Criteria for examining whether the service should be continued or terminated:

1. **The person's will:** The person's will to continue with the service or terminate it. In this regard, a distinction should be made between a person's wish to remain in contact with the supporter (for various reasons, such as the supporter being a confidant, or to ease loneliness) and their wish to continue receiving decision-making support.

2. **The need for support:** Inasmuch as support services are a public resource, an external evaluation should also be made as to whether continued support is required. As part of this evaluation, consideration should be given to the following: other modes of support given to the person, which may render the support service redundant; the extent to which the support promotes the person's autonomy and liberty and the extent to which the termination of the support may harm them. The effectiveness of the support given thus far should also be reviewed.

> **Mother of pilot participant:**
>
> How can we continue protecting her, helping her, mediating, while giving her, at the same time, the right to make choices and the possibility to grow and build independence and the ability to build her own identity?

H. Personal characteristics affecting support

Any support should accommodate the person's individual needs. However, several general characteristics that considerably affect support may be identified:

1. **Age:** As noted, the participant's age and personal history may influence the support process. Young participants between 18-21 years of age may not be able to benefit from the full potential of the supported decision-making service, as they still attend educational institutions and have a limited degree of decision-making control over their lives. However, their admittance into this sort of service may reduce the chance of having a guardian appointed, which is common in this age group. The issue of accommodating supported decision-making to senior citizens is discussed in detail in Schedule G.

2. **Type of living accommodations:** The supporter's role is greatly affected by the nature of the person's living accommodations – out-of-home of living arrangements, living with family members (in most cases the parents) or independent living accommodations. The more limited the person's support sources, such as a person living independently without supported housing services, the broader and more vital the role of the decision supporter may be. However, when the participant lives in a housing program, supported decision-making issues may increase and may also include the person's difficulties vis-à-vis the service providers within the program, thoughts about leaving the program and services that are not provided by it. Possible tensions between the supporter's role and the role of the housing program staff should be considered.

3. **Functioning and independence level:** Supported decision-making services may be offered to participants with varying levels of functioning and independence. Supporting persons who are well aware of their wishes and experience difficulties mainly in implementing them will be very different from providing support to persons who experience difficulties in establishing their will (either due to pressures exerted by the environment, absence of clear will or lack of decision-making experience).

Along with the above factors, many additional factors should be mentioned such as religion, gender, economic situation, stage in life, family status etc. We disagree with the current trend of considering the type of disability as a major element in designing the services provided to a person seen within welfare services. In keeping with prevalent attitudes in the field of disabilities that put the emphasis on needs rather than disabilities, our position is that supported decision-making services should also put the emphasis on the person's specific needs. So, for instance, some pilot participants with psychosocial disabilities needed assistance with understanding information, linguistic simplification and exploring their will, in a manner which was not materially different from the needs of participants with intellectual disabilities. In addition, 12 out of the 22 pilot participants had more than one disability and therefore the division into different categories of disability does not suit reality. However, we do believe it is important to highlight, in supporter training and practical coaching, certain aspects of the different disabilities, related to typical ways of coping, if such exist, and any relevant services and rights that may be relevant to said disability.

> **Pilot participant:**
>
> 👍 Michal comes to see me once a week. She is smart, patient and sensitive. She really tries to help me. I can call her if I have a problem. I am not alone. A reaching hand is a huge thing. I would like to be understood rather than judged, to be accepted despite the difference. Without paternalism and without condescension.

I.   Ethical principles for supporter role

We attach a great deal of importance to further establishing the ethical principles for the role of supporter. The following is a preliminary list of ethical principles formulated following the pilot:

1.   The person is the expert on their life.

2.   Every person has the right and ability to exercise their wishes and preferences given suitable support.

3.   Every person decides how to lead their life and bears responsibility for their decisions.

4.   The supporter's role is not to provide care for the person or focus on their internal change processes, but rather to assist them in the decision-making process and in overcoming environmental barriers.

5.   The supporter will not exert undue influence on the person.

6.   The supporter owes a duty of confidentiality towards the person.

7.   The supporter will not hold meetings about the person without the latter's knowledge, or, to the extent possible, in their absence.

8.   The support process and all information in the supporter's possession will be known and accessible to the person.

9.   The supporter will not assist the person to carry out unlawful actions.

10.   The supporter may withhold support for the person's actions which are extremely contrary to the supporter's moral convictions.

11.   The supporter will refrain from receiving any gift in any way or manner from the person or their family members.

J.   Risk and harm scenarios

One of the main issues repeatedly raised with respect to persons with disabilities under guardianship is the issue of risk and harm. In the development of an alternative supported decision-making service, questions arise regarding the supporter's level of liability in cases of concern over risk or harm to the participant, and the supporter's preferable course of action in such circumstances.

We are of the opinion that the great and disproportionate place that risk and harm occupy in the discourse about persons with disabilities is more damaging than the risk situations themselves. However, to prevent over involvement by the supporter, clear guidelines should be outlined with respect to supporter conduct in risk situations. We propose as follows:

1. **Imposing a reporting obligation according to the Penal Law**: The Penal Law imposes an enhanced reporting obligation on a person responsible for a helpless person and on different professionals such as care and education professionals. Despite the fact that the supporter is not 'responsible' for the person and although the person receiving the support is not 'helpless', we are of the opinion that in view of the extreme cases included in the reporting obligation, extending the enhanced reporting obligation to supporters should be considered.

2. **Internal reporting**: The supported decision-making service should include an internal reporting mechanism regarding risk-related dilemmas, both in order to avoid leaving the supporter with sole responsibility, and in order to ensure that all considerations relevant to the preferable intervention by the supporter and the support service are taken into account.

3. **Withholding support**: The supporter is not a care professional and therefore has different responsibilities from care professionals. While more stringent rules apply to care professionals as far as risk prevention is concerned, supporters – by their nature – should refrain from adopting a paternalistic position and avoid substituting considerations of the person's wishes with considerations involving their best interests, as viewed by the supporter. At the same time, supporters can refuse to support a person who wishes to pursue harmful decisions or suggest bringing another person into the discussion about the decision. In this case too, care must be taken to avoid over-protection and an overly risk-averse approach.

4. **Limiting supporters' liability**: The law should expressly provide supporters bear no liability in case of harm, provided they acted according to these guidelines.

K. Termination of supporter – participant relationships

The initial condition for supported decision-making is the person's motivation to receive it. Consequently, the person can decide at any given moment to terminate the support. Over the course of the pilot, it seemed that in some cases the support had been exhausted. So, for instance, one of the participants asked to continue seeing her supporter, but for companionship rather than support. We believe the support process, which can have ups and downs, should not be terminated hastily, and that a dormant support process, that can be reactivated if the need to make another decision in the person's life arises, should be provided for. Finally, in cases of long term service with no fixed term, it is advisable to establish points at which the desire and need for continued support is to be examined.

> **Pilot participant's parents:**
>
> 👍 As the pilot progressed we became aware of small changes in Yair and in ourselves. Yair started to make more decisions without parental intervention and we, the parents, gradually relinquished our role as mediators…. Today, Yair understands perfectly well that we are there for him but that we are willing to be in the 'background', assuming the role of supporters.

L. Partners in the support process

It is very important, in the support process, to understand the person's life and to get acquainted with the important people in their life. These individuals, who form the person's natural and professional support net, can take part in the support process, but may sometimes act as a barrier that has to be addressed during the process. The main partners are the person's close environment (family members, friends and the community) and their professional environment (service providers, social workers, counselors and other professionals). The work vis-à-vis said partners must consist of three aspects:

1. **Familiarity**: It is recommended that the supporter gets acquainted with person's different supporter providers with the latter's consent, and meet them together with the person.

2. **Coordinating expectations**: The supporter enters a person's life and therefore their role and how it interfaces with other supporter providers should be clearly defined. Meanwhile, it must be clarified that the supporter will speak about the person with others only with the person's knowledge, consent and to the extent possible, presence. In addition, the difference between the role of the supporter and other care professionals should also be made clear.

3. **Advocating and enlisting external support:** Supported decision-making can also include an element of advocacy and enlisting external support for the person's decisions. The supporter should help the person advocate and enlist the support of people and institutions around them to join in the process and, when necessary, help the supported person with resistance from the environment.

M. Supporter training and hands-on counseling

The training and hands-on counseling provided to the supporters along the way is of great importance. The guiding principles for training and hands-on counseling are as follows:

1. **Field-based training**: Supporters' training should be based on the practical, daily experiences of persons with disabilities. Therefore, the theoretical background for supported decision-making and the rights of persons with disabilities should take second place, and the emphasis should be put on the practical aspects of the support.

2. **Core values of the service**: The training should express the core values of supported decision-making which include a human rights approach to persons with disabilities and their right to make decisions, and a critical approach to disability that sees disability as the product of the interaction between a person and an environment that fails to accommodate their needs. The supporter's role is to help accommodate the entire field of decision-making to the person. Consequently, supporters' training should refrain from reinforcing stigmas and from making generalizations about persons with disabilities, and should enable persons with disabilities participate in the training itself.

3. **Individual and group hands-on counseling**: We recommend that supporters undergo a training course before they begin their role. However, the core of supporter training is achieved through hands-on counseling provided throughout the support period. This includes group sessions with the participation of all supporters, intended for peer learning and the establishment of a professional support community. At the same time, individual hands-on counseling should be provided to enable each supporter to thoroughly discuss the different support processes they are participating in.

Schedule C to this report consists of a detailed summary of the training and hands-on counseling provided during the pilot.

Next Steps

While working on the model, an important development occurred in Israel. The Legal Capacity and Guardianship Law underwent a reform as a result of which supported decision-making is now legally recognized (see Schedule D). The law has left the regulation of many aspects to secondary legislation to be enacted by March 2018. Hence, the next two years are crucial for designing the nature of supported decision-making in Israel. Over the course of 2016-2017, Bizchut plans to promote supported decision-making training based on the model presented above, in partnership with additional organizations. We are pursuing short-term training for the person's confidants, as well as long-term training for care professionals or family members wishing to become more professional in the new role of decision-making supporter. Israeli courts are increasingly using the supported decision-making model and the relevancy of the model proposed herein increases by the day. It is a preliminary proposal for a model and we have no doubt that it will undergo additional revisions and adjustments. We invite and welcome all bodies to use the model and adjust it to their unique characteristics. We hope to soon witness an increasing number of pilots and field initiatives aimed at turning CRPD Article 12 into a reality in Israel and abroad.

Pilot participant:

👍 "It is very, very difficult for me to write, so she (the supporter) would help me write and, together with a (sign language) translator, we understood, we created a WhatsApp group among the three of us… for example, if work isn't going well, I want the supporter to talk to my boss so that I can understand what is going on there, or maybe something else…let's say the court, she can help me understand what is happening, or letters I receive that I don't understand and she helps me understand them."

Pilot participant:

👍 She wasn't embarrassed to sit with me in Aroma (a coffee shop).

Schedules

Schedule A

Bizchut Article 12 Pilot

Background

In August 2014, as part of a European Union grant, Bizchut launched the Article 12 Pilot Project, designed to test the supported decision making model on the ground. Several organizations partnered in the pilot project: Beit Issie Shapiro helped to structure and supported the formulation of the model, as well as trained participants; and the Jerusalem Municipality Welfare Department helped find participants and spread the word about the pilot, which was held in the Jerusalem area. The pilot had an advisory committee composed of government and civil society representatives, as well as persons with disabilities and their families. The Office of the Commissioner for Equal Rights for Persons with Disabilities at the Ministry of Justice hosted all advisory committee meetings and partnered in promoting the knowledge gathered in the pilot in a concluding conference.

Schedule A includes a short review of the pilot, beginning with its purposes and goals, through its stages and structure and ending with dilemmas that came up during the pilot and the major insights gained from it. Schedule B provides the summary of the assessment study conducted throughout the pilot. Schedule C details the pilot's training program.

1. Pilot goals and purposes

Pilot purpose:

Persons with disabilities over the age of 18 will enjoy freedom and independence in making decisions about their affairs.

Pilot goals:

1. Developing and formulating a 'supported decision making' model.

2. Running a pilot for twenty people, currently under guardianship in the Jerusalem area.

3. Disseminating the model among persons with disabilities, family members, professionals and policy makers in the field.

2. Pilot stages

a. Decision making supporter recruitment: The pilot budget allowed the employment of two part-time supporters. To broaden the project, and examine a model of volunteer supported decision making services, more supporters were recruited. Following a screening process, 14 supporters were selected to undergo training. Some dropped out during the training, and the support process began with 11 supporters.

Supporter Features

Employment type

2 paid supporters

3 Bizchut volunteers

6 other volunteers

Gender

7 female supporters

4 male supporters
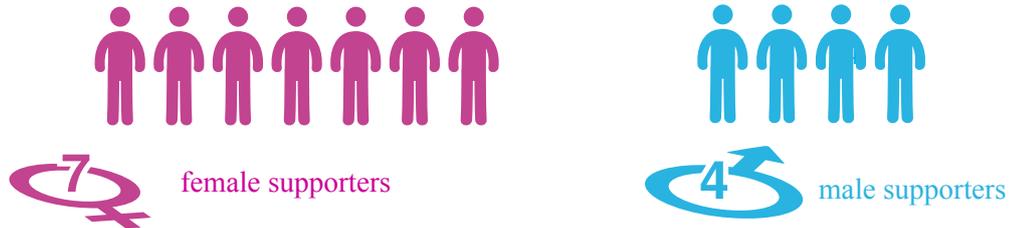
Academic training in disabilities

6 with academic training

5 without academic training

Employment experience with persons with disabilities

6 with experience

5 without experience

b. Supporter training and practicum: Maya Goldman, of Beit Issie Shapiro, and Yotam Tolub, of Bizcchut, the pilot director, designed and delivered the training and practicum program. Training included eight sessions with four 45-minute units each. The practicum consisted of 20 sessions of 3 45-minute units each. Individual counseling sessions were provided to the supporters throughout the year. The training and practicum program is detailed in Schedule C.

c. Partner recruitment: For the sake of efficiency, the pilot was restricted to one geographic area, Jerusalem. In order to do so, a partnership was created with the Jerusalem Municipality Welfare Department, which included a department representative on the advisory committee, and a presentation of the pilot to the four rehabilitation offices in the city, in order to help identify potential participants.

d. Establishment of advisory committee: The advisory committee supported the project from beginning to end, discussing the dilemmas that came up during implementation. The committee included representatives from the government and civil society with clear personal or professional expertise in the field. The committee convened seven times over the course of 14 months.

**e. Assessment study design and implementation:** The pilot was conducted in conjunction with an assessment study by Tal Kahana and Dr. Shira Yalon-Haimovitz. The study was based on quantitative interviews with pilot participants, supporters, family members and guardians. A summary of the assessment study findings is presented in Schedule B, and the full study is available in Hebrew on the Bizchut website: bizchut.org.il/he/2405 (Hebrew).

f. Participant recruitment: Four criteria were put in place for participation in the pilot. 1) Participants must be over 18; 2) They are already or soon to be under guardianship; 3) They must reside in Jerusalem or its vicinity; 4) They must be motivated to receive support in order to advance their independence in decision making. Note that the reason for choosing persons already or soon to be under guardianship was the need to test the supported decision making model as an alternative to guardianship for people who would have unquestionably been appointed a guardian today. To increase the chances of success, and for legal reasons, another condition for participation was the consent of the participant's guardian, which meant that the guardians participating in the project were open to the notion of supported decision making from the outset.

g. Recruitment included four stages:

1. Introductory meetings with the person and the people in their circles (family members, professionals).

2. Opening interviews: once a person decided to participate in the pilot, an hour-long opening interview was conducted.

3. Matching supporters to participants: Each person was offered a specific supporter, after an evaluation of the most suitable match. After an introductory meeting between the person, the supporter and a Bizchut staff member, the person was given the opportunity to ask for a different supporter. No one availed themselves of this opportunity.

4. Beginning of support.

The participant recruitment stage lasted several months and carried into the beginning of the pilot. The last participant joined the pilot in January of 2015. A total of 22 participants were recruited and began the pilot. Over the course of the year, three participants withdrew from the pilot as they did not wish to continue. The following is a breakdown of pilot participants:

Participant Features

Gender

Female Participants **12** | **10** Mail Participants
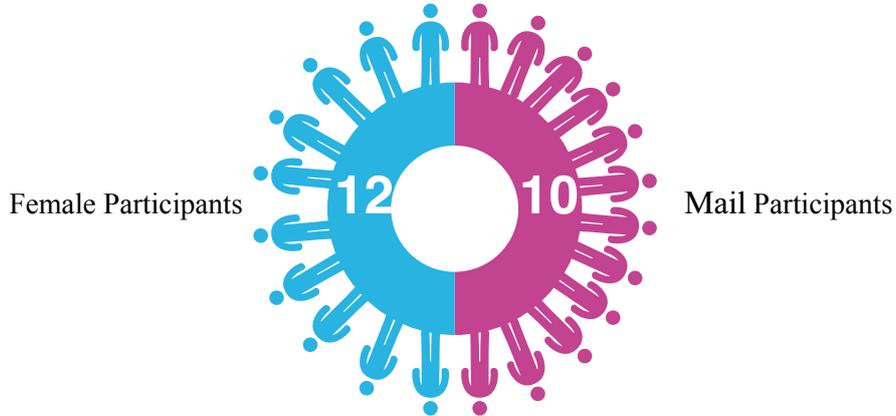
Main disability
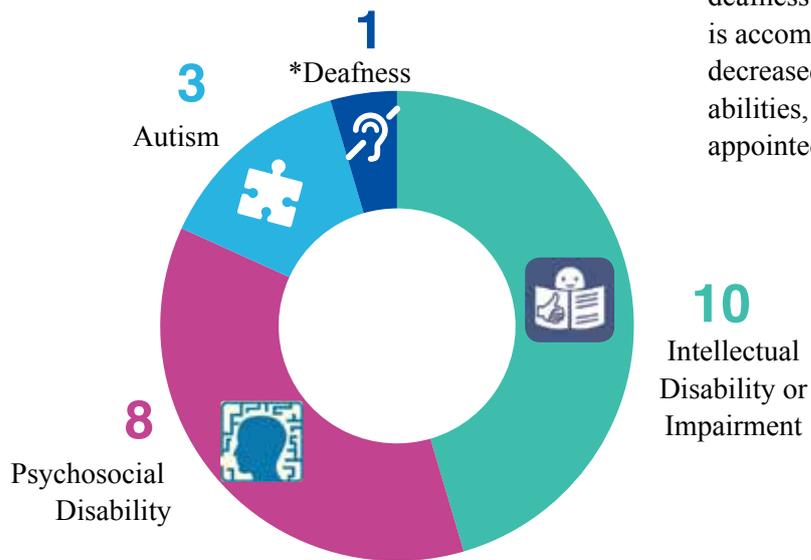
*Sometimes, when deafness or blindness is accompanied by decreased cognitive abilities, a guardian is appointed

1 *Deafness

3 Autism

10 Intellectual Disability or Impairment

8 Psychosocial Disability

Age

4 Older Adult (Over 60)

7 Intermediate (30-60)

11 Young (18-30)

Supported by

13 $

Paid Supporter

9 !

Volunteer

Guardianship

4
no guardian (one was subsequently appointed a guardian)

9
Family Member

7
guardianship corporation

2
Private External Guardianship
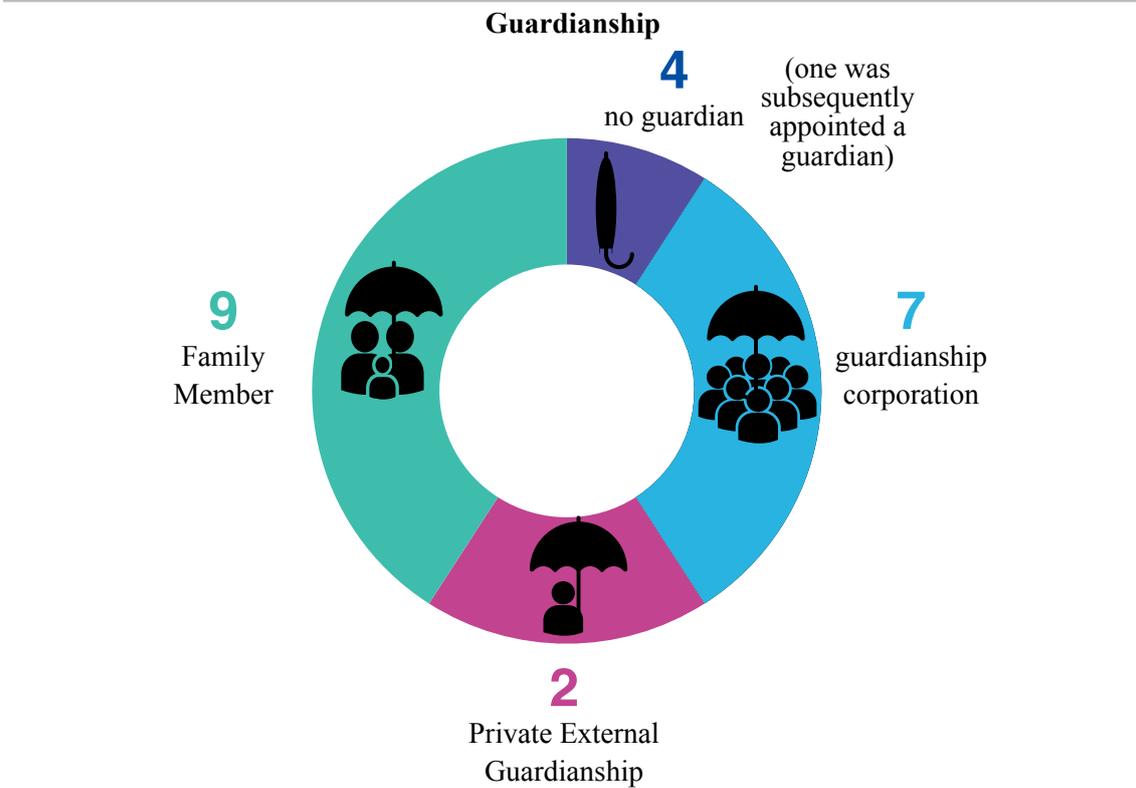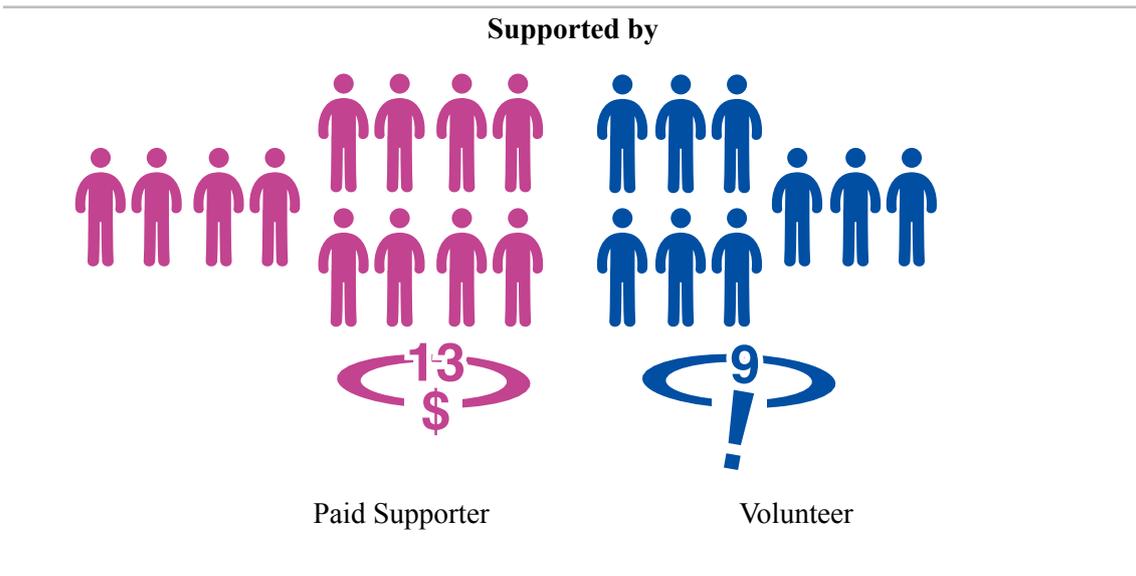
e. **Support process:** Support was provided for a year on average. The process included weekly one to two hour meetings between the person and the supporter. On average, each participant attended 30 support meetings throughout the year.

f. **Reporting:** Each supporter filled out an online report after every meeting. The object of the report was to document the meetings, help the supporter follow the process, and allow for monitoring and evaluation.

g. **Meetings with family members:** Beginning January 2015, pilot staff held five meetings with the family members of the young participants (mostly parents), in the absence of the supported persons. The object of these meetings was to introduce parents to the worldview underpinning the pilot, and enlist their support for it.

3. Axes of influence

Developing a new concept, a new profession and a new practice with respect to the independence of persons with disabilities requires the cooperation of stakeholders from various circles. The table below illustrates the pilot's focus on three major stakeholder groups and describes the actions and objects related to each one. Aside from these three main axes, public advocacy was undertaken in order to enlist wider support for supported decision making services and effect legislative changes on this issue.

Supporters	Participants	Family members and professionals
recruiting supporters	recruiting participants	presentation of model and pilot
▼	▼	▼
training	providing support	enlisting support for pilot participation
▼	▼	▼
group practicum	increasing autonomy and independence	enlisting support for worldview underpinning pilot and discussion of dilemmas
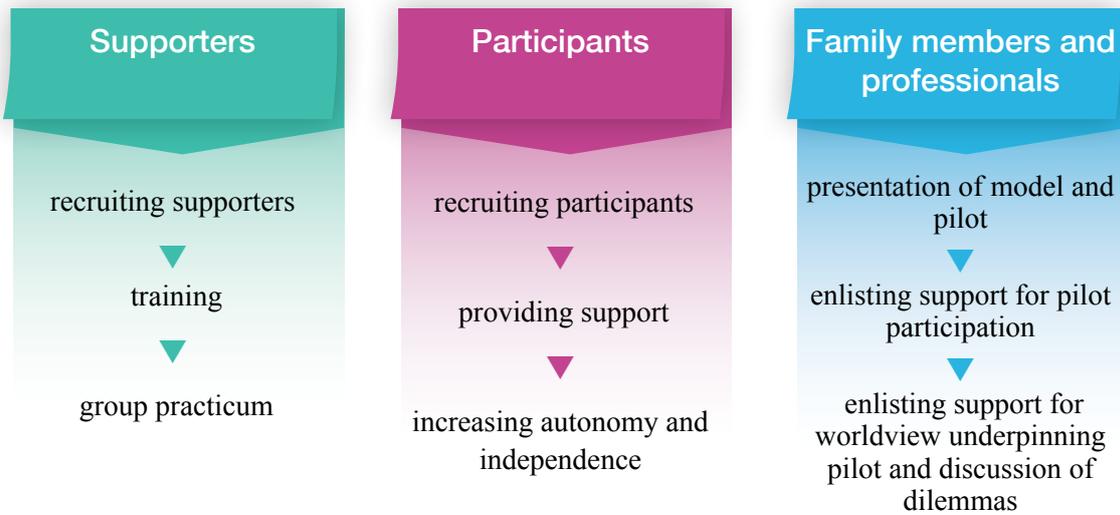
Pilot organizational structure

Project director
Yotam Tolub

Advisory committee

Supporter training and practicum
Beit Issie Shapiro, Maya Goldman

Accompanying Study
Tal Kahana
Shira Yalon-Haimovitz

Supporters

B!ZCHUT *The Human Rights Center for People with Disabilitis*
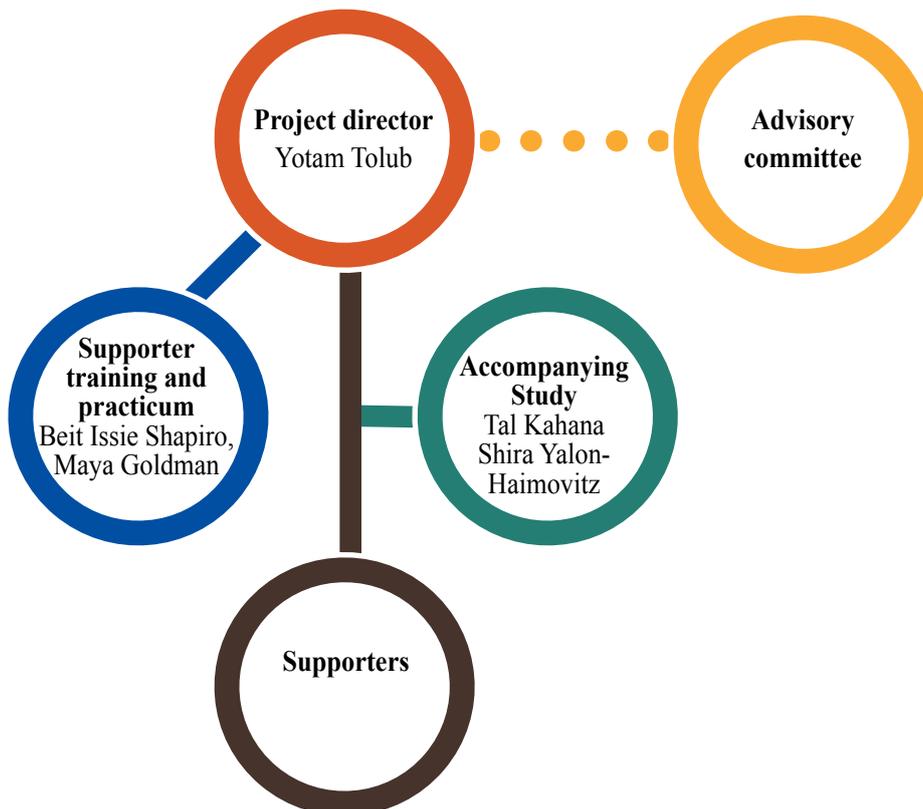
4. Dilemmas that arose during the pilot

Supporters came across many dilemmas during the pilot. We believe these dilemmas are educational for future support schemes. There are no textbook answers to these dilemmas, and there is usually a range of solutions that need to be explored according to the particular circumstances of each case. Therefore, there is value in raising supporter awareness of these dilemmas and discussing them during the training:

a. Dilemmas concerning the relationship between the supporter and the supported person:

- Issues with establishing contact: the person forgets meetings with the supporter, the person is habitually late for meetings, does not answer the supporter.

- Supporter/person relationship crises or trust building failure.

- Difficulties on the part of the supporter to communicate with or understand the person.

- Establishing boundaries within the support process (whether to provide cell phone number, whether to accept an invitation to see a performance together etc.).

b. Dilemmas concerning the support itself:

- What level of support should the supporter give? Should the supporter take a proactive approach to support? Is it legitimate for a supporter to try to speed up processes?

- How to deal with a process that remains stuck without progress.

- To what extent should the supporter represent the person to external actors?

- To what extent should the supporter state their personal opinion during the support process?

c. Dilemmas concerning the person receiving support:

- Health conditions affecting the process, such as psychiatric hospitalization.

- What happens when the major change required concerns an internal change within the person (motivation, anxiety, etc.) and veers toward therapy?

d. Dilemmas concerning the people in the supported person's circles:

- Tension between the person and the people in their circle (objection to a decision, over-involvement, lack of trust).

- Tension between the supporter and the people in the supported person's circles.

e. Dilemmas concerning the supporter

- Frustration and attrition over the course of the process.

- Lack of faith in the person receiving support and in the process.

5. Major insights gained from the pilot

Based on the assessment study, advisory committee discussions and the many discussions held by the support team – several major insights can be taken away from the pilot:

a. **Efficacy of support process:** The major insight gained from the pilot, and confirmed by the assessment study, is that the supported decision making process is effective. Despite the short time in which supported decision making services were given, most participants and their family members indicated there had been a change and that the participants' awareness and skills in making decisions about their lives had improved.

b. **Guardianship alternative:** The absence of an established legal basis for appointing decision making supporters, which was the situation at the time the pilot was held, and the decision to include only participants already or soon to be under guardianship resulted in a unique set of circumstances wherein most of the participants were under guardianship while receiving decision making support. There were many disadvantages to this, particularly, the need to have every action approved by the guardian, and a low 'glass ceiling' for support. Members of the advisory committee were divided on the question of whether to approve decision making support for persons under guardianship without revoking the guardianship. Bizchut's position on this is that these are two contradictory schemes. Decision making support services should be provided as an alternative to guardianship, rather than as a concomitant service.

c. **Choice of goals:** The supported decision making process can be seen as a goal-oriented process, but does not necessarily have to be conceived in that manner. Where a person has clear goals, they should, preferably, be laid out as the foundation of the support process. However, it is important to remember that decision making support is not meant to serve the realization of dreams, but rather provide assistance with the many decisions every person has to make in the course of their life. Therefore, the support process could be composed of a great many 'small', daily, changing, goals. So, for instance, support could include help in deciding on a purchase, acquiring information from a service provider, such as a doctor, planning an expense with disability benefit money and more.

d. **Ongoing services:** There was consensus that the pilot was too short, and that, looking to the future, decision making support services should not have a time limit, as some persons need support throughout their lives. Our recommendation is that any extended supported decision making services pilot continue for at least two years.

e. **Universal and adapted services:** There is a strong debate over whether decision making support should include support for realizing the decision, or whether the two are separate services. Without stating an opinion on this fundamental issue, it is clear to us, upon pilot completion, that without support for realizing the decisions, the support process, is, in many ways, partial. In practical terms, most of the supporters did more than provide support in decision making, but also supported the realization of the decisions made.

f. **Training and practicum:** The supporters' most meaningful learning occurred during the practicum and through peer consultations. Training and practicums should be based on practical experiences and the dilemmas arising from the ground.

g. **Unique features affecting support:** Many of the participants' attributes impacted the support process, for instance, the level of external support they have (people without any support vs.

people surrounded by professionals and family); financial circumstances (people with financial abilities vs. people living in poverty). Within all these variables, two unique attributes had a dramatic impact on the support and should be addressed:

- **Young participants:** Support for very young persons (18-21), who are still in educational institutions was substantively different and included more practice with making decisions. In light of this insight, there is a need to develop specific supported decision making services for young persons attending special education facilities, with a focus on acquiring skills, help with managing disability benefits and support vis-à-vis parents in exploring the possibility of implementing supported decision making in the person's life without appointing a guardian.

- **Fluctuating functioning:** One of the main challenges in support related to participants with fluctuating functioning, such as participants who had experienced psychiatric or medical hospitalization over the course of the year. In some of these cases, the need for the supporter became more acute during these emergency situations, when the person's needs enhanced support for making decisions during the hospitalization. Attention must be given to how support can be adapted to the changing circumstances of the participant's life.

h. **Paid supporters:** The pilot was blessed to have devoted and professional volunteers. However, the investment in the training of volunteers who supported only one person was rather high, and the level of commitment and learning undertaken by the paid supporters, who supported several persons, was much higher. Our conclusion is that supported decision making services should be remuneration-based rather than volunteer-based. Volunteer based support responses can and should be included (for instance, help from a finance professional with building a financial plan), as an extra layer to boost support.

Schedule B

Article 12 Supported Decision Making Pilot

Summary of Assessment Study Findings

Tal Kahana and Dr. Shira Yalon-Chamovitz

EXECUTIVE SUMMARY

In 2012, Israel ratified the Convention on the Rights of Persons with Disabilities (CRPD). Article 12 of the CRPD calls for moving from a model of substitute decision making to one of supported decision making. Supported decision making can be defined as a process in which adults who need help in making decisions, receive the support they want and need in order to understand the situations they face and the possibilities and courses of action available to them. Through this support, they are able to make the decisions affecting their lives and avoid the need for a guardian.

The 'Article 12 – Supported Decision Making' Project was established with the intent to restore people's control over their own lives through an effort to develop a model for supported decision making and conduct a pilot to examine the efficacy of the model by providing support in practice.

Project vision:

The intent of the 'Article 12 – Supported Decision Making' Project is to make certain that all persons with disabilities can benefit from 'independence support' services which will help them fulfill their independence and autonomy with full legal capacity. Consequently, 'Article 12' seeks to bring about a change in Israeli society and its attitude towards persons with disabilities.

Project goals:

1. Persons with disabilities over the age of 18 will enjoy freedom and independence in making decisions about their affairs.
2. Development of support services based on the wishes and choices of the person.
3. Public and legal recognition of supported decision making as a preferred alternative to guardianship.
4. Expansion of the service into an Israeli public service.
5. Change in the attitude of Israeli society to persons with disabilities and recognition of their right to independence and autonomy.

The pilot project focused on the second element of the goals – the development of a support service based on the wishes and choices of the person.

Pilot features:

The pilot included 22 participants with a wide variety of disabilities (psychosocial, intellectual, autism spectrum), some of whom also had physical disabilities. Three participants dropped out during the project. Eighteen of the participants had a guardian at the beginning of the pilot, while four of them did not (a guardian was appointed to one of the four later on).

The pilot team consisted of the pilot director – Adv. Yotam Tolub who is in charge of guardianship at Bizchut, and 11 supporters (two salaried and nine volunteers) who were trained during July and August 2014, and continued to undergo training during the pilot itself.

The support meetings were held from September 2014 to October 2015. An average of 30 meetings were held with each participant. In addition, five family members meetings intended for guardians of young participants were also held. These meetings addressed issues of independence and the advancement of supported decision making.

Accompanying assessment study

The purpose of the assessment study **was to examine the extent to which the support process, as implemented in the pilot, contributed to an increase in the participants' level of independence in making decisions. This was a preliminary step in assessing the model as an alternative to guardianship.**

In order to examine this, a comparative (before-after) research model was built, focusing on studying the differences observed at the beginning and end of the pilot with respect to a number of key indicators. The selected indicators were: The degree to which pilot participants understood the significance of the decision-making process, the extent of their desire and inner motivation for independence in making decisions and the extent of their actual independence in making and implementing decisions.

The Research Method:

The assessment study included in-depth interviews with the participants in the program, guardians and supporters. These were carried out in two stages:

Stage A – 12 interviews with the pilot participants and six interviews with guardians.

Stage B – At the end of the pilot – 12 interviews with the participants, six interviews with guardians and three interviews with supporters.

Study limitations

1. The limited scope of the pilot regarding the number of participants, the number of participants without guardians and the duration of the pilot – only one year.

2. The number of external guardians who were interviewed – two representatives from one guardianship corporation. This means that the study does not fully reflect the perspective of external guardians.

Summary of the assessment study findings

In this section, the main findings and conclusions, as they emerged at the end of the pilot will be presented. A separate summary of the first stage of the pilot can be found in the body of the report.

The assessment study that accompanied the Article 12 Pilot indicates that the supported decision making model used for the pilot managed to significantly advance the participants' ability to understand decision making processes, make decisions and implement them. Progress was observed among all interviewees (12 out of the 22 pilot participants were interviewed), whether they had intellectual or psychosocial disabilities (some also had a physical disability). Significant changes that occurred during the pilot and can be attributed to the support received, were observed among all the participants who were interviewed, without exception. However, it should be taken into account that changes did not necessarily occur among all pilot participants.

Given the limitations of the pilot and the assessment study, it appears that the supported decision making model, with its unique features (supporters who are not experts on caring for people with disabilities, training across various disabilities, adaptation of the support process to the person's unique characteristics rather than to his or her specific disability), may be effective for people with different characteristics: type of disability, age, marital status, type of housing etc.

The study identified that the only element supporters had difficulty dealing with was functional fluctuation on the part of the participant, for instance, due to an episode of mental illness. It seems that the model has to be adapted to suit this characteristic as well.

Three types of changes that occurred among interviewees and can be attributed to the supported decision making process were identified:

- **Internal changes** – Including improvement in various stages of the decision making processes (awareness and understanding of the decision-making process, decision making skills, ability to execute decisions), development of self-advocacy abilities, and improvement in money management (desire to manage the money independently, more careful, less wasteful management, increased motivation to save for the future.)

- **Changes related to guardianship** – for six of the participants, procedures were launched for the removal of the guardian. At the time of writing this report, two of the procedures have been completed. With other interviewees, changes were detected in the relationship with their guardians that reflected a desire for more independence on their part in making decisions in various areas of their lives and a stronger insistence on their opinions vis-à-vis their guardians.

- **Changes related to the participant's contact with external actors:** The pilot provided the participants with an opportunity to actualize ambitions or test the limits of their abilities without judgmental outside intervention vis-à-vis external actors: in making purchases, volunteering, procuring services, exhausting rights and more. The supporters' support contributed to the success of these experiences. The experiences themselves, and the sense of the success they provided had a positive effect on the participants' self-confidence and understanding of their abilities.

Beyond the results among pilot participants, interviews with guardians who were family members indicated that the pilot contributed to them as well (particularly meetings with the pilot director and the meetings with the other families) in a number of ways:

- Better understanding and formation of a clearer concept about what their role is in advancing the family member with a disability,

- Knowledge and tools as to how to steer the participant toward more independent decision making.

- Information regarding a variety of possible solutions that can meet the needs and wants of the family member who has a disability.

It appears that the work conducted with the guardians during the pilot identified and responded to their genuine need.

Recommendations

This section collates the main recommendations arising from the two stages of the assessment study. These recommendations are based on a preliminary pilot and a preliminary assessment with a small number of participants, and the effectiveness of the supported decision making pilot should continue to be assessed in tandem with the continued development and use of the model.

1. **Pilot expansion** – It seems that trials using this model should continue for longer durations and with more participants. It is recommended to test the model with persons who have been put under guardianship, but no guardian has yet been appointed – in order to test the efficacy of the model as an alternative to guardianship and continue developing it.

2. **Adapting the model to specific features** – The assessment study shows that the model was effective for interviewees with intellectual or psychosocial disabilities (including when there is also a physical disability). It seems, however, that there is a need to adapt the model to individuals whose function fluctuates. There may be other elements to which the model will have to be adapted. To test this, the model should be used with a broader group of people who have different characteristics.

3. **Duration of supported decision making services** – The pilot lasted one year. The interviews clearly indicate that this is not enough time for the supported decision making process to reach its full potential. Since supported decision making services are differential by definition, there is a need to adapt the duration of the services to the personal needs of each individual, including the need to change habits entrenched over many years. Some persons with disabilities will presumably need support throughout their lives.

4. **Bringing other actors on board with the support process** – It is important to integrate supported decision making into the overall arrangements involved in the lives of persons with disabilities. It is recommended to make the effort and devote resources to bringing relevant actors on board with the process

5. **Financial management guidance** – It is recommended to incorporate a structured element of financial management guidance into the support model (when the participant has the need), or referrals to other actors who can provide this guidance.

6. **Continued development of the supported decision making model** – It is recommended to continue developing the decision support making model on following points:

   • **Defining the supporter's role** as distinguished from a friend or care giver and defining the expectations a person with a disability might have with respect to this role.

   • **Guiding supporters on how to help participants through the stages of decision making**

   ✓ Understanding the concept of "independent decision making," as opposed to "independent functioning."

   ✓ Understanding the concept of "decision making" with everything entailed.

   ✓ Finding out if there is a drive to make decisions independently and whether it should be strengthened.

   ✓ Identifying areas in which the participant is interested in making independent decisions, as opposed to areas where he or she prefers to transfer the decisions to someone else based on a conscious choice.

✓ Identifying and distinguishing between matters on which the participant already <u>effectively</u> makes decisions independently, areas in which he or she is involved in the decision and areas in which someone else makes the decision for the participant.

One way to help participants understand the different concepts and stages of decision making is to name concepts like: making a decision, will, initiative and choice during the ongoing meetings between participants and supporters.

• **Social aspects in the connection between the supporter and the supported person** – Training supporters how to manage and end the social-emotion connection they develop with the supported person.

• **Exploring limits and abilities** – It is recommended to ensure that supporters are able to implement the approach of the supported decision making model, according to which the supported person's journey of discovering his or her personal abilities has to be made as a process of searching, trying and personally coping with failure and success. Adopting this approach is a challenge for some supporters as well.

7. **Strengthening family support for persons with disabilities** – It is recommended to conduct in-depth inquiries into the needs of family members in the context of advancing persons with disabilities, exploring what needs can be met using the model, and define meetings with family members as an inseparable part of the model – an element that directly contributes to achieving the goal of independent decision making, and sometimes even to the removal of guardianship.

Schedule C

Training in the framework of the pilot – summary

Dr. Benny Homzi and Maya Goldman

בית איזי שפירא
לשיפור באיכות חייהם של אנשים עם מוגבלויות
בקמפוס ווילי וסיליה טראמפ

Summary of decision-making supporter training incorporated into Article 12 pilot

By:

Dr. Binyamin Hozmi, Academic director, Beit Issie Shapiro

Maya Goldman, social worker, lecturer and counselor, Trump Institute, Beit Issie Shapiro

Background

The international convention entrenching the rights of persons with disabilities includes Article 12 which addresses guardianship. Acknowledging the fact that persons under guardianship are denied many rights, and based on recent developments abroad in the area of alternatives to guardianship, Bizchut launched a pilot for "decision-making supporters" intended to offer alternative models to guardianship. The pilot included a training program to decision-making supporters, delivered by Bizchut in partnership with Beit Issie Shapiro. The program consisted of a course which was held during July – September, 2014, followed by support and supplementary training meetings during a period of one year – until September, 2015. The course was held in David Yellin College in Jerusalem, and the supplementary meetings were held at Bizchut in Jerusalem. This document includes an overview of the training course and supplementary group meetings, focusing on main insights gained from the process.

The objectives of the initial and supplementary training sessions were:

- To enrich the knowledge of decision-making supporters in content worlds relevant to their work;

- To provide the trainees with relevant skills for the role;

- To identify main relevant elements for the purpose of designing a working model;

- To support trainees' field work and enable them to raise practical issues and dilemmas in their work.

Target audience: 11 decision-making supporters who took part in the project and provided services to 22 individuals.

Decision-making supporters: 11 candidates were selected following a screening process which consisted of a call for applications and personal interviews upon the conclusion of which 50% of the applicants were accepted. The recruitment process focused on candidates, 25 years of age and older, who are morally committed to the values of the pilot.

Course coordinators: Advocate Yotam Tolub, program director, Bizchut

Social worker Maya Goldman, lecturer and counselor, Beit Issie Shapiro

Part A – Training course for decision-making supporters

The concept underlying the course conceived by the steering team was to equip participants with maximum necessary basic knowledge in the shortest time possible, in order to match them to service recipients and continue the learning process "in action". Another guiding principle was to integrate into the training program instructors with disabilities to enable firsthand learning from persons who have experience, rather than learning "about". The training course consisted of eight sessions, with four 45-minute units each. Each session focused on a main content world and concluded with a closing discussion facilitated by the course coordinators and targeted at extracting applicable tools for designing the role of a decision-making supporter.

Course program

Meeting	Date	Hours	Issues	Meeting description
1.	July 1, 2014	17:00-20:15	Introduction Vision presentation Dilemmas	After the introduction session Yotam presented the vision of the pilot. In the second part, dilemmas of independence and autonomy were presented through movie clips.
2.	July 8, 2014	17:00-20:15	Intellectual disability – not only cognitive deficiency and meeting with a person with intellectual-cognitive disabilities	The meeting commenced with a personal discussion with a person with intellectual-cognitive disabilities which was followed by a lecture about life challenges faced by persons with intellectual-cognitive disabilities.
3.	July 15, 2014	17:00-20:15	Psychosocial disability and meeting with a person coping with the disability	The meeting commenced with a personal discussion with a person coping with a psychosocial disability which was followed by a lecture about life challenges faced by persons coping with psychosocial disabilities and the rehabilitation concept from illness to recovery. In addition, services available to persons coping with psychosocial disabilities were presented.
4.	July 22, 2014	17:00-20:15	Barriers, decision making routes and a personal meeting	The different decision-making stages, identifying barriers and their removal, followed by a discussion of intervention strategies.

5.	July 29, 2014	17:00-20:15	Guardianship – the current situation and criticism, Article 12 revolution + a personal meeting	Meeting with two social workers who support persons with disabilities and a person who had been released from guardianship. The meeting included a discussion in which they presented their approaches, positions and personal and professional experience in the area of guardianship. Thereafter, Yotam presented an introduction to guardianship and alternatives to guardianship.
6.	Aug. 3, 2014	17:00-20:15	Supplementary background on life challenges of adults with intellectual-cognitive disabilities Self-advocacy -concept and tools Decision-making and self-advocacy – from theory to practice	Session began with supplementary background material about life challenges faced by adults with intellectual-cognitive disabilities was completed. Yoav Krim presented the area of self-advocacy and its development, followed by presentation by self-advocates regarding issues material for effecting a change in their life.
7.	Aug. 12, 2014	17:00-20:15	Support in decision-making – theory and implementation Personal meeting and discussion	The decision-making process in the pilot: will, information, options, choice, evaluation of the different support stages. Followed by a meeting with two parents: a parent of a person coping with psychosocial disabilities and a parent of a person with intellectual-cognitive disabilities.
8.	Aug. 19, 2014	17:00-20:15	Action model Supporting the supporters (consultation, reporting, ethics) Procedures and records Getting started and communications towards introduction meetings with service recipients	Summary, coordination and procedures for commencing the process; coordinating expectations and guidance regarding the format of the supplementary training.

Part B – Supplementary training sessions

The supplementary training sessions were intended to serve three main objectives: receiving feedback from the supporters regarding their work, while raising principle issues for peer discussion and learning; expanding the supporters' knowledge through structured learning; and personal counseling for any supporter interested in receiving same. Sixteen support training sessions were held, each consisting of three 45-minute units, once every three weeks, throughout the term of the decision-making supporters' pilot (September 2014 – September 2015). The first unit was dedicated to gathering and sharing by the supporters, while the two additional units were dedicated to hands-on training with respect to a specific issue. In addition, individual training per supporter (a fourth unit) was offered. The table below outlines the subjects and descriptions of the sessions.

Session	Date	Subject	Session description
1.	Sep. 2, 2014	Communicating with guardians, getting acquainted, and trust building	Meeting with representatives of a guardianship service. Yotam led a discussion about communication with guardians Maya led a meeting about trust building and familiarity. We discussed four elements which should be emphasized in the initial trust-building meetings: meeting location, who participates in the meeting, what is subject is covered in the meeting, and what method is applied. Watched a short movie: "Walking in someone else's shoes" in conclusion.
2.	Sep. 30, 2014	Goal setting and personal program (including tools)	The session focused on two main subjects: how to establish the relationship with the service recipient, and how to set goals for the process. With respect to establishing relationships – an emphasis was put on how important it is to let the person to present themselves through their areas of interest and make the process reciprocal. Issues which may be touched through dialogue, activity, having a coffee together: what are your dreams, what are the barriers in your life, who are the significant persons in your life, what are your greatest fears, etc. With respect to goals: it was decided that several realistic goals should be defined for a one year process consisting of two weekly hours. It was recommended to define two major goals and at least one short-term goal for the next few months. It is important to build a process for the purpose of achieving the goals.

3.	Oct. 27, 2014	Decision channels and barriers	Many dilemmas were presented in the session, raising questions and uncertainties: what should be done with a goal that does not seem realistic to us; what is the place of the parents and guardian in the process; how should goals with which the supporter does not feel comfortable be handled, etc. The learning focused on decision channels: different, diverse and creative ways of action, stemming from the approach that there are no correct and incorrect ways to respond and support the participants, but rather accommodating and non-accommodating ways.
4.	Nov. 18, 2014	Inter-personal communication	During the gathering, an interesting discussion evolved about the supporter's place in relation to a participant who had been involuntarily committed to hospital and how much one should cooperate with unrealistic desires/expectations. The learning focused on the issue of inter-personal learning – the Palo Alto model. In the session, very important points were raised regarding the obligation to report, the functional differences between supporters and social workers, care counselors or just assistance provided by a person who is kind to the supported person.
5.	Dec. 8, 2014	Parental involvement in the process	The main dilemma in this session was how much to "teach recipients how to fish", versus how much to "give them fish", for instance, writing a letter for them. Supporters also discussed ways to bring parents onboard and to remove barriers.
6.	Jan. 19, 2014	The supporter's role	The meeting focused on actual dilemmas and mainly – on decision-making processes, costs and benefits and how they should be conveyed to the service recipients and absorbed by them. There was also a discussion about conflict between the will of the service recipient and the family's position.
7.	Feb. 10, 2015	Goal realization	The session focused on goal realization – successes and difficulties. How active or passive the supporter should be in the realization process. In addition, what happens when goals may be risky for the person, such as using public transportation; what happens when the person has no motivation to set goals or when goals are set with the service recipient but they experience fluctuation in their mental state.

8.	March 3, 2015	Concern over risk and harm	Discussion with Advocate Ayelet Sasson from the legal department of the Ministry of Welfare. The session focused on risk and harm situations, on the reporting obligation of professionals and particularly on the supporter's status and obligations in such situations.
9.	March 31, 2015	Support services to other populations	Discussion with Meital Peleg, Executive Director of the not-for-profit association 'Shoulder to Shoulder'. Learning about how the association provides support to families living in poverty, focusing on the numerous similarities to the "decision-making supporters" project.
10.	May 12, 2015	Mid-course feedback	The session focused on the supporters' mid-course feedback. Again, the issue of parental involvement was raised – whether, when and to what extent. Withdrawal and passivity of some of the service recipients in the processes and the prescribed time frame were discussed. One of the supporters suggested that supporters should have prior relevant professional qualifications.
11.	June 9, 2015	A person's support circles	The session focused on promoting awareness to the person's support circles: the personal circle, the professional circle and other social circles. It is important that the service recipient fully participates in the dialogue conducted by the supporter with people from these support circles. It is important to establish the support circles for the service recipient.
12.	June 29, 2015	The support experience	Towards the end of the pilot – the purpose of the meeting was to evaluate how the supporters experience the process and how, in their opinion, the service recipients understand its nature.
13.	July 21, 2015	Support as opposed to treatment and real-life dilemmas	The session focused on the issue of support as opposed to treatment – whether it is possible to create sterile support. Will it always touch on therapeutic aspects? If the answer is yes – are they included in the supporter's mandate, and if so, what are the limits? With respect to goals, a dilemma was raised – when the service recipient has no goals, should the supporter encourage them to establish goals or should the extent of support given be reduced, such that when the person does have a goal, the supporter will be more intensively involved.

14.	Sept. 1, 2015	Learning from successes	The session focused on learning from successes. The supporters summarized the process while focusing on the successes and the insights gained from the supported decision-making process.
15.	Oct., 13, 2015	Farewell and termination of support	Different ways of parting with the service recipients were discussed. The goals were reviewed **vis-à-vis** the achievements. The post support stage was discussed and how supports may be established for the service recipients after the termination of the pilot.
16.	Nov. 12, 2015	Pilot summary	Pilot summary – macro level discussion – the project's strengths and necessary improvements.

* In addition to the group training, paid supporters met with Advocate Yotam Tolub once a week whereas volunteer supporters received consultation mainly by telephone, according to need.

Part C – Raising awareness – meetings with parents and guardians

One of the main goals of the decision-making supporter training program was to raise awareness to the evolving alternative to guardianship and to expand the program's reach. From a systemic perspective, it was clear that in order for the change to take hold, the parents and/or guardians of service recipients must also be familiarized with and informed about the program. About seven parents and guardians participated in each meeting and the goal was to raise their awareness about supported decision-making and its importance. The table below outlines the subjects and descriptions of the sessions:

	Date	Issue	Description
1.	January 4, 2015	"The fear to let go"	How can we give our dependent children autonomy?
2.	February 1, 2015	"Stand with me – not against me"	Choosing independence – difficulties and concerns. Discussion with a young man with an intellectual disability who does not have a guardian.
3.	March 1, 2015	"Independence – to what extent?"	The story of a parent of a woman with an intellectual disability who is married and works as a full time day-care assistant.
4.	April 19, 2015	Living in the community	The meeting was canceled due to lack of participants
5.	June 21, 2015	"From theory to practice"	Presentation of alternatives to guardianship and supported decision-making
6.	October 18, 2015	Towards the end of the pilot	A meeting in which parents gave feedback about the project.

Main insights and recommendations for the training model:

1. The training sessions started with sharing and reflection – ranging from a more general round of "how is it going?" to case presentation by one or two supporters, followed by enrichment. The impression is that the training structure used in the pilot answers the needs, and, based also on the feedback received from the supporters who participated in the project, a short course followed by reflection "in action" is the right work model.

2. The contents of the course which incorporated learning from persons with disabilities, their family members and other stakeholders – preserve the practical nature of the supporter's role. The approach of the course was to reduce theoretical learning and expand learning from the personal narrative of persons with disabilities and the way they cope with dilemmas. The dilemmas were discussed extensively in the group discussions, with an attempt to hone in on basic issues arising from them.

3. Training must clearly reflect to the supporter that their role is not therapeutic but should rather focus on providing decision-making skills and helping the person making the decision see reality with all its opportunities and challenges.

4. It is important to incorporate an introduction to the main types of services and rights into the initial and support training program, in order to expand the supporters' their tool-box.

5. The course must include practical tools for communication with the persons themselves (when to support and do things for the person and when to push the person to take pro-active steps for themselves and their personal vision) and for communication with family members and guardians.

6. It is recommended that the supporters are remunerated and regulated. This would allow them to provide support to several service recipients and gain a broad perspective regarding challenges and opportunities. It would also increase their sense of commitment to participate in the attendant aspects of supported decision-making as well.

7. The personal and group training sessions are crucial for the success of the process. It is recommended that personal meetings be held with each supporter on a bi-weekly basis and that group meetings will also be held on a similar basis. A sympathetic ear and availability to supporters and their experiences play a very important role in formulating ideas and creative solutions and in providing support in moments of frustration, stagnation and difficulty.

8. It is recommended that a direct peer communication and consultation forum be established for decision-making supporters.

9. The introduction and information sessions for parents were important and should continue. Seventy-five percent of the parents are also the guardians of their children. It seems that the parents wish to receive more information, tools and a sympathetic ear to their questions/opinions and that they are less interested in creating a support group. The personal stories of persons with disabilities and parents constituted an important factor in effecting a change in participants' positions.

10. The steering team of the training program deliberated on whether a structured preparatory training should also be provided to the service recipients but it seemed that due to the highly heterogeneous composition of the group, individual preparation was preferable – as was done in this pilot.

11. It is important that the counselors facilitating the training program are also the ones providing individual support for the supporters as part of the program structure. The counselors' exposure to the personal stories may greatly contribute to focusing the training and counseling on the most substantial issues with tangible examples that the participants can relate to. The counselors' involvement in individual and personal counseling will formulate a body of knowledge that can be turned into a specialization.

Schedule D

Introduction to the new Israeli Legal Capacity and Guardianship Law

Dr. Tal Peleg-Shulman

Introduction to the new Legal Capacity and Guardianship Law

On March 29, 2016, Israel's parliament, the Knesset, voted in favor of amending the Legal Capacity and Guardianship Law. The amendment constitutes a veritable reform and includes several dramatic changes:

- Recognition for supported decision making
- Recognition for enduring powers of attorney
- Revocation of the term "ward"
- Reduction of the instances in which guardians will be appointed to cases in which it is necessary to prevent harm to the person in question and when no less restrictive measure is available
- Revocation of the possibility to appoint a general guardian without specifying the matters over which he or she has powers
- Definition of a person's wishes as the guiding principle for the guardian's discretion
- Definition of the rights of people under guardianship, such as the right to receive information from the guardian, the right to independence and the right to privacy
- Definition of the right to legal counsel through legal aid in cases of medical decisions
- Restriction of guardians' ability to impose a decision on fundamental issues

At the same time, the law still has some ground to cover, including:

- The law does not specify an unequivocal duty to hear the person in court in any proceeding pertaining to that person
- The law does not revoke the concept of legal incapacity
- The law does not revoke the principle of "best interest", as it still gives precedence to a person's "best interest" over their wishes
- The law does not stipulate a broad right for legal representation
- The law does not define a maximum timeframe for appointments
- The law offers no solution for situations in which third parties (banks, physicians) doubt a person's legal capacity and require the appointment of a guardian in order to execute legal actions
- The law is still based on the concept of "capacity", which divides people into those with or devoid of legal capacity.

At the end of the day, the law brings true progress in the field, both in terms of developing alternatives and within guardianship itself. Now, the principles of the law and its provisions have to be assimilated and made a reality for tens of thousands of persons with disabilities as well as older adults.

More on the major innovations in the law

Supported decision making

The law recognizes supported decision making as a new legal tool (section 67b), which will come into effect in two years. The law briefly defines the supporter's functions – help with obtaining information, help with understanding the information and the available alternatives and help executing the decision and expressing it to third parties. The law empowers the minister of justice to introduce regulations that would help formalize supported decision making, such as establishing who may be appointed as a supporter, what training is required, the supporter's duties and responsibilities, when support ends and how to enter a support arrangement through an agreement. The law emphasizes that a decision making supporter will not make decisions instead of the supported person, and compels the court to consider appointing a decision making supporter before opting for guardianship. Though the supported decision making clause is to enter into effect only in two years' time, the law does stress (section 53), that the courts may make use of section 68 (which grants the court general jurisdiction to take the necessary steps). This means that the court may start appointing decision making supporters now, based on this section.

Guardianship

The law introduces many innovations with respect to the process of considering guardianship and the rights of persons under guardianship, including:

1. **Stringent test for appointing a guardian**. The previous law allowed to appoint a guardian for any person who could not take care of their own affairs. The new law (section 33a(a)), introduces two major tests that must be passed before a decision to appoint a guardian can be made.
   a. The principle of necessity – a determination that without the appointment, the person's rights, interests and needs would be harmed.
   b. The principle of the less restrictive measure – a determination that no alternatives that are less restrictive on the person in question can be selected, such as an enduring power of attorney or supported decision making.
   When appointing a guardian, the court is required to provide the reasons for the decision and the considerations weighed prior to making it (section 33a(h)).

2. **Reduced applicability of guardianship law** – The new law (section 33a(d)), lacks the option to appoint a general guardian for a person's entire affairs, as is the case today. The judge will have to choose the areas of guardianship – a specific affair, medical matters, personal affairs, property or a combination of several areas. The judge will be required to restrict guardianship to the necessary areas only.

3. **Reduced guardianship duration** – While the law does not restrict the duration of a guardianship appointment, it does instruct the judge to order the shortest duration required (section 33a(e)).

4. **Deletion of the term "ward"** – The new law replaces the term "ward" with the term "a person for whom a guardian has been appointed" (section 80).

5. **Choosing a guardian** – A person who is deemed to have legal capacity may define who they wish to have appointed as a guardian in case a decision to appoint one is made in the future (section 35a). The law also contains an instruction to consider a person's wishes when a guardian is appointed (section 35).

6. **Annulment of duty of obedience** – Section 43 of the previous law, which provided for the ward's duty to obey the guardian, has been removed.

7. **Guardian will** – The law allows guardians who are relatives to instruct, in their wills, who they wish to take over as guardian of their relatives in the event of their death. The court will give preference to this choice after hearing the person concerned (section 64a).

8. **Principles and guidance for guardians** – The law contains a list of guiding principles for guardians' actions. These include, for instance, the guardian's duty to provide the person with information, to promote the person's independence, to allow the person to make decision regarding their own affairs, to take into account the changing capacity of the person and respect cultural issues (section 67e).

9. **A person's wishes as a guiding principle for guardians' discretion** – Thus far, the guiding principle for the guardian's discretion was the person's best interest. From now on, the leading principle will be the person's wishes (whether they are current or have been expressed in the past). A person's best interest may be relied upon only when it is impossible to find out what the person's wishes are (section 67f(b)).

10. **Restrictions on guardians' power** – Guardians may not force their opinions in cases of substantial disputes over personal or medical issues (section 67f(b)(4)). Accordingly, a guardian cannot consent to an action that restricts the person's freedom of movement (such as forced psychiatric hospitalization) (section 67g).

11. **Accommodations and accessibility** – The guardian must make all information accessible to the person in accordance with their needs (section 67f(c)).

12. **Partial right for legal representation** – Where an application for guardianship appointment was made, or where a guardian has been appointed for the purpose of a medical procedure, the person has a right to legal counsel provided by legal aid, regardless of income (section 68a).

13. **Oversight by the public guardian** – The law formalizes and expands the oversight powers granted to the public guardian (section 67c).

14. **Medical certificates** – The law instructs to enact regulations to formalize, for the first time, the part expert reports play in the process.

Enduring power of attorney -

A major part of the amendment is dedicated to formalizing a new alternative to guardianship – an enduring power of attorney – to enter into effect within a year. An enduring power of attorney is a document a person may sign while still with legal capacity, wherein they instruct who is to make decisions on their affairs in the event that they lose legal capacity. The law also includes the option of signing advance directives to inform what decisions are made with respect to the person. An enduring power of attorney can cover property and personal affairs, which also include medical matters. The law formalizes a process which includes signing in the presence of a specifically trained lawyer who ensures the person understands, as well as a duty to deposit the document with the public guardian. The law regulates who may be given power of attorney, that person's powers, duties, functions, decision making process and more, and stipulates a complaint review mechanism and court intervention. The law also acknowledges Ulysses Agreements in the area of psychiatric hospitalization, in other words, a person's ability to sign an enduring power of attorney, via special process, that allows them to empower the appointee to consent to hospitalization despite the appointing person's objection. In these cases, the person may be involuntarily hospitalized for 48 hours only.

Schedule F

Guardianship in the Sharia Courts

Guardianship in the Sharia Courts in Israel

The efforts to enlist supporters and participants from the Arab community to take part in Article 12 pilot were unsuccessful. Regretfully, the pilot did not include participants from the Arab community. As part of the effort to expand Bizchut's activities in the Arab community and increase awareness of the need to promote alternatives to guardianship, Bizchut conducted a short study concerning guardianship procedures in the Sharia courts, which adjudicate the vast majority of the cases involving the appointment of guardians to Muslims in Israel. The following is a summary of said study.

Background

The judicial system of the state of Israel consists of secular courts and religious courts that have jurisdiction over specific issues. Legally, family courts and religious courts have jurisdiction to declare persons as wards and to have guardians appointed for them. In practice, however, while for Jews, guardianship is almost exclusively adjudicated by family courts and is consequently based on the Legal Capacity and Guardianship Law, 5722-1962, for Muslims it is almost exclusively adjudicated by Sharia courts. Therefore, changes in legislation and reforms promoted in areas pertaining to the right to legal capacity and supported decision-making in the framework of Israeli law do not directly impact the majority of the Muslim population in Israel. Given that Sharia law and the proceedings in the Sharia courts are conducted in Arabic, and in view of the autonomy of the Sharia courts in the Israeli judicial system, there is a considerable gap between the legal reality experienced by the Jewish population and that experienced by the Muslim population in Israel.

In this schedule, we briefly provide some background and present the customary practice of the Sharia courts in Israel in the area of guardianship. The purpose of this schedule is to provide accessible information to persons with disabilities in the Muslim community and their family members. This schedule is also intended as a means of familiarizing the public at large with proceedings in the Sharia courts and helping to bridge the gaps between secular law and religious Sharia law.

The Sharia court system in Israel

Eight Sharia courts operate in Israel: Acre, Nazareth, Haifa, Baka al-Garbiyeh, Taibe, Jaffa, Jerusalem and Beer Sheva. A single court of appeals is located in Jerusalem. As of 2012, the courts use computerized systems and it is estimated that since then and until 2016, 5,500 guardianship orders were issued. Most of the guardianship appointment orders issued by Sharia courts are not transferred to the Guardian General. Auxiliary units are currently being set up in the Sharia courts, with the first one opened in the Jaffa Sharia Court.

Legal capacity under Sharia law

Sharia law draws a distinction between capacity for rights and obligations (passive capacity) and capacity to perform legal actions (active capacity). Capacity for rights and obligations does not depend on a person's age or intellectual abilities and is in fact the legal tool enabling them to be entitled to benefits (such as national insurance) and obligations (such as the obligation to

pay alimony). On the other hand, active capacity, namely the capacity to perform legal actions is based on a person's judgment ('Aqal), and may be full, partial or non-existent (revocation of capacity). Sharia law presumes active capacity from adulthood to death. However, active capacity may be curtailed if a person's judgment is impaired. Minors from the age of seven until adulthood have partial capacity and minors younger than seven years old have no legal capacity to perform actions. Persons with intellectual and psychosocial disabilities can fall under any one of the above categories.

A key concept pertaining to a person's judgment is *Rashad* which refers to a person's capacity to manage financial matters. Legal actions taken by a person who does not have legal capacity – are null and void *ab initio*. Under certain circumstances, the guardian can validate them *a priori* (namely, before the transaction is made).

Finally, the main considerations for the appointment of a guardian are whether the person needs protection and whether a person's dignity needs to be protected and the appointment of a guardian is the way to do so.

The Sharia courts are somewhat affected by the Legal Capacity and Guardianship Law. In the past, Sharia courts have not considered it at all, based on their position that Sharia and Islamic law are comprehensive enough to regulate the matter on their own right. However, in HCJ 1129/06, the High Court of Justice ruled that Sharia courts are bound by the laws of the State of Israel when considering issues involving legal capacity and guardianship applications.

Guardianship Applications

Most guardianship applications in the Sharia courts pertain to persons with intellectual disabilities. To the best of our understanding, guardianship is seldom used for persons with psychosocial disabilities. As noted, the medical report plays a crucial role in the appointment procedure and when persons with intellectual disabilities are concerned – the decisive document is the report of the evaluation committee. Based on the medical report, the Qadi decides whether the appointment of a guardian on a full or partial basis is required. According to the representatives of the Sharia courts we interviewed, the court's approach is that the failure of the court or the Qadi to meet with the ward will constitute cause for revocation of the decision to appoint a guardian. This is a progressive approach compared to the approach customarily taken by family courts where the judges seldom meet the person.

In a 1994 judgment issued by the Sharia Court of Appeals (Sharia Appeal 50/94, given on July 5, 1994), it was held that since guardianship proceedings involve the revocation of rights, they must be based on solid grounds. Therefore, an expert report was required and a report issued by a health fund (*Kupat Holim*) physician was insufficient.

The Qadi's role in guardianship proceedings is substantially different from the role of a family court judge. The Qadi is regarded as holding the position of acting Guardian General for persons with disabilities. Because of this responsibility, Qadis sometimes initiate the appointment themselves.

Since the Qadi is responsible for all persons with disabilities, he sometimes initiates the appointment of a guardian for a person in need himself, and supervises all guardians appointed.

Procedure

Like the secular courts, the Sharia courts also greatly rely on medical reports while examining guardianship applications. However, welfare officers' reports and legal representation by counsel on behalf of the legal adviser to the Welfare Ministry are used much less frequently. In recent years said practice underwent changes in several courts. For instance, in the Sharia court in Jaffa, welfare reports are used in most cases and the position of counsel on behalf of the legal adviser is obtained. Jaffa is also exceptional in that the appointment orders which are given in Arabic are translated into Hebrew and are transferred to the Guardian General for monitoring purposes.

Before the guardian appointment order is given, the court is obligated to meet the person for whom a guardian is about to be appointed. The person must be brought to court to enable the Qadi to see whether the person can express an opinion, how much they understand, what they think about having a guardian, etc. Sometimes, the Qadi visits the person in their home for said purpose. Failure to meet the person before an appointment order is given constitutes cause for the revocation of the appointment order by the Sharia Court of Appeals.

The mandatory presence of the person in the hearing was reaffirmed in an appeal from 1995 (Sharia 15/95 (dated July 11, 1995) where it was held that a person had a natural right to know of the proceeding conducted in their matter particularly when the results of the proceeding may violate their right to take action and make decisions in their affairs.

Since the duty to take care of persons with disabilities is mainly a religious duty, the appointed guardian must be Muslim. However, a combination of the necessity principle in Islam (according to which prohibited things should be permitted when necessary) coupled with the overarching court principle of the person's best interests, makes it possible in exceptional cases to appoint a guardian who is not Muslim. Another, more practical difficulty in the appointment of guardian corporations approved by the Guardian General, is that said corporations do not have enough Arabic speaking employees.

Following issuance of the appointment order

Following the appointment, the powers vested with the guardian are limited to the powers granted to them by the court, including management of the person's benefits and maintenance. Any investment, apartment acquisition or gifts given out of the person's funds must be approved by the court. In addition, persons with intellectual disabilities may not be married without the Qadi's approval, whose duty is to examine the genuine necessity of the marriage and society's interest in it.

In the past, due to regulations promulgated by the British Mandate – judgments against minors, incompetent persons and Waqf properties, were automatically transferred to the Sharia Court of Appeals. Currently, the definition of the term "against" is in dispute. The interpretation given to this term by the Sharia Court of Appeals in Israel is that all judgments in cases of minors, incompetent persons and Waqf institutions should be automatically transferred to the scrutiny of the court of appeals.

Information sources

Meeting with the Honorable Qadi Dr. Iyad Zahalka, Director General of the Sharia Courts

Meeting with the Honorable Qadi Muhammad Rashid Zabda, Qadi of the Jaffa Sharia Court

Conversation with Ms. Tami Sella, Supervision of Guardians Unit Managing Director

Oren Asman, Legal Capacity against Psychosocial Background in the Israel's Courts, Sharia Courts and Rabbinical, JD dissertation, November 2011, The Hebrew University

Schedule G

Suitability of the Model to Senior Citizens

Prof. Israel (Issi) Doron

Decision Making Model for Senior Citizens

Prof. Israel (Issi) Doron[1]

Preface

Israeli society is aging. It is in the midst of a demographic transformation from a young society to one in which the fastest growing group is the 65 and over age bracket. The aging of Israeli society presents opportunities for a revaluation and renewal of attitudes toward the "new older adults", but there is also a danger of increased discrimination and alienation of all persons who are not members of the "young" hegemonic group. In addition, these new social circumstances emerge against the backdrop of an increased awareness of the social phenomenon known as "Ageism", which like other social phenomena, such as racism or sexism, embodies negative social structuring of old age and discrimination of a social group labeled as weak and impotent simply because of its chronological age (Doron, 2012).

Specifically, and from the perspective of protecting the rights of senior citizens, the appointment of guardians for senior citizens is a major issue that reflects the ageist conceptualization of senior citizens' status in Israel, alongside the illustration of the materialization of the typical paternalistic approach to protecting older adults and senior citizens who are regarded as a weak and helpless group. Thus, the need to expose the injurious aspects of the legal structure of the guardianship institution as it currently exists under applicable Israeli law, and to present practicable alternatives which are not only less injurious but also empower and strengthen the population of senior citizens in Israel, is a very important challenge. This document, ancillary to the important project of presenting a supported decision-making model, is therefore another step in the effort to bring about a social-legal change in this area.

A. The situation prior to Amendment 18 to the Legal Capacity and Guardianship Law and the problems associated with it: Senior citizens under guardianship in Israel

A.1. The situation prior to Amendment 18

This schedule was documented before the Legal Capacity and Guardianship Law (Amendment No. 18), 5776-2016, was approved in April 2016. A comprehensive overview of the ramifications of the amendment exceeds the scope of this document and a concise summary of the amendment is included in Schedule D of this report. It is clear that this latest amendment is meant to dramatically change legal reality surrounding guardianship in general and guardianship for senior citizens in particular. However, since it is still unclear whether this change will, in fact, take effect and how far reaching this change might be, it is important to understand the situation that was in place (and still is place at the practical level) at the time of writing and publication of this document. We shall therefore review the reality that preceded the amendment, and, in many ways, helped effect it.

Many studies have been conducted over the last few years of the existing situation in the area of

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guardianship for older adults and the provisions of the Legal Capacity and Guardianship Law (Alon, Schindler, Hughes and Doron, 2013). In general, it is well known that the Legal Capacity and Guardianship Law, 5722-1962 (hereinafter: the "Legal Capacity and Guardianship Law") addresses the legal aspects of legal capacity, the restrictions imposed on legal capacity and the appointment of guardians. The law does not manifestly refer to the population of senior citizens as distinct from other populations – but rather provides solutions to persons who due to intellectual or psychosocial impairment or for other reasons are unable to manage their affairs and make legal decisions. However, in reality, the vast majority of adults currently under guardianship are senior citizens.

Specifically, and as outlined in section 33(a) of the law, there are two reasons for appointing a guardian for senior citizens: first, pursuant to section 33(a)(3) of the law, for a person who is "legally incompetent", namely, "a person who, by reason of mental illness or defect of mind" is unable to manage their affairs. The other, according to section 33(a)(4) of the law, for "any other person who is unable, permanently or temporarily, to manage their affairs, in whole or in part, and there is no one who is either authorized or willing to manage their affairs in their stead."

With respect to the first reason for declaring a person "legally incompetent", section 8 of the Legal Capacity and Guardianship Law gives the court the power to declare a person legally incompetent only when the person is unable to manage their affairs as a result of mental illness or intellectual impairment. Court judgments indicate that said intellectual impairment or mental illness should be permanent at least for some time, rather than a temporary condition. In addition, the inability to manage one's affairs pertains to all of the older adult's affairs, or at least the vast majority of them. Finally, declaring a senior citizen "legally incompetent" means a near complete restriction of their legal capacity and a severe violation of their personal autonomy, "reverting" them back to the status of "minor" as defined by the law.

With respect to the second reason, the appointment of a guardian for "another person who is unable to manage their affairs" requires no medical reports, and it suffices to show that the person is unable to manage their affairs in whole or in part, permanently or temporarily, for any reason whatsoever and there is no one who is either authorized or willing to manage their affairs in their stead (CA 445/81). However, the judgments of the Supreme Court indicate that guardian appointments under this cause should also be subject to the presence of some impairment impinging on the person's judgment (CA 4377/04).

Although an appointment for "another person who is unable to manage their affairs" does not limit the autonomy and legal capacity of senior citizens as severely as it does in the case of persons deemed legally incompetent, and senior citizens have the ability to continue performing certain legal actions – there is still a significant violation of their autonomy. The ward is obligated, under the law, to fulfill the guardian's instructions in all guardianship matters as determined by the court; and most importantly, the guardian in fact manages the ward's affairs including management of their bank accounts, assets, decisions on medical issues, living accommodation, etc.

Assuming that cause for appointing a guardian under the law does exist, pursuant to section 33(b) of the law, the proceeding may be instituted and the guardianship application may be filed only by the person's spouse or relative or by the Attorney General or their representative. When the proceeding is launched, the identity of the proposed guardian should be specified. This can be an individual, a corporation or the Public Guardian (section 34 of the law). In actual fact, most guardians of senior citizens are relatives, while guardian corporations (such as the Fund for Care of Wards) are appointed for older adults who have no family or who are abused by their family

members. As a general rule, a guardian will be appointed provided that the guardian agrees to the appointment, and the court finds them suitable to fulfill the duty of protecting the ward's best interests.

Procedurally, an application for a guardianship appointment should enclose an affidavit supporting its facts. A medical report describing the person's medical condition should also be provided (this last requirement applies only when a declaration of legal incompetency is requested). In addition, it is incumbent upon the court to hear the person prior to the appointment (however, this obligation applies only when the person is capable of understanding the matter and their opinion can be clarified – section 36 of the law). Finally, the consent of the designated guardian should also be included with the application.

For the "day after" the appointment of the guardian, the law prescribes several material arrangements. Firstly, it obligates the guardianship to operate for the benefit of the person. Secondly, the law obligates guardians to hear the person before making decisions in their matter. Thirdly, the law specifies a host of issues in which guardians are not authorized to make decisions absent the court's approval. Finally, the law establishes a general reporting scheme to be submitted by guardians as part of structured monitoring and supervision over their activities. In practice, supervision over guardians in Israel until recently focused only on the aspect of property and financial management. It was only in the last year that a pilot was launched by the Guardian General for the development of a monitoring and supervision unit which would also examine the activities of guardians with respect to decisions pertaining to the person and their care.

The scope of authorities and detailed judgments in the area of guardianship for senior citizens is limited. Despite the fact that there are thousands of judgments in which guardians are appointed for senior citizens, the majority of these judgments are not published (as they are privileged according to the Family Court Law) and usually do not include deliberations or detailed and thorough legal explanations. Nevertheless, the judgments given by the Supreme Court in this area express recognition of the importance and great caution which should be exercised when applying the law to senior citizens. For instance, in the case of Dr. Dvora Cohen (CA 1233/94) the Supreme Court held as follows:

> In exercising the power, the basic normative premise is that the fundamental right of every person – including older adults – is to have their dignity, privacy, property and personal autonomy protected. These rights which have always been the supporting pillars in our legal system, are currently entrenched in Basic Law: Human Dignity and Liberty".

In view of the above, the court proceeded to hold: "No such violation shall exceed proper limits, nor shall it be greater than required."

A.2. The problems in the current situation

The legal situation described above has been extensively criticized (for an article summarizing the criticism in the area see: Barel M., Doron I., Striar R. (2015). Guardianship – Critical Overview. **Social Security**, 96, 55-85). Said criticism relied in part on general arguments from the perspective of the conceptualization of rights of senior citizens and anti-ageism, and in part on findings of empirical studies in the area conducted in Israel. Roughly, the criticism may be described as touching on two main aspects; one – the procedural aspects of the current situation; and the other – the substantive aspects of the current situation.

The criticism of the procedural aspects of the appointment of guardians for senior citizens touched mainly on the following issues:

A.1.2.: The "Invisibility" of senior citizens in guardianship proceedings

Testimonies and studies in this field indicate that in guardianship proceedings involving senior citizens, their voice is not heard, they are not represented and the courts make decisions regarding their person and property without seeing and/or hearing the senior citizens personally and directly (Doron and Casdi, 2004; Waxman, 2010). This issue was also raised by the State Comptroller who found that in certain cases, senior citizens were not even summoned to the hearings which were scheduled in the applications to appoint a guardian in their matter. As a result of this reality, senior citizens are deprived of their fundamental liberty without receiving the right to be heard, without receiving the opportunity to defend their case, and consequently the courts are unable to formulate an opinion of their position based on a direct and personal impression. This reality is obviously in direct contrast to the rules of natural justice and the basic principles of administrative law.

A.2.2.: Lack of "professionalism" in the medical evaluation procedure

Testimonies and studies in the field indicate that there are no clearly defined rules regarding the level of professionalism required of physicians writing reports in guardianship proceedings at the basic level of primary or secondary legislation. Moreover, executive circulars ostensibly addressing this issue fail to specify the medical criteria and standards by which the capacity of senior citizens should be examined in the medical evaluation. Consequently, studies conducted in this area indicate these reports are relatively meager and lacking in scientific-medical basis. Here too, the result is that senior citizens are "put" under guardianship without undergoing the required professional medical and scientific examinations and evaluations.

Criticism regarding substantive aspects of guardianship appointment proceedings for senior citizens touches mainly on the following issues:

A.2.3.: Deprivation and very severe violation of human rights, liberty and autonomy of senior citizens

Testimonies and empirical findings indicate that in almost all cases in which applications are filed for a guardian appointment for senior citizens – the application is indeed accepted. Moreover, in the majority of the cases "global" guardianship is granted, for both person and property matters in a manner which deprives them, almost sweepingly and absolutely, of their legal independence.

A.2.4.: Ageism

Another substantive and interpretive criticism in this field holds that the "unbearable lightness" with which Israeli courts take the liberty to appoint guardians for senior citizens in Israel in such a sweeping and total manner stems from ageism on the part of the judges and the Israeli legal system. Ageism – like racism or sexism is the negative and stereotypical social structuring of senior citizens due to their chronological age and their tagging as "elderly" (a comprehensive overview of this term exceeds the scope of this schedule. For further discussion see: Doron I. (2013) (Editor) **Ageism in Israeli Society: Social Structuring of Old Age in Israel**. Jerusalem: Van Leer).

A.2.5.: Less injurious alternatives are not used

Finally, one of the additional substantive criticisms against the manner in which guardianship procedures are applied in Israel pertains to the fact that the possibility of applying alternative legal planning tools as an alternative to guardianship is hardly ever considered as part of the

process. Following the enactment of the Patient's Rights Law, 5756-1996, and the Dying Patient Law, 5766-2005, in particular, Israeli law has legal mechanisms that obviate the need to appoint guardians (such as: medical power of attorney, advance instructions, or power of attorney pursuant to the Dying Patient Law). Though legally controversial, there is an approach arguing that a continuing economic power of attorney may also be drafted (before Amendment 18 to the law which has expressly regulated this issue) which would also be valid in the event of intellectual capacity deterioration. These planning tools enable senior citizens not only to choose their substitute decision-makers (without the court's "approval") independently, but also subject the decision-makers to the standard of the person's will rather than to their "best interests". However, regretfully, studies and testimonies suggest that in practice, the courts almost completely ignore these alternatives in context of guardianship appointment procedures for senior citizens.

A.3. Specific issues in the area of guardianship for senior citizens

Beyond the criticism described above which highlights the problematic use of guardianship with respect to senior citizens generally (criticism which is also relevant to other populations such as persons with disabilities), several specific points related to criticism against the application of guardianship to senior citizens should be highlighted:

A.1.3.: The progressive nature of cognitive decline in old-age related diseases (such as dementia)

Senior citizens may also suffer from recognized disabilities that cause a sharp, extreme and sudden change in cognitive and functional abilities. Strokes, accidents (falls, traffic accidents, etc.), or onset of mental disease and the like occur in older ages as well, and abruptly change the state of awareness and functional abilities of the affected senior citizen. However, usually, and contrary to the more common state of younger persons with disabilities, the loss of abilities is gradual, progressive, and lasts years. Diseases such as Alzheimer's dementia or Parkinson's dementia are not only characterized by the fact that they may continue to live for many years, but also by the fact that the functional decline – both physical and mental – occurs over a period of time. For instance, in terms of cognitive abilities, memory loss occurs gradually, when the different memory "types" are damaged on different levels and in different stages of the disease. Therefore, it is not rare to find senior citizens in different stages of their disease who have lost skills and abilities in certain areas but at the same time still have a good command over skills and abilities in other contexts. This "dynamic ability" can also be greatly affected by medication imbalance, periodic mental states and many other variables (such as nutrition, fluids, or environmental context). Changes in these variables may result in changes in comprehension and functionality levels within time spans of hours or days. Therefore, not only is it impossible to conceptualize these changes in a "binary" manner (competent/not competent), but the dynamics of the functional fluctuations are not linear (although the general tendency is clear, it increases, decreases and changes).

A.3.2.: The complexity of cognitive evaluation tools and the limitation of screening tests such as MMSE or MoCA

Directly related to the gradual and non-linear progressive uniqueness described above, one can identify the difficulties and complexities in the execution of "competency assessment" tests for senior citizen on the medical-scientific level. The above does not only stem from the absence of professionalism in this field (as noted above), it stems from an inherent limitation of the "measuring tools" customarily used in this field and the lack of understanding of their nature and

logic. So, for instance, well known and recognized cognitive tests such as MMSE or MoCA are vastly used as "proof" of senior citizens' incompetency in guardianship procedures. However, a thorough examination of the nature of said cognitive tests reveals that these are, at most, initial "screening" tests whose "score" is only an initial indication that a "problem" exists, but they cannot in and of themselves determine the level of competency and functional and decision-making abilities in different and diverse contexts. Indeed, there are cases in Israeli jurisprudence in which senior citizens were "defined" as incompetent based on a low "score" in tests such as MMSE; but when they underwent a thorough and comprehensive competence evaluation, it became evident that they were still competent in many and diverse contexts, had comprehension ability and the ability to make decisions independently. Therefore, it is acknowledged with good reason that "competency evaluation" of senior citizens requires time and a multi-dimensional, inter-disciplinary examination to gain a reliable picture in the field, and in most cases the picture is complex, relative and not one-dimensional or unambiguous.

A.3.3. "Alzheimerism"

The importance of ageism (the social structuring of old age) has already been noted as an explanation for the relative ease with which guardians are appointed for senior citizens and with which their liberties and rights are revoked. Nevertheless, beyond the general stigma of old age, the stigma and prejudice commonly held by the public at large and by professionals toward dementia – in general, and Alzheimer's dementia, in particular (hereinafter: "Alzheimerism") should also be emphasized in this context. The prevalent stigma in this context sweepingly attributes to persons with dementia the inability to comprehend what happens around them and/or inability to exercise "their self-determination" in the sense of making choices and decisions. Dementia is still regarded as "senility", the absolute and total loss of self-identity and a need for a "responsible person" who will "look after their best interests". A combination of empathy, pity and concern for the wellbeing of the "poor elderly" clearly leads to the stigma and stereotypes underlying the lack of criticism in which guardianship is applied to senior citizens.

A.4. Summary of the current situation and the opportunities following the amendment to the law

There is no dispute that there are situations in which applying the guardianship "tool" to senior citizens is not only appropriate but also required and necessary. For instance, in situations of substantive loss of cognitive ability (for instance, in very advanced stages of Alzheimer's disease) or where human rights are clearly at risk (for instance, in circumstances of severe abuse and exploitation by family members on whom the senior citizen depends), it seems that there would be justification to use it. However, as described above, in many cases the institution of guardianship may be altogether avoided by using alternative planning tools, or may be used in a moderate, tailored and much more proportionate manner which would maintain the rules of natural justice. It is no coincidence that in recent years, senior citizens' rights organizations have increasingly criticized the institution of guardianship and called for a comprehensive reform in the current law in the area.

Following the criticisms described previously and the call for a statutory reform, indeed, a far-reaching reform has recently been made in this area. At the time of writing, it is still unknown whether and to what extent the reform will succeed to truly change reality, and what its full consequences will be. It is also understood that significant change is a long process that requires

training, comprehension and implementation – all of which take time. Therefore, it will take years to understand and assess how successful Amendment 18 to the law has been. At the same time, it is clear that the adoption and implementation of a model endorsing the alternative of decision-making support has not only become relevant and accessible for senior citizens – but is also required and mandated by the new amendment to the law, opening the door to and creating an opportunity for a real change to guardianship in Israeli society.

B. Support in decision-making: definition and relevancy for senior citizens as an alternative to guardianship

The conceptual framework of support in decision-making as an alternative to "classic" guardianship on the one hand and as an alternative to the institution of "substitute decision-making" on the other, has been known for many years in the realm of guardianship, long before the Convention on the Rights of Persons with Disabilities was drafted and adopted. Various European models which were developed as early as in the 70's and 80's of the previous century, adopted a world-view according to which instead of subordinating senior citizens to the "authority" of a guardian, a legal mechanism should be created offering an array of public-social services in the framework of which senior citizens (and persons with disabilities) are provided with a support system in the form of a "friend" or "supporter" or a sort of assistant, who provide assistance and support in decision-making processes without depriving the senior citizen of their liberty and legal status (for an overview of such systems in countries such as Sweden or Germany (see: Doron, I. (2002) Elder Guardianship Kaleidoscope: A Comparative Legal Perspective. International Journal of Law, Policy and the Family, 16(3), 368-398).

Although these new legal settings have not conceptualized or defined the term "decision supporter" in a unified manner, they have clarified its main underlying principles as follows: firstly – it is not a classic guardianship in the sense that one individual is "subordinated" to the "control" of another; secondly – the individuals are not "deprived" of their capacity, but rather, continue to have the capacity and power to make decisions; thirdly – the individuals are not "replaced" by substitute decision makers who make decisions on their behalf, even if the decisions purport to reflect the position of the individuals themselves. It is a procedure which acknowledges the fact that legal capacity is a fluid, gray term that is difficult to identify and conceptualize. It is a procedure which acknowledges the fact that universally, almost all human beings make decisions following consultation, assistance and support they receive – obviously, at varying levels and in diverse manners. Finally – it is a world-view which believes that through empowerment, support, and provision of information, accessibility and respect, almost any individual will be able to express his will and preferences in a real and authentic manner, and that said will and preferences must be respected. These are the principles underlying all new alternatives to guardianship which adopt one model or another of support in decision-making (unlike guardianship and unlike "substitute decision-making").

The call for and interest in the development and adoption of a legal mechanism of support in decision-making as an alternative to guardianship for senior citizens has obviously been greatly affected by the drafting, accession and adoption of the Convention on the Rights of Persons with Disabilities. Although senior citizens are not "persons with disabilities" by definition, the vast majority of senior citizens in whose case guardianship procedures were undertaken fall under the category of persons with disabilities (for instance, due to their cognitive disability as a result of dementia). Consequently, a new "trend" of endorsing the development of procedures for the

appointment of decision-making supporters also in the context of the discourse on guardianship for senior citizens can be identified (see, for instance, a manifestation of said tendency in the US: Kohn, N., Blumenthal, J.A. & Campbell A.T. (2013). Supported decision making: A viable alternative to guardianship? Penn State Law Review, 117(4), 111-1157).

Partly due to the above described criticisms against the manner by which the institution of guardianship is applied to senior citizens, in Israel during the last three years, attempts have been made to implement and offer supported decision-making mechanisms as an alternative to placing older adults under guardianship. These attempts were made in the framework of the activities of not-for-profit associations promoting the rights of older adults (including "Yad Riva" and "The Law in the Service of the Elderly Association"), and in light of the leadership and personal initiative of individuals such as Dr. Adv. Meital Segal-Reich and Dr. Advocate Michael (Mickey) Schindler. Indeed, in several precedential judicial decisions given by family courts in Haifa and the northern district, decision-making supporters were appointed to senior citizens who were undergoing guardianship proceedings as an alternative to guardianship. This is, undoubtedly, a promising and creative development whose progress should be followed, together with monitoring of how successful the "supporters" are in performing their duties in practice. At the same time, it should be remembered that as of yet, there are only early and few decisions that were given in the context of "judicial development" without a supporting statutory infrastructure in place (this refers to the situation which preceded the amendment to the law).

It is important to also note in this context that alongside the movement that encourages and supports the development of the mechanisms for support in decision-making as an alternative to guardianship for senior citizens, criticism has also been voiced, calling for caution in the adoption of these mechanisms as far as they relate to senior citizens. This criticism was mainly made in North America, where the preferred alternative model to guardianship for senior citizens was usually "substitute decision-making", under which persons either designate, in advance, a "substitute decision-maker" or a close family member is automatically appointed as a substitute decision-maker, and in this context decisions are made reflecting the wills and preferences of their family member.

This criticism can be summarized into the following arguments: firstly, as of yet there is no sufficient evidence for the success of this approach in practice; secondly, it does not provide a proper solution to situations which frequently apply to senior citizens, in which cognitive ability is almost non-existent and "support" or substantive or meaningful dialogue with the senior citizen who lacks cognitive abilities is not something that can be considered; finally, senior citizens – unlike a significant part of the population of persons with disabilities – can prepare, as competent adults, legal planning tools (such as powers of attorney, advance medical instructions, etc.) without "support" or "assistance", and therefore, if and to the extent they reach the stages in which they would need support and assistance in decision-making, this could be better and more efficiently pursued simply based on the planning tools they had prepared, rather than by appointing a "supporter" or any other assistant. This criticism, as such, does not invalidate or negate the development of supported decision-making mechanisms as an alternative to guardianship for senior citizens, but it definitely challenges the discourse in the area and calls for a thorough and meticulous examination of it.

C. Suitability of Bizchut model to senior citizens

In this part of the document, having presented the current legal situation with respect to guardianship for senior citizens under Israeli law; criticism of it; and the current situation as it applies to support in decision-making as an alternative to guardianship for senior citizens, I shall now examine the model, as presented in Bizchut's 'Supported Decision-Making Service for Persons with Disabilities Service Model' document, from the specific perspective of the extent to which it accommodates – in my humble opinion – the population of senior citizens.

Preface, background and vision

First, it should be remembered and emphasized that the most adults currently under guardianship are senior citizens. Therefore, and without detracting from the role and importance of the institution of guardianship as far as the rights of persons with disabilities are concerned, any change or reform in the institution of guardianship in Israel will mainly affect the population of senior citizens.

Second, senior citizens are not "persons with disabilities" as such. Aging is a natural biological process, and does not necessarily involve disability. Most human beings age, reach old age and even very old age without disability, or with impaired functioning that does not interfere with or deprive them of the ability to continue to conduct an independent and autonomous life.

Third, without detracting from the above said, there is a clear correlation and connection between increasing chronological age (mostly in advanced ages in the eighth decade and beyond) and an increase in disability rates – both physical and cognitive. Accordingly, for instance, data points to a significant growth in the rate of senior citizens suffering from dementia (mostly Alzheimer's dementia) in advanced ages. Therefore, a connection exists between advanced chronological age and an increasing disability rate in these age groups.

Fourth, unlike the population of persons with disabilities, senior citizens are exposed to and suffer from the phenomena of ageism. This phenomenon, although it shares characteristics that are likened to other similar phenomena such racism, sexism or ableism, is unique and pertains to the social structuring of old age. In general, the elderly are stereotypically labeled as senile, helpless and incapable of caring for themselves only due to their chronological age, regardless of their individual abilities. At the same time, and similar to the experience of the population of persons with disabilities, ageism very easily facilitates and justifies the violation and interference in the life and liberty of the elderly, justified by the need to "protect" them. It also exposes them to discrimination and exclusion based on ageist prejudice and stereotypes manifested partly in the manner and form in which the guardianship institution is applied to them.

Fifth, senior citizens who have dementia suffer from what may be referred to as "Alzheimerism", a social structuring and a specific stigma pertaining to what was referred to in the past as "senility", and what is currently regarded as "living death". This specific stigma consists of a quasi "medical/ scientific" aspect which goes beyond the above described "ageism", and facilitates not only social disregard for the violation involved in guardianship, but also, a sort of "surrender" or "resignation" with respect to using alternatives such as "supported decision-making" since "either way" they will eventually lose all ability and capacity of any kind.

Sixth, the cognitive abilities of many senior citizens, unlike (generally speaking) other populations in the realm of persons with disabilities – and particularly in states of chronic and progressive

illnesses – are in a dynamic, changing and relative condition. Gradual loss of abilities occurs over time – sometimes a very long time (decades); it occurs in different contexts, to different extents and with respect to different functionality areas; it is neither linear nor "binary" in the sense that until very advanced stages, senior citizens still maintain functional and decision-making abilities in specific and different areas.

To conclude this section, in the context of guardianship, senior citizens undergo an experience partially similar (but consisting of unique characteristics) to the experience of the population of persons with disabilities, resulting in excessive revocation of their personal liberty and disproportionate violation of their rights. Therefore, the vision of developing a supported decision-making service model as an alternative to guardianship, whose implementation would prevent unnecessary violation or revocation and/or disproportionate restriction of the legal capacity of senior citizens – is a vision which is definitely shared by persons with disabilities and senior citizens.

However, considering the unique nature of the population of senior citizens – namely, the fact that throughout the years they had built an independent and autonomous "life course" (usually without disabilities), and that throughout their life they "made" personal and family choices – the supported decision-making service model should be "one of the alternatives" rather than an exclusive and/or preferred "alternative", over the current institution of guardianship. Many senior citizens may (and this assumption should be empirically substantiated in the future) prefer or choose the alternative of "advance directives" or the alternative of "enduring power of attorney" – over a "supported decision-making service", for different personal reasons and motives. Moreover, due to the progressive nature of diseases such as dementia, a supported decision-making service could become limited in its ability to provide a solution to the real needs at a certain point of time, and other alternatives which were mentioned above, will prove to be more effective in securing senior citizens' wills and preferences. In this context, it should be remembered that the last amendment to the law has significantly expanded the scope of enduring powers of attorney and the areas to which they may be applied (such funds and property management) which did not exist in the past.

Target population

As noted above, in practice most older adults placed under guardianship in the State of Israel are senior citizens. The characteristics of this population, at least those placed under guardianship, are different from those of the population of persons with disabilities. At least according to currently available data (which are limited in scope), this population is characterized as having a larger female majority ; advanced in age; single (in the sense of absence of spouse); and living in institutional settings for the elderly (senior citizens' homes and nursing homes). According to this data, a significant part of the above population experiences different types of dementia, but mostly Alzheimer's dementia, entailing (in the more advanced stages of the disease) profound cognitive impairment.

Similar to the pilot project conducted with persons with disabilities, it is advisable an identical pilot project be conducted with the population of senior citizens – in general, and with senior citizens suffering from dementia (of different types) – in particular.

Objectives, goals, values and guiding principles, and decision-making processes

The description of the objectives, goals, values and guiding principles of the project with persons with disabilities in its entirety is and/or can be suitable for the population of senior citizens. Naturally, the model's values and guiding principles could have been conceptualized through different configurations and forms using alternative terms (dignity, autonomy etc.), but with respect to its suitability and applicability to senior citizens it seems that the proposed model can be suitable without issue.

An important point which should, nevertheless, be emphasized in this context pertains to the importance and role played by family members and additional significant persons in connection with decision-making processes of senior citizens. As aforesaid, a large part of the senior citizen population has a significant family support system created throughout the years based on long term choices and design (for instance, long term spousal relations). Studies show that these family members play a significant and substantial role in decision-making processes in advanced ages, and that these family members also play a central and substantial role in providing solutions to care and nursing needs. Therefore, the *a-priori* role and status of family members forming a substantial and integral part of decision-making processes of senior citizens is a point which should be emphasized when building a supported decision-making model for this population.

"Decision supporters" service model

Here, again, the entire model established for persons with disabilities seems to be suitable and appropriate for senior citizens, but I shall try to highlight a few important points:

(1) **The "dynamic" nature of the support in decision-making:** senior citizens are exposed to chronic and progressive disease processes characterized by changes over time which are not always linear or uniform. Therefore, the process and content of the "support" in decision-making provided to them should be "dynamic" and "flexible" in two unique respects: firstly – there is a continuing obligation to re-evaluate the changes in the abilities and preferences of senior citizens; secondly – there is an obligation to accommodate and change the pattern, scope, extent and content of the support in view of the changes arising from the periodic evaluation of abilities.

(2) **The dilemma of the "authenticity" of the will of dementia patients:** although the dilemma is not "unique" to senior citizens suffering from dementia, it should be emphasized that a specific dilemma arises around the issue of "respecting" the latter's will, particularly when they express will, choices or preferences which "contradict" their past values or the values of their families or culture (for instance: an observant woman from a religious background who suddenly manifests a will and preference to act in a manner which ostensibly contradicts her past values). While some argue that such will manifestations should be disregarded since they do not reflect the real person but rather the expression of their "disease", others contend that there is a moral obligation to respect this "new" will, which reflect the "new"/renewed self of the person in their current state. In this unique context – and without resolving the debate on its merits – the role of "support in decision-making" has a special importance, as it can echo the past choices and preferences of the senior citizens, and try to ascertain that the "new" choices and decisions of the senior citizens do indeed reflect a conscious and clear choice of a will to adopt a new and different form of identity and personality.

(3) **End-of-life issues:** one of the most important issues preoccupying senior citizens is the end-of-life issue: how to die; where to die; in what manner to die; the scope and type of medical treatment to receive before death; burial arrangements; and more. Specific issues may arise regarding the role of the decision-making supporter in providing assistance for the realization of the person's wills and preferences regarding the end of their life (for instance, by not taking drugs). These issues in their entirety are neither included nor discussed under "Health Issues" in Bizchut's model, and taking into consideration the provisions of the Dying Patient's Law, 5766-2005, the issue becomes even more complex.

(4) **Issues of support and inter-generational money transfer:** another issue of crucial importance for senior citizens concerns economic inter-generational transfer. Senior citizens choose, to whatever degree, to support their family members, children and grandchildren. The support is provided in different ways, including by diverse monetary and property transfers. Here too, these issues are not sufficiently discussed in the "Financial Issues" section.

(5) **Issues of training and exposure to the array of services and rights of senior citizens:** the section which discusses supporter training should provide specific information regarding the practical and daily challenges faced by the population of senior citizens (which is different from that of the population of persons with disabilities). There is room to equip supporters with specific knowledge regarding the diverse array of services, support systems and knowledge available to this population.

(6) **The issue of support in the preparation of additional alternatives to guardianship:** one of the features of the need for guardianship for senior citizens is that it usually involves a continuing and progressive process which entails changing, declining abilities, and requires increasing levels of support to the point in which the support model may not adequately provide a solution to the formal legal needs. For instance, in states of advanced stage dementia, cognitive or mental decline may reach a state in which even the highest level of support will not enable a person to make decisions that express and reflect their preferences at that specific point in time. To avoid the need to "move" to the level of guardianship at that stage, it is advisable that at the time supported decision-making is obtained, at the person's choice and in a proactive and planned manner, the person be presented with the additional legal planning options (such as preparing powers of attorney and/or advance medical instructions), as a tool which would obviate the need for guardianship if and to the extent the support model does not enable decision-making.

(7) **The legal status of decision-making supporters:** for diverse reasons, different service providers in the area of gerontology are reluctant to respect the status and role played by decision-making supporters of senior citizens – particularly when the decision runs contrary to their position. The above pertains mainly to professionals who are of the opinion that the decision of the senior citizen is erroneous (namely, is contrary to their recommendation), and that it is "influenced" by their supporters (family members). Precisely to prevent circumstances in which decision-making supporters of senior citizens are excluded, and to prevent the redundant use by professionals of the argument that "guardianship is necessary" – it seems that entrenching the status of decision-making supporters on a statutory level is justified.

Conclusion

In general, a supported decision-making service as an alternative to guardianship is a welcome, relevant and important model for the population of senior citizens. Senior citizens – like the population of persons with disabilities – experience disproportionate and injurious use of the guardianship institution. Therefore, a move that would enable to provide a service that limits the use of guardianship and provides a proper, adequate and empowering alternative – is a welcome and proper move in terms of promoting the rights of senior citizens in Israel.

Specifically, several points for consideration or deliberation should be highlighted with respect to the issue of implementing and adapting the proposed model to the population of senior citizens:

a. Senior citizens are not necessarily persons with disabilities. They suffer from stigma and discrimination due to ageism. Some of them, mostly in advanced ages, develop disability as a result of which they may be classified, in addition to being senior citizens, as belonging to the population of persons with disabilities.

b. Senior citizens, like persons with disabilities, experience in the context of the institution of guardianship a similar reality when guardianship over their person and property is "too liberally" appointed.

c. Senior citizens have unique circumstances and needs as far as support in decision-making is concerned pertaining to the types of infirmities and impairments from which they suffer as well as the "connection" to their past preferences and values.

d. Therefore, a vision offering an alternative to the institution of guardianship as it currently exists under Israeli law, emphasizing liberty, autonomy and respect while maintaining full legal capacity at the highest level possible – is a vision shared by senior citizens and persons with disabilities alike.

e. At the same time, as far as it pertains to senior citizens, the supported decision-making model should be one of various different models from which senior citizens are able to choose, including additional models such as advance instructions, powers of attorney, and substitute decision-making – all according to the choices and preferences of the senior citizens themselves. Therefore, in any support service model some of the support services to senior citizens should also actively include support and exposure (subject to the person's will and preference) to additional legal planning tools as future alternatives to guardianship (such as powers of attorney and/or advance directives).

f. As far as the population of senior citizens is concerned, the social support network (mainly family members) which was built and designed based on personal choices over the course of many years – is of great importance in supported decision-making processes. In most cases, family members are the ones that both in practice and often also by the choice, will and preference of the senior citizens practically fulfil the role of the supporters in the decision-making process. Therefore, the supported decision-making service model should also *a-priori* give room and weight to family members of senior citizens (according to the will and preference of the senior citizens themselves). This can be achieved by giving the family members the opportunity to act as decision-making supporters, as well as by making an allowance for their positions and preferences in the overall considerations and information to be taken into account in the decision-making processes in which decision-making supporters are involved together with senior citizens.

g. Specific information and training should be provided in the area of old age in Israel, including regarding the available service systems, rights and the psycho-bio-social characteristics of aging, in all services, to persons designated to take up the role of decision-making supporters, including training, enrichment and education.

h. A separate and distinct pilot project exclusively focusing on senior citizens should be conducted in order to examine, on an empirical level, the dilemmas, advantages and disadvantages of the model as it pertains to this population.

i. In this targeted pilot specifically, special emphasis should be put on the challenges and support patterns for senior citizens exposed to dementia (of its different types and stages).

Participants and supporters of Bizchut's pilot

BIZCHUT

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for People with Disabilitis