Supported Decision-Making: Applied Aspects, Supervision, and Defining Optimal Support

International Review

Hila Rimon-Greenspan Mariela Yabo
Rinat Namer-Furstenberg Dori Rivkin

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Editor (Hebrew): Ronit Cohen Ben-Nun
Graphic design: Anat Perko Toledano

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Myers JDC Brookdale Institute
P.O.B. 3886, Jerusalem 9103702, Israel
Tel: 02-6557400
brookdale.jdc.org.il/en | brook@jdc.org

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Abstract

Background

Supported decision-making (SDM) is an official arrangement to allow individuals with disabilities who find it difficult to understand information and to make decisions concerning themselves to use the help of another person in order to understand information and make decisions about monetary, personal or medical matters. In 2016 the Guardianship and Legal Capacity Law was amended, and Israel joined the states that recognized the practice of SDM as a preferable alternative to guardianship. The amendment emphasizes the need to act on the basis of an individual's wishes and protect their autonomy. It stresses the principal of "less restrictive measures" and suggests SDM as an alternative to guardianship. In fact, the law now requires the courts to consider SDM when ruling on requests for guardianship. It also specifies that regulations shall be put in place by the Ministry of Justice and procedures stipulated for the practice of SDM. In the wake of the amendment, the Ministry of Justice established the SDM Service and is planning inspection provisions for the supervision of SDM. Prior to formulating the final regulations, the Ministry issued provisional regulations for SDM. These steps situate Israel among the leading countries in promoting the use of this arrangement.

This review was prepared at the request of the SDM Service at the Ministry of Justice and of JDC-Israel Unlimited. Its purpose is to make available the latest experience and practical knowledge of SDM from around the world, for purposes of formulating SDM procedures in Israel, including a supervision and inspection system.

The document reviews main issues in SDM based on the practical experience accumulated in five countries and three pilot programs. The appendices provide a description of the status and application of SDM in each of the countries reviewed, as well as a description of the pilot programs reviewed.

Goals

- To survey how SDM is applied in the countries surveyed and in selected pilot programs around the world
- To examine the various mechanisms of safeguards and supervision or inspection of SDM arrangements
- To define optimal support for decision-making

Methodology

1. In order to provide as comprehensive and up-to-date a picture as possible of SDM, the review included academic publications as well as documents published online such as research reports and program information on various SDM-related aspects.
2. Semi-structured interviews were conducted with experts in SDM in the United States, Australia, and Latvia.

The data were collected during February-June 2020.

The locales chosen for the review have either considerable experience with SDM or detailed programs for its establishment: The province of British Columbia in Canada, the state of Victoria in Australia, the state of Texas in the United States, Sweden, and Ireland. The pilot programs selected operated in Latvia, New York City, and the state of Massachusetts. They were chosen for their comprehensiveness and importance, and due to their role in the acquisition of SDM practical experience, knowledge, and the design of practice. These pilot programs may occasionally precede and promote legislation on the topic.

Conclusions

The review found that currently there is no comprehensive model for SDM safeguards and supervision or inspection, these are addressed only to a limited extent in the countries that practice SDM and in the pilot programs reviewed. Based on the practical experience we reviewed, a range of practices and mechanisms were grouped, mapped, and categorized according to safeguards, supervision, and inspection mechanisms.

Similarly, the review found that there is no comprehensive definition of optimal SDM. Based on the review, preliminary insights were formulated of optimal SDM components

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1. Introduction

Supported decision-making (SDM) is an official arrangement between two or more people to allow an individual to use the help of another person in order to make decisions about financial, personal or medical matters or to understand information. SDM is intended for adults with disabilities or older adults (hereinafter "the decision-makers) who find it difficult to make decisions or to understand information pertaining to their affairs but have the capacity to make decisions with the appropriate assistance and support of another person (hereinafter "the supporter").

In 2016 the Legal Capacity and Guardianship Law was amended (Legal Capacity and Guardianship Law Amendment 18, 2016) and Israel joined the countries that recognized supported decision-making as a preferable alternative to guardianship. The Amendment emphasizes the need to act in accordance with the will of the individual receiving support and seeks to protect their autonomy. In the wake of the Amendment, the Administrator General (Public Guardian) in the Ministry of Justice is working to establish a service and supervision of supported decision-making arrangements, headed by the Supported Decision-Making Supervisor. It was also determined that regulations would be enacted regarding the practice of supported decision-making, and procedures established for such practice. Promulgation of the regulations is underway at the time of the writing of this document.

In the meantime, the Administrator General has published a proposed procedure for supported decision-making arrangements. With the implementation of the amendment and establishment of the supported decision-making service in the Ministry of Justice, Israel became one of the leading countries promoting the use of this arrangement.

This review was written at the request of the Supported Decision-Making Supervisor in the Office of the Administrator General at the Ministry of Justice and at the request of JDC Israel Unlimited (the Joint) and funded with their assistance. The aim is to present the latest experience, knowledge, and insights on supported decision-making worldwide in order to formulate work practices in this area in Israel. The review, for the first time, undertakes an extensive examination of applied supported decision-making, surveys safeguards and supervision of supported decision-making practice and defines what constitutes optimal supported decision-making.

The review places strong emphasis on the definition of optimal support in making decisions, in order to develop criteria for supervision of a supported decision-making arrangement in the future. Also emphasized is the distinction between a supported decision-making arrangement based on a court order ('legal channel') as opposed to a supported decision-making arrangement concluded in the framework of an agreement between

the decision-maker and their supporter or supporters ('agreement channel'). This method is acceptable in most countries of the world, and is currently also being examined in Israel, with a view to its adoption both in practice and in legislation.

This document, for the first time, reviews in depth key issues in supported decision-making and the applied experience accrued in several countries, states and in several pilot programs around the world: a definition of the components of supported decision-making; the decision-makers and the supporters; legal aspects of supported decision-making arrangements; safeguards and supervision; and a definition of optimal support.

2. A description of the review

2.1 Goals

- To review how supported decision-making is managed in the countries and states reviewed and in selected pilot programs around the world
- To examine different mechanisms for safeguarding and supervising the supported decision-making arrangement
- To define optimal supported decision-making

2.2 Method

1. An international review of publications in academic journals and websites was undertaken, including research reports and information on programs dealing with different aspects of supported decision-making in selected countries and states and in selected pilot programs. The items reviewed were carefully chosen to obtain as current a picture as possible of the aspects of supported decision-making under examination.
2. Semi-structured interviews were conducted with experts with practical experience in supported decision-making from the United States, Australia and Latvia. The information was collected during February to June 2020.

The countries and states chosen for the review have practical experience with supported decision-making arrangements. They are: the State of British Columbia in Canada, the State of Victoria in Australia, the State of Texas in the United States, and the countries of Sweden and Ireland. While Ireland does not have applied experience in this area, a new act was passed in 2015 recognizing supported decision-making, pursuant to which a special government service is being set up at the time of the writing of this document. Therefore, it was deemed important to study its structure and organizational infrastructure.

The pilot programs selected for the review are from Latvia, New York City and the Commonwealth (State) of Massachusetts in the United States. These pilot programs were chosen because they are comprehensive and of vital importance to the countries in which they operated, because they provide hands-on experience and knowledge, and because they helped to shape the practice of supported decision-making. These programs often precede and promote legislation on supported decision-making.

The pilot programs reviewed were:

1. A Latvian pilot program run in 2018-2019. The program was initiated and operated by the Resource Centre for People with Mental Disability "ZELDA"[1].
2. Supported Decision Making New York - SDMNY is a pilot program funded by the Developmental Disabilities Planning Council in New York State and run by the City University of New York. The program operates primarily in New York City and in four other locations in New York State: the metropolitan areas of Westchester County, Greater Rochester, Long Island, and the Capital Region. The program was launched in 2016 and was planned for five years. The review primarily addresses the experience and knowledge accrued in the New York City pilot program.
3. Six pilot programs that operated in the Commonwealth of Massachusetts since 2015, some of which are still operating. The programs are managed by the CPR (Center for Public Representation).
4. The review also cites the pilot program run by the Office of the Public Advocate in the State of Victoria, Australia. This pilot program was the first of several that followed. The program is mentioned because of its precedence, its importance, and the fact that it preceded legislation in Victoria. However, the program is mentioned only briefly, because of the lack of sufficient information available.

[1] For further reading, see: https://zelda.org.lv/en/about-us

3. An overview of the development of supported decision-making as an alternative to guardianship - in Israel and around the world

3.1 The institution of guardianship and criticism of it

At the end of 2018, a total of 60,813 individuals in Israel had an appointed guardian, some of them individuals with disabilities and some were older adults (the Administrator General, 2018). Initially, the institution of guardianship was designed to serve as a protective mechanism and to help individuals who presumably do not have the capacity to take care of their own affairs. This was achieved by restricting their legal capacity and appointment of a guardian by the courts (Kanter & Tolub, 2017; Werner & Chabany, 2016). Over the years, criticism has grown of the guardianship model which deprives persons appointed a guardian of their human rights, their independence and their right to self-determination (Barel, 2018; Blanck & Martinis, 2015; Dinerstein, 2012; Tolub, 2015; Tolub & Kanter, 2014). Criticism of the institution of guardianship has been greatly influenced by the growing critical approach to disabilities, including the social model of disability (Tolub, 2015; Tolub & Kanter, 2014).

Unlike the medical model of disability, which views the impairment as the source of the individual's limitation, the social model of disability views disability as a social phenomenon and points to the social, cultural, economic, and legal forces that shape and define it (Mor, 2012; Rimon-Greenspan, 2007). Similarly, according to the social model of disability, appointing a guardian and depriving an individual with a disability of legal capacity constitute a violation of basic rights to independence and to self-determination. This approach asserts that individuals with disabilities can make their own decisions if they are given the support they need to do so (Kanter & Tolub, 2017; Tolub, 2016).

The belief that persons with disabilities have equal rights and human dignity, with its core concept of personhood[2] as a guiding principle in determining policy and legal conduct, has also led to harsh criticism of the institution of guardianship. According to the concept of personhood, all people are equal, both philosophically and in the eyes of the law, and therefore they are entitled to legal capacity and to the right to make decisions about themselves. Consequently, appointment of a guardian to make decisions about the life of a person with disabilities effectively violates that person's basic rights (Flynn & Arstein-Kerslake, 2014).

[2] N/A

3.2 Supported decision-making as an alternative to guardianship

Following the criticism of guardianship, various countries began to consider possible alternatives, the most notable today being that of supported decision-making (Booth-Glen, 2017; Dinerstein, 2012; Tolub, 2015; Tolub & Kanter, 2014). Unlike guardianship, which revokes the right of an individual to legal capacity and grants it to a third party, supported decision-making enables individuals to make decisions on their own, assisted by another person (Ordinaire, 2017).

While the literature does not offer a uniform definition of supported decision-making, researchers argue that the guiding principle of this practice is that individuals have the right to express their needs and wishes and to realize them (Davies et al., 2017). The significant difference between guardianship and supported decision-making is the shift from the guardian acting for the individual's "benefit" to helping the individual make their own decisions in accordance with their needs and wishes. In a supported decision-making arrangement, people who need help to make decisions in their lives receive the support they want and need in order to understand various life situations that they encounter and receive an explanation of the options to deal with those situations. In this way, they can make decisions about their lives by themselves without the need for a guardian (Tolub, 2016).

The change in the approach towards the rights of people with disabilities with regard to legal capacity and towards the institution of guardianship were preceded by the Convention on the Rights of People with Disabilities (CRPD) adopted by the United Nations in 2006. The Convention sought to secure the rights of people with disabilities to equality, freedom, independence, and full participation in society, including the right to make decisions about their lives (Barel et al., 2015; Kanter & Tolub, 2017; Werner, 2012). Article 12 of the Convention deals with the right of each individual to legal capacity and stipulates the right of individuals with disabilities to equal recognition before the law and emphasizes their equal right to legal capacity in all aspects of life. Article 12 also states that individuals with disabilities must be guaranteed access to the support they need to exercise their legal capacity. Article 12 effectively constitutes the basis for an alternative to guardianship and for instituting the practice of supported decision-making (Kanter & Tolub, 2017; Werner, 2012).

Since the United Nations adopted the Convention on the Rights of People with Disabilities (CRPD) member countries around the world have been attempting to implement it, including Article 12 (Penzenstadler et al., 2020). Many countries have started to consider changes in the institution of guardianship and to move towards the practice of supported decision-making (Ordinaire, 2017). Different models of supported decision-making exist. Some were developed before the Convention on the Rights of People with Disabilities, such as the models in Sweden and British Columbia in Canada, and some were developed after its ratification.

North America (the United States and Canada) and several West European nations began creating alternatives to guardianship as far back as the 1980's and 1990's, long before the adoption of the Convention. The alternatives that these countries created range from reducing the scope and duration of the guardians' appointments, developing various legal arrangements, such as power of attorney and representation agreements, and ultimately shifting to supported decision-making arrangements. In recent years, additional countries, including India, Hungary, Latvia, the Czech Republic and Israel are beginning to move from guardianship to supported decision-making (Tolub & Kanter, 2014).

3.3 Amendment of the Guardianship Law and recognition of supported decision-making in Israel

Israel's ratification of the Convention on the Rights of People with Disabilities in 2012 can be considered another milestone in the social, cultural, and legal changes which occurred in recent decades, which grew out of the struggle of people with disabilities for recognition of their rights to equality. The struggle included mass demonstrations and protests as well as efforts to promote legislation and policies, including legislation of the Equal Rights for Persons with Disabilities Law in 1998 and subsequent amendments, as well as the ratification of the UNCRPD 2012 (Mor, 2012; Rimon-Greenspan, 2007 [Hebrew]; Rimon-Greenspan, 2007). Criticism of the institution of guardianship followed soon after and argued that the guardianship law was outdated and incongruent with current ethical and legal understanding of the rights of people with disabilities, and that the institution of the guardianship should be revoked, or at very least, greatly reduced (Kanter & Tolub, 2017; Tolub & Shlomai, 2019).

In 2014, Bizchut[3], the Israel Human Rights Center for People with Disabilities, led a coalition of 19 organizations advocating for and representing people with disabilities and the elderly to demand that the Knesset (the Israeli parliament) reform the Legal Capacity and Guardianship Law (Kanter & Tolub, 2017; Tolub & Shlomai, 2019). During 2014-2015 Bizchut also ran a supported decision-making pilot program which earned the support of the United Nations. Bizchut subsequently developed a supported decision-making model, with the view to Israeli law adopting the model (Tolub, 2016).

In 2016, the Legal Capacity and Guardianship Law was amended and Israel joined the countries that recognized the practice of supported decision-making as preferable to guardianship (Barel et al., 2015, Kanter & Tolub, 2017). The amendment was the result of a complex process spearheaded by coalition of organizations led by Bizchut

[3] https://www.bizchut.org.il/

as well as two government ministries - the Ministry of Labor, Social Affairs and Social Services and the Ministry of Justice (Holler et al, 2020; Kanter & Tolub, 2017; Schindler & Segal-Reich, 2016).

The amendment states the requirement of the guardian to act in accordance with the individual's will, thereby protecting their autonomy, as distinct from acting solely according to the "best interests" of the individual. The amendment also emphasizes the principle of "the least restrictive means" and offers two alternatives to guardianship: supported decision-making and an Enduring Power of Attorney (Resznizky et al., 2019). The amendment requires the court to consider the option of supported decision-making when ruling on appointing a guardian. In addition, a timeframe of two years was established for writing the regulations and procedures for the practice of supported decision-making (Schindler & Segal-Reich, 2016).

Following the amendment, the Ministry of Justice is working to establish a service which will supervise supported decision-making arrangements, headed by the Supported Decision-Making Officer. Until such time as the regulations are completed, the Administrator General has published a proposed procedure detailing the supported decision-making arrangements. With the implementation of the amendment and establishment of the supported decision-making service in the Ministry of Justice, Israel is one of the world leaders in promoting the use of this arrangement.

4. Supported decision-making: definition and components

4.1 What is supported decision-making

In most of the countries and states reviewed, supported decision-making is defined as a process or service designed to help those who need it (the decision makers) to make decisions in different areas of life while safeguarding their rights, dignity, wishes and autonomy. In a supported decision-making arrangement, the individual exercises their right to make decisions according to their preferences with assistance and support according to their needs, without relinquishing their autonomy. The persons providing the decision-makers with assistance and support are called 'decision making supporters'. British Columbia is an exception as the legislation stipulates that supported decision-making may also include making decisions for and instead of the individual, but that such decisions must be aligned with the individual's preferences, beliefs and values (Davidson et al., 2016).

All of the countries and states reviewed consider supported decision-making an alternative to guardianship. Several countries and states, such as New York and Ireland (Kelly, 2014) still adopt an "all or nothing" approach currently deemed outdated, according to which an individual either possesses or does not possess legal capacity to make decisions about their life, without the option of having the right to decide in some areas and not in others. While guardianship still exists in all of the countries and states reviewed, supported decision-making is an alternative that can be used to safeguard the rights of the individual, and that can be fully or partially implemented, adding flexibility to how the individual's legal capacity is defined. In some countries, an attempt is made to refer individuals to supported decision-making instead of guardianship; for example, in the Texas legislation (https://www.disabilityrightstx.org; Theodorou, 2018). In a Massachusetts amendment (Lovely et al., 2019) a judge called upon to appoint a guardian for an individual with a disability is obliged to first consider less restrictive alternatives. Another example is the pilot program in New York City intended for people with disabilities appointed a guardian or at risk of such an appointment, which aims to use supported decision-making agreements as a means for preventing or revoking the appointment (http://www.sdmny.org).

Some countries and states have **guiding principles** for implementing supported decision-making. In Victoria (Australia), four principles were established as the basis for legislation on the subject: every person has an equal right to make decisions that affect their life; supported decision-making must be provided for persons in need of it to participate in decisions that affect their lives; decisions must be directed by their preferences; and legal

arrangements must be developed to protect those in need of supported decision-making from exploitation or undue influence (Bigby et al., 2017; NHMRC Cognitive Decline Partnership Centre [CDPC], 2019). In Ireland, legislation is based on the principles of the autonomy of the individual and of minimal intervention (Kelly, 2017). In Texas, too, autonomy is a core principle of the legislative reforms promoting the issue (https://tcdd.texas.gov). The New York City pilot program also addresses the wider implications of supported decision-making; it is perceived as empowering people with intellectual disabilities, and allowing them to develop life skills, to steer their lives on their own, to avoid risky situations and to learn how to handle them, and to develop relationships that provide a safety net against possible harm (http://www.sdmny.org).

4.2 The goals of the support and the areas it deals with

4.2.1 The goals of the support

In the countries and states reviewed, supported decision-making ranges from open-ended long-term support to short-term support intended to achieve specific objectives, generally within a set timeframe. At one end of the spectrum is the legislation in Ireland (Kelly, 2017), British Columbia and Texas (Texas Council for Developmental Disabilities [TCDD], 2018), in which support is long-term and pertains to extensive areas of life. At the other end of the spectrum is the support service in Sweden (Tolub, 2015). The legislation in Victoria (Office of the Public Advocate https://www.publicadvocate.vic.gov.au); [OPA], 2018), and a Massachusetts bill (Kendrick, 2019) offer tools that can be used both in continuous support and in support dedicated to specific situations.

4.2.2 The areas the support deals with

Supported decision-making is provided in three main areas: personal, medical, and financial. Making information accessible is central to providing support in all of these areas. Although it is not a separate area of life, sometimes accessibility to information is all that the decision-maker needs, i.e., sometimes support in accessing information is the purpose of the support arrangement and not solely a means to an end.

Different countries and states have different criteria for determining the areas and issues on which support can be provided. Decisions pertaining to personal matters may include choosing and adjusting a place of residence, accessing services in the community, finding work, obtaining education or vocational training, forming friendships and relationships, strengthening the social network, and buying food and clothing. In some countries and states, it also includes access to legal services (in British Columbia, divorce proceedings are excluded). Financial decisions may include accessing the individual's money to pay for personal expenses, such as food and rent,

paying bills, making cash withdrawals and deposits, and purchasing insurance policies for the individual or for their assets. Decisions on medical matters may include use of general health care services and mental health services, choosing medical treatment, and communicating with health care providers. In some countries (such as Sweden), medical decisions are included in the area of personal matters.

In medical and financial matters, some countries and states exclude specific issues and do not allow their inclusion in supported decision-making arrangements. In Victoria, for example, separate legislation exists for supported decision making on medical issues as opposed to mental health issues (https//www.publicadvocate.vic.gov.au; OPA, 2017). In British Columbia, a supporter cannot deal with certain medical decisions, such as refusal to accept lifesaving treatment. In Victoria (https://www.publicadvocate.vic.gov.au) and British Columbia (the Representation Agreement Act of 1996), a supporter may deal with routine financial matters, but not major financial matters, such as the purchase or sale of real estate. The pilot program in Victoria did not deal with financial matters at all (Burgen, 2016).

4.3 Components and practice of the support

Supported decision-making components and praxis are still being formed in the various countries and states. In some of the countries and states and in some of the pilot programs, certain components and practice of the support are addressed directly, such as frequency of contacts with the supporter or defining which actions the supporter is expected to carry out and which he or she is prohibited from doing. In other countries, this issue is not addressed.

4.3.1 The frequency of the support

Unlike pilot programs, that address the frequency of the support contacts, the existing legislation does not address this issue. In the Victoria pilot program, the supporters, who were volunteers and not family members or friends of the decision-maker, were required to be in weekly contact with the decision-maker and to meet quarterly with the program coordinator (Burgen, 2016). In the Latvian pilot program, which employed paid supporters, three levels of support were defined, according to the number of hours of support provided monthly. These levels were based on the decision-maker's needs: 6 hours, 16 hours, or 30 hours. Moreover, 10 additional monthly hours were allocated for situations in which additional support was required, such as a mental health crisis or moving house. That said, at times, a decision-maker in the program needs less than 10 hours of support in a particular month, while others need more than 30 hours (I. Leimane-Veldmeijere, personal communication, 12.2.20). In the New York City pilot program, a preliminary process, concluded with drawing up and signing of an official support agreement, generally takes about 12 to 18 months. During this time, the program's facilitator maintains regular

contact with the decision-maker and the supporter, though the frequency and type of contacts are not defined and may consist of face-to-face meetings, phone calls or other forms of communication.

4.3.2 The support activities

The activities included in the supported decision-making arrangements are defined in most of the countries and states and pilot programs, but not in all. In the countries and states and pilot programs in which the functions of the supporters are addressed directly - Victoria, New York, Sweden, Ireland, Latvia, Texas and Massachusetts, the following components are generally included:

- Identification of opportunities in which the individual can make decisions
- In-depth clarification of the decision maker's wishes and preferences
- Finding information relevant to the decision
- Providing the decision-maker with access to relevant information and explaining it
- Assistance in weighing the implications and possible risks of the various options that are being considered
- Assistance in exercising rights
- Assistance in expressing, mediating, and delivering the individual's decision to other parties

Another important component of the supported decision-making arrangement as expressed in the countries and states reviewed is **carrying out actions to implement the decision-maker's decisions**. This component was found to be more problematic than others in several of the pilot programs reviewed. In the Victoria pilot program, great difficulty was experienced with the implementation stage of a decision due to a lack of willingness (and even substantial resistance) on the part of staff and professionals, in housing facilities for example, as well as of service providers (Burgen, 2016). The Latvian program also discussed the supporter's role in the implementation of the decision - is the supporter's role only to help with the decision or also to take action to carry it out. Ultimately, it was decided that the supporter must not only assist in making the decision, but also with its implementation (I. Leimane-Veldmeijere, personal communication, 12.2.20). Furthermore, for some of the supporters, additional components are defined as part of the support. For example, a medical supporter in Victoria can also represent the interests of the decision-maker in matters of medical care, even when the individual's condition deteriorates and the individual is temporarily unable to make decisions. In the case where there is a supported decision making agreement on mental health, professionals are obligated to consult with the supporter about the decision-maker's care (https://www.publicadvocate.vic.gov.au; OPA, 2017). The Massachusetts bill stipulates that one of the supporter's functions is to accompany the decision-makers and to participate in discussions with other people when decisions are being made or to obtain information for the decision makers.

5. Decision-makers, supporters and other roles

5.1 Decision-makers

5.1.1 Target population

Most countries and pilot programs reviewed designate supported decision-making for people with a specific disability (sometimes the definitions differ from country to country); some for older adults with age-related disabilities. Only a few countries intend it for all people with disabilities. Furthermore, in different locations supported decision-making is intended for people with different levels of ability who need different levels of support.

In most of the countries and pilot programs the decision-makers are **individuals with intellectual disability**. Thus, for example: in the Massachusetts pilot programs, most of the participants are people with intellectual disabilities with varying levels of functioning (Pell & Mulkern[4], 2015). The New York pilot program is also aimed at decision-makers who have intellectual disability or autism. The New York pilot program is aimed at young people who are about to graduate from special education schools and are now faced with the possibility (an almost certainty) of guardianship being imposed on them or have recently been appointed a guardian and wish to revoke the process ('restoring of rights'). The pilot program was designed to address the needs of a diverse population in terms of cultural background, economic status, type of community (urban, suburban, and rural), age, and citizen status (citizens or undocumented immigrants). The pilot programs in various regions of Australia designated supported decision-making for **people with cognitive disabilities** (Bigby et al., 2017). The population includes people with intellectual or mental health disabilities, brain injuries as well as older adults with dementia (OPA, 2017). In Victoria, the law determines four possibilities for appointing a supporter[5], all of them referring to people with cognitive disabilities who have the capacity to make decisions. In the event of appointment of a medical support person, even a minor with intellectual disability who possesses capacity can be assigned such a supporter (https://www.publicadvocate.vic.gov.au). The Victoria pilot program included 18 participants aged 20-65 with a mild intellectual disability living in the community or in residential facilities, but who are socially isolated or without an available support network (Burgen, 2016).

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[4] The Massachusetts bill is also primarily aimed at people with cognitive disability (Lovely et al., 2019).

[5] For details about the alternatives to the appointment of a supporter in Victoria, see https://www.publicadvocate.vic.gov.au

In some countries and states, the target population for supported decision making consists of **people with a mental health disability**. For example: the PO (personal ombudsman) model in Sweden was intended for people with a mental health disability with exceptionally low-level function, but over the years, the target population has been extended to include anyone with a mental health disability (Tolub, 2015). In Texas, the supported decision-making arrangement is intended for adults with **a physical or mental health disability** that significantly limits their functioning in at least one area (https://www.disabilityrightstx.org).

In some countries and states, the legislation or the pilot programs were also aimed at **older adults**, who, for various reasons, need support to make decisions, such as the Massachusetts bill (Lovely et al., 2019). Another example is the Texas law, advanced to provide a solution for older adults; however, in practice, most of the population receiving supported decision making were young people with disabilities during the period of transition from special education to adulthood.

Some countries and states designate the supported decision-making service **for all or most people with disabilities** (as opposed to people with a specific disability) **as well as for older adults**. The law in British Columbia stipulates that in effect, any adult can make a support and representation agreement provided they meet several criteria: they understand the role of the representative, demonstrate the ability to choose, and have the ability to express approval or disapproval (Kerzner, 2011). In Ireland, the service is aimed at people whose capacity to make decisions is somewhat impaired, but who, with the aid of the necessary information and explanation, can make decisions, including people with an intellectual disability, people with a mental health disability, people with an acquired brain injury and older adults with dementia (Mental Health Commission [MHC], 2020). In the Latvian pilot program, the participant decision-makers were individuals with intellectual disabilities or autism, and people with a moderate or severe mental health disability (I. Leimane-Veldmeijere, personal communication, 12.2.20).

5.1.2 Prerequisites

As supported decision-making is intended for people with disabilities with the capacity to make decisions, but need assistance to do so, some countries and states have prerequisites or criteria specifying who can be included under this definition.

In both Victoria and British Columbia, the law makes clear reference to the capacity or competence tests required to enter a support agreement, while other countries and states have criteria but do not employ capacity tests. In Latvia, for example, the emphasis is on the cooperation of the individual. An individual who is not prepared to cooperate cannot be granted support in making decisions. In Texas, individuals with disabilities must have the

capacity to understand that they need support in making certain decisions, must choose a friend or relative as a supporter, and must be capable of making decisions with the supporter's assistance. At the same time however, there are no official admission tests, and the law does not stipulate any prerequisites to enter into such an agreement (https://www.disabilityrightstx.org).

In the rest of the countries and states reviewed - Massachusetts, Sweden and Ireland, as well as in the New York pilot program - no direct reference was found to prerequisites for a supported decision-making arrangement.

5.1.3 Preparing the decision-makers

Supported decision-making sometimes involves preparation that may include the decision-maker, the supporter or supporters, and other relevant people. Sometimes, the preparations are conducted before the individual decides to enter the supported decision-making process; other times, the preparations take place after they have started the process.

In some of the countries, the preparation consists primarily of providing exposure to supported decision-making as an option. Thus, for example, in Massachusetts, this is done among youth in special education settings, as part of individualized education plan meetings (Lovely et al., 2019). A similar process takes place in Texas. In 2017, a law was passed requiring schools to include the topic of supported decision-making in the transition curricula of students with disabilities; and as of the 2018 academic year, when informing parents about their child's educational rights after completing special education[6] the school must include information about guardianship, alternatives to guardianship, including supported decision-making, and additional services that may enable the students to live independent lives. In addition, the student's yearly individualized plan must consider and discuss opportunities to enable the student to develop decision-making competencies and must examine the availability of appropriate services and support to advance their independence and autonomy (Theodorou, 2018).

In New York, the preparations are lengthier and more complex. Following recruitment of the decision-makers to the pilot program, signing them up to the service and assigning them to a program facilitator, a preliminary process for drafting the support agreement begins, consisting of three stages. The process involves the decision-maker, the facilitator, and later, the supporter as well. The process addresses the four 'big questions' of the support agreement: **which areas** does the decision-maker want support in; **who** does the decision-maker want

[6] The Special Education Law in the United States stipulates that the parents of an individual with a disability are accorded the right to make decisions about the individual's education until the individual reaches the age of 18. Upon reaching the age of 18, these rights and the related services are transferred to the individual (https://sites.ed.gov/idea/regs/b/e/300.520).

to provide him/her with that support; **what kind of support** is the decision-maker interested in; **and how** does the decision-maker want to receive the support.

The first stage in the process is dedicated to the facilitator getting to know the decision-maker and developing a relationship with him or her. This stage also focuses on learning how the decision-maker customarily makes decisions, what areas the decision-maker wants support in, and who can serve as a potential supporter or supporters for the decision-maker. **In the second stage**, the facilitator works with the supporters chosen by the decision-maker, teaches them about supported decision-making, works with them to change their mindset - from makers of decisions for the individual to supporters of independent decision-making, including discussion of various aspects of decision-making that incur a risk and the concept of 'dignity of risk'. This concept was proposed by Perske (1974), who argues that overprotection of people with intellectual disabilities is effectively an indignity because it tends to prevent their taking normal risks that other people take. Decision-making incurs a risk that is an intrinsic part of normal life and that also facilitates making the most of opportunities that arise. Perske further argues that making decisions that incur a risk is part of human development and growth, and part of regular and normative life. He asserts that people with intellectual disabilities need to experience situations that incur reasonable risk and to learn to deal with them and, in his opinion, they have the capacity to do so. Rather than preventing such situations, they should be given the tools for contending with such risks. **In the third stage**, the facilitator works with the decision-maker and the supporters on the wording of the support agreement, reviews the wording with them, and makes sure that the agreement and its contents are understood by all the parties involved and is acceptable to them. The end of the process is marked by a ceremony in which the decision-maker and their supporter or supporters sign the support agreement. A decision-maker who wishes to revoke the guardianship is referred to the 'legal arm' of the pilot program to restore their legal rights. The facilitator or the pilot program staff maintain regular contact with the decision-maker and the supporters as part of the preparations and support.

The interim conclusions of the pilot program were that there is indeed a need for preparation and a long period of guidance before a support agreement is drawn up, and that a one-time meeting to simply sign the agreement is inadequate. This period is necessary to ensure that the process that the decision-maker undertakes - building their ability to make various decisions about their life and building the support relationship between the decision-maker and the supporters - is a real process that will be of benefit to the decision-maker later as well. Furthermore, it was found that most of the decision-makers recruited for the pilot program, young adults transitioning from the special education system to adult life and, for the most part, facing transition to permanent guardianship, do not know how to make any decisions in their lives. The facilitators spent a considerable amount

of time working with the young decision-makers on developing this capacity. One of the important conclusions of the evaluation study of the pilot program was that one of the aims of the process leading up to the signing of the support agreement should be teaching the decision-makers how to make decisions and not only to sign an agreement (Booth-Glen, 2017).

In the first pilot program in Victoria and in other subsequent pilot programs in the state, both the supporter and the decision maker were given training about decision-making. Information was presented on supporting decision-making practices, such as supporting the decision-makers to take reasonable risks, the ability to change their mind, the ability to make decisions that others might not like, and the ability to broaden their experiences. One pilot program focused particularly on the capabilities of the decision-maker, and adopted a preliminary process called the decision readiness stage. The aim of this stage was to develop decision-making capabilities in individuals with cognitive disabilities and to provide the decision-maker and their supporter with training and support (Bigby et al., 2017). In the rest of the countries included in the review - Latvia, British Columbia, Sweden, and Ireland – to the best of our knowledge, the decision-makers did not undergo any preparatory process.

5.2 The decision making supporters

5.2.1 Criteria for selecting supporters

Each country or pilot program has different criteria for selecting supporters, and in some cases, there are no criteria at all. Supporters are, for the most part, relatives, or other people from the decision-maker's close circle. In other instances, especially in the case of pilot programs, the program staff assign supporters who are professionals or volunteers who are not acquainted with the decision makers. In these instances as well, the decision-maker must consent to the choice of supporter or at least not express any objections.

In the Massachusetts bill, for example, the decision-maker is meant to choose the supporter (Brashears et al., 2019; Kendrick, 2019). Therefore, the supporters in the Massachusetts pilot programs were mostly family members, while some were friends of the decision-maker, or a member of the team providing the decision-maker with care (Pell & Mulkern, 2015). Similarly, in Victoria, a supporter may be a relative, friend or another person that the decision-maker knows and trusts, provided that that person is over the age of 18. Persons who are insolvent under administration (bankrupt) cannot be supporters. In contrast to Massachusetts, where an individual's caregiver can be appointed to the role, in Victoria anyone serving as the individual's paid caregiver or providing the individual with health care or housing services cannot serve as their supporter. If, during the appointment, the supporter becomes a paid personal caregiver, a provider of health care services or living facility services

to the decision-maker, that supporter must give up the appointment and inform the decision-maker (Powers of Attorney Act, 2014). Moreover, if the supporter is appointed to aid on financial matters and has a prior conviction of an offense of fraudulence, the supporter must notify the individual and indicate the fact on the appointment form (OPA, 2018). During and after the pilot program, laws were approved in Victoria that recognize different options for supported decision making. These options are based on the decision-maker's informal support network, and volunteers were recruited mainly from other programs of the Office of the Public Advocate (Burgen, 2016). In British Columbia, adults over the age of 19 can serve as supporters ('representatives'), so long as they do not provide the decision-maker with paid personal care services or paid medical care services and do not work at the decision-maker's residential facility that provides the decision-maker with personal care services or medical care services. Parents, children, and spouses are exempt from these restrictions. Others who can be appointed to the role include the guardian or public trustee. In agreements that do not cover personal or medical matters, a representative of a credit union or a trust company can also be appointed (Representation Agreement Act, 1996).

On the other hand, there are countries in which the supporters appointed do not have a personal or a prior relationship to the decision-maker. In Sweden, for example, the supporter (Personal Ombudsman) is an independent professional, usually an attorney or social worker, but may also be from a different professional background if s/he has an university degree (Penzenstadler et al., 2020). Supporters in Sweden are employed by NGOs. They are not beholden to or committed to a specific psychiatric or social work service and are not always part of the social services or official health service (Series, 2015). According to the Director of the ZELDA organization in Latvia, supporters in that country are paid professionals with no prior acquaintance with the decision-makers. The criteria for their selection: a minimum of a university degree in a caring profession, such as social work, special education, or in another area, such as economics or law. The choice of paid professionals to serve as supporters is based on experience and lessons learned from a previous pilot program conducted in Latvia between 2014-2016, during which 57 family members were trained to become supporters. The model was not successful because few truly served as supporters, while the rest tended to make the decisions for their family members (I. Leimane-Veldmeijere, personal communication, 12.2.20).

Some countries and states do not have criteria for appointing supporters. In Texas, there are no state restrictions regarding who can serve as a supporter in making decisions, but for the most part, they are a relative or a friend of the decision-maker (https://tcdd.texas.gov). The supported decision-making agreement is based on trust, and therefore the decision-maker must choose a person that they can rely on, and the law prohibits dictating to the decision-maker who they should choose (https://www.disabilityrightstx.org). The New York pilot program also did not specify criteria for choosing supporters, and it is the decision-makers who choose their supporters as

part of the drafting of their support agreement, though in most cases, their supporters are family members or close friends. Ireland also does not make any direct reference to criteria for choosing supporters.

5.2.2 Paid support versus volunteer support

Whether the support is paid for or provided by a volunteer is a function of the law in the country, how support in making decisions is practiced, and the nature of the model in the various pilot programs.

Paid support is provided in cases in which the supporters are professionals without prior acquaintance with the decision-maker. Thus, for example, in Sweden supporters are professionals providing the support service for pay. In the pilot program in Latvia, the supporters were professionals paid by the organization that ran the pilot program and were employed in a full-time capacity to support several decision makers (I. Leimane-Veldmeijere, personal communication, 12.2.20).

In instances in which family members or friends serve as supporters, the support is usually voluntary and not paid. In Massachusetts for example, most of the supporters are relatives or persons known to the decision-maker and who do so voluntarily (Brashears et al., 2019; Kendrick, 2019). Victoria is another example of unpaid support - the law stipulates that supporters must be persons known to the individual - relatives, friends, or other people that the individual trusts, and they are not allowed to receive payment for the appointment (Powers of Attorney Act, 2014). In Texas, the agreement is a voluntary one; the decision-maker chooses the supporter whose help s/he wants in making decisions (https://tcdd.texas.gov). A person can serve as a supporter only on a voluntary basis, and there is no option for the agreement to include paid support. Activists who promoted legislation on the subject in Texas were apprehensive about the possibility of "paid supporters"; it was therefore determined that supported decision-making would be conducted in a natural manner within the day-to-day life of the individual, and the supporter would be part of their natural support network. However, the wording of the law does not actually contain any provisions preventing organizations from rendering such services and offering the service to anyone interested in it (Theodorou, 2018).

5.2.3 The number of supporters

The assumption in most countries is that an individual with a disability has more than one person in their life who could provide support. The appointment of multiple supporters enables the decision-maker to benefit from the help of a network of supporters who can split the support between them, each supporter according to their ability and preferences and according to the preferences of the decision-maker. In such cases, the supporters need to work together to preserve the autonomy of the decision-maker.

More than one supporter can be appointed in most of the countries and states; sometimes each supporter is responsible for a different area, and sometimes they are responsible for the same areas of support. In British Columbia, the decision maker can appoint more than one supporter (representative). The representatives can act jointly in one area, or the decision maker can appoint a representative for each area. Substitute representatives can also be appointed during the drawing up of the agreement (Representation Agreement Act, 1996). In Victoria, too, several persons can be appointed, one for each of four different support roles, and alternative supporters can be appointed in the event that the supporter is unable to continue to perform their role (OPA, 2018). In the Massachusetts pilot program, most of the participants chose a support circle of three or more supporters, each of whom was responsible for a different area (Pell & Mulkern, 2015). The New York pilot program also enables the appointment of more than one supporter.

In the case of paid professional supporters, one supporter may possibly support several decision-makers. In Sweden, for example, each supporter supports an average of 15-20 decision makers (Tolub, 2015). In the Latvia pilot program, too, each supporter worked with about 15 decision makers (I. Leimane-Veldmeijere, personal communication, 12.2.20).

5.2.4 Ongoing training and instruction for supporters

In all **the pilot programs** reviewed, paid or volunteer supporters were given some form of training. Sometimes, family members and friends who served as supporters were also given training. In most cases, the training for paid and volunteer supporters was significantly longer than that for family supporters. In contrast, in **the countries reviewed**, the legislation does not obligate training of supporters, regardless of the supporter's status - paid or volunteer - and in fact, no actual training exists in these countries. The only exception is the Personal Ombudsman service in Sweden, where training is provided by law through organizations and not directly by the local authority. It should be noted that in this instance, no comprehensive training exists, but rather supervision of new supporters by experienced supporters (Tolub, 2015).

In Latvia, the supporters who worked in the pilot program underwent one month of training. The training included a seminar with representatives from the local authority. The training was conducted in a group of 11 people, where they learned about person-centered intervention, how to interview an individual with a disability, and how to create an individualized support plan together with the individual. The training also included logistic aspects, such as entering reports in the information system, and ethical aspects, as well as background material on types of disabilities and ways of communicating with people with disabilities. The training was accompanied by a comprehensive training manual. During their work in the pilot program, supporters participated in professional

meetings with other supporters once a month. These meetings were provided following the realization that supporters need support, given the challenges and the emotionally demanding nature of the work (I. Leimane-Veldmeijere, personal communication, 12.2.20).

In Texas, the Disability Rights Texas organization representing the Texas Council for Developmental Disabilities received a grant to deliver lectures and information and raise awareness about supported decision-making. The organization gave lectures to 6,000 people with disabilities, relatives, judges, service providers, educators, etc. (https://www.disabilityrightstx.org; Theodorou, 2018). The Texas Supported Decision-Making Agreement Act did not provide state funding for training on the subject. However, the state's law on alternatives to guardianship stipulates that of the four hours of training required for attorneys appointed by the court in guardian appointment proceedings, one hour shall be dedicated to alternatives, supports and services, including supported decision-making. The law extends these training requirements to all attorneys representing a party in such appointment proceedings (Theodorou, 2018).

In Massachusetts, six pilot programs operating since 2015, and managed by CRP (the Center for Public Representation) and other organizations, provide supporters with training. One of the conclusions of the pilot programs was the vital importance of emotional support for the supporters on practical issues such as advocacy, training, coaching, and responding to questions and dilemmas that arise (Kendrick, 2019). Under the Massachusetts bill, a training program for supported decision-making will be established. This program will include training government agencies such as the Department of Mental Health and the Executive Office of Elder Affairs. The training program will be delivered to supporters and to decision-makers and will include the rights and obligations of the various parties to the agreement (https://malegislature.gov/Bills/191/S2490).

The New York pilot program included recruiting of supporters (mostly based on the recommendation of the decision-makers, from among their close circle of family and friends), training them, recruiting and training facilitators (program officers assisting the decision-makers in shaping the support agreement), and appointing mentors to accompany the facilitators (from among the program's senior staff). The facilitators consisted mostly of volunteers or students doing their practical training, and they received two days of training and a comprehensive companion training manual. During the drafting of the support agreement based on the pilot program model, potential supporters participated in meetings with the facilitator, with or without the decision-maker, whichever decision-maker preferred. The main aim of this was to teach the supporters about supported decision-making and to encourage them to adopt this approach, including making decisions that incur a reasonable risk, based on the concept of dignity of risk, and not deciding for the individual. When training the facilitators, one of the

main aims was to teach them to move away from "goal speak" and achieving objectives to decision-making by breaking down objectives into a series of decisions, both in their work with the decision-makers and in their supervision of the decision-makers and their supporters. The pilot program provides the facilitator with ongoing training. Throughout the support agreement drafting process (which can take 12 to 18 months), a program mentor oversees the facilitator on an ongoing basis and is available to the facilitator for consultation on any matter or difficulty (Pell, 2019).

In the Victoria pilot program, the volunteer supporters also had a training session prior to their being assigned to the decision-makers. This session focused on the implications of intellectual disabilities for life skills and problem resolution, and on the right of individuals with disabilities to make decisions themselves. The training also emphasized the importance of acquaintance with the decision-maker and developing a relationship of trust between the supporter and the volunteer (Burgen, 2016).

In Sweden, supporters do not receive specific professional training, but their work is initially supervised by an experienced supporter. They also participate in consultation groups with other supporters (Tolub, 2015).

5.3 Other roles involved in the support

In all the pilot programs reviewed, reference is made to other roles apart from supporters, who fulfill various roles in the support program. In some of the programs, the roles were defined in advance. For example: in the Latvian pilot program, the role of the "facilitators" was to train and supervise seven supporters for the duration of the program. (I. Leimane-Veldmeijere, personal communication, 12.2.20). In the Massachusetts pilot program, **case managers** participated in meetings between the decision-makers and potential supporters to get to know each other, and they met with the participants during the program to monitor their satisfaction (Pell & Mulkern, 2015). In the New York pilot program, two people from the program are involved in decision-making processes. One is a volunteer **facilitator** (some of the facilitators are social work, education, or occupational therapy students) who supervise the decision-makers in drafting the support agreement as well as the supporter during its implementation. Another role is that of "**mentor**", a paid employee of the program who supervises the facilitators during the drafting of the support agreement and its implementation and is available for consultation and problem resolution throughout the program (Pell, 2019).

No such roles were defined in advance in the Victoria pilot program, but throughout the program, a **program coordinator** was effectively involved in the support. When needed, she employed an attorney, intervened with third-parties, as necessary, helped implement decisions, resolve problems between the participants, and

intervened in situations of danger or conflict for the supporters (Burgen, 2016). It was the program coordinator who led the first pilot program in Victoria, and who developed another pilot program, as well as a supported decision-making model and training model. The program defined the role of **facilitator** (as distinct from the role of supporter), with whom the decision-maker signs a short-term agreement (up to six months). The facilitator is responsible for organizing regular meetings of all the people in the decision-maker's immediate environment relevant to the decision to be made (such as family members and professionals) in order to make decisions and implement them (Nicholson, personal communication, 27.2.20).

In contrast to the pilot programs, the countries and states reviewed did not mention additional functions involved in the support arrangement. The exception was British Columbia. When a representative agreement is drawn up that deals with financial matters, in addition to the supporter, a monitor is also appointed. Section 7 of the Representation Agreement allows an individual to appoint another person to help them make decisions or to decide on their behalf. At the agreement signing and as a prerequisite for its validity, the monitor needs to sign the agreement as well as a Certificate of Monitor (An official certificate that stipulates their role as a monitor under the Representation Law). Different agreements specify different components for the role of the monitor, including re-examining the agreement with the decision-maker yearly in order to jointly identify any need for changes or need to revoke the agreement; deal with disagreements, including use of mediation services where the monitor is given authorization to facilitate the process; and sometimes also playing a role when a third party approaches the monitor for help in communicating with the supporter after difficulties have arisen, or to explain the decision-maker's wishes to a third party (Representation Agreement Resource Centre [RARC] & Nidus, 2005).

6. Legal aspects of supported decision-making arrangements

6.1 The legal standing and legal validity of supported decision-making arrangements

In some of the countries and states reviewed, such as British Columbia, Texas, and Victoria, supported decision-making agreements have legal standing. In Sweden, supported decision-making is recognized by a legal capacity law that the local authorities are responsible for. The same applies to one of the types of supported decision making provided in Victoria through the state's Department of Social Security. There are countries and states that are in various stages of approving and implementing legislation, such as Massachusetts, where a bill was introduced and is in the advanced stages of approval. In Ireland, some of the issues are in different stages of legislation and some have already been approved, but the law has not yet gone into effect.

In many cases, the countries and states have used or are using pilot programs to examine the use of supported decision-making and as a preliminary step to legislation. These programs are developed by government, by NGO's or by government and non-government collaboration. In such cases, the programs provide the opportunity to examine and develop mechanisms for supported decision-making arrangements or to form the basis for drafting and promoting legislation on the subject.

In some of the pilot programs reviewed, a lack of legal standing and lack of legal validity for supported decision-making was a barrier to implementation of the arrangements, especially in respect to carrying out decisions vis a vis third parties and in respect to privacy of information issues.

6.2 How the agreements are drawn up

All the countries, states and pilot programs reviewed used supported decision-making agreements. In the agreements, the role and authorities of the supporter can be clearly defined, both in interactions with the decision maker and with third parties. If an individual has more than one supporter, the agreement can divide areas of responsibility between them or define them as equally responsible in the various areas. Moreover, agreements define the areas in which support is provided and address various issues, such as the privacy of the decision-maker's information. In some cases, the agreement can help the decision-maker define the needs, wishes and goals that s/he wants to focus on, and to choose the supporter or supporters best suited for those purposes.

6.2.1 Witnessing of the signing of the agreement

The manner in which the agreement is drawn up differs from one country or state to another. In Massachusetts (Kendrick, 2019), Texas (https://tcdd.texas.gov), British Columbia and Victoria (OPA, 2018), the agreement is made between the decision-maker and the designated supporter or supporters. The agreement requires the signature of two witnesses or a public notary (or an attorney in the case of British Columbia). In some of the countries and states, restrictions exist as to who can serve as a witness. For example: in Victoria, one of the witnesses at the signing of an agreement for support regarding medical issues must be authorized to witness an affidavit under oath or must be a registered physician (OPA, 2017). In British Columbia, the witnesses must declare that they understand the type of communication that the decision-maker uses or that they received a translation. In these countries and states, the agreement enters into effect upon signing by the decision-maker, the supporter/s and the witnesses. It is advisable that a copy of the original be kept by each of the parties for presentation purposes, and there is no need for additional official approval.

6.2.2 Authorization of the agreement

In some of the pilot programs, the agreement is drafted and signed between the decision-maker, the designated supporter, and a representative of the organization running the pilot. The same applies if the supporter represents a service provider, such as in Sweden or certain cases in Victoria. In these instances, the agreement is not signed by witnesses and is not subject to additional authorization. The main aim is not legal, but instead, to define the areas or the decisions for which the decision-maker seeks support and to define the supporter's role.

Unlike countries and pilot programs, in which signing in the presence of the witnesses or mediation by the pilot program operator is sufficient for the agreement to come into effect, in the process planned in Ireland, the agreement will go into effect only after it is submitted to the Government Decision Support Service for inspection and registration. (Decision Support Service [DSS], 2019; MHC, 2020).

6.2.3 The format of the agreement

The countries and states reviewed employ several formats for the agreement: (1) a standard agreement specified in advance by the law or by the pilot program; (2) a standard agreement whose provisions can be modified, as necessary; (3) an agreement drafted by the parties involved, sometimes with the aid of social organizations or the pilot program operators. Texas, for example, takes the second approach, offering a structure for the support agreement that can be revised, so long as it relates to several essential provisions required by law. The standard agreement can be downloaded from various websites, and assistance in modifying the form is available from

organizations such as DRT (Disability Rights Texas), which also offers wording of an agreement in plain language (https://www.disabilityrightstx.org). This is also the approach in the bill on supported decision-making being advanced in Massachusetts at this time (as of November 2020) (Kendrick, 2019).

A different approach is taken in the New York pilot program. The agreement that is signed between the decision-maker and the supporter is the culmination of a long process of guidance and preparation lasting 12 to 18 months. A proposed template for the wording of the agreement exists, and the decision-maker and the supporter, with the facilitator's mediation, draft the final version of the text. Afterwards, the text is submitted to the program director and program coordinator for approval (both are attorneys). Only at this stage is the signing ceremony held, in the presence of the facilitator. Afterwards, the agreement is submitted to a notary public for signing. One of the program's aims is to enable the agreement to be used, as necessary, and subject to the will of the individual, in legal proceedings to revoke guardianship and to restore the individual's rights, and it is therefore meant to signify the integrity of the decision-making process to the judges and other stakeholders. The agreement reflects the desire to create a useful template employing legal language that may eventually be incorporated in future legislation, alongside the desire to draw up a document that is understandable and accessible to the decision-makers.

6.3 Legal capacity tests for the decision-makers

Among the countries and states reviewed, Victoria and British Columbia are carefully examining the issue of legal capacity for entering a supported decision-making arrangement. In Ireland, legislation enacted, and legislation being drawn up, includes greater flexibility with respect to how legal capacity is viewed; legal capacity will be assessed according to defined areas and timeframes. Therefore, unlike outdated legislation, an individual may have legal incapacity in one area and full legal capacity in another area (Kelly, 2014). This approach to legal capacity based on relevant areas also applies in Victoria and British Columbia.

Legislation in Victoria (OPA, 2020) specifies that in order to enter into a supported decision-making arrangement with a supporter and a medical decisions supporter the individual must have decision-making capacity. This capacity exists if the individual can understand the information regarding the appointment of the supporter and the implementation of the support agreement; understand information relevant to the decision and its consequences; retain the information for the duration required to make a decision; use and weigh the information in order to make the decision; and communicate their decision and their needs following the decision (by speech, gestures, or other means). All these can be done using adaptive devices, supports, assistive technology, etc. The

assumption is that the individual possesses decision-making capacity unless there is evidence to the contrary. At the signing of a supported decision-making agreement, the witnesses are asked to testify that the individual appears to have decision-making capacity to execute the supporter's appointment.

In British Columbia, the law states that any person can execute a supported decision-making agreement, unless they are not competent to do so, but different provisions of the law define the capacity required to execute the agreement differently. In an agreement under Section 9 of the Act, the capacity test is similar to that of Victoria, including establishing the individual's ability to understand information and weigh the possible consequences of decisions (a representation agreement under Section 9 grants the supporter a broader range of authorities in the areas of care and health, and is, in effect, not used as a supported decision-making tool, but instead, as substitute decision making (a quasi 'guardian in agreement').

Conversely, in an agreement under Section 7 of the Act, the capacity test is more flexible, and includes four requirements of the decision maker: expression of the desire that the supporter assist him or her in making decisions; demonstration of the ability to make a choice and to express agreement or disagreement; awareness of the supporter's role; and a relationship of trust with the supporter. One of the goals of a more flexible capacity test is to enable people who do not have legal capacity in certain areas of their lives to sign a supported decision-making agreement under Section 7 regarding other areas. However, criticism has been voiced as the issue has not been presented in sufficient detail (for example: who actually tests the capacity), leaving the practice in a state of uncertainty in many cases.

In many countries the law specifically states that lack of capacity to make decisions or to execute a supported decision-making agreement cannot by determined simply because the individual makes a decision that is not perceived by others to be a "correct" or "good" decision. However, if the individual makes, or intends to make, a decision that carries a high risk of harming their health or welfare, this (in combination with other components) may indicate that the individual is not able to understand information or to weigh information relevant to the decision or to its consequences.

6.4 The legal liability of supporters

In several of the countries and states reviewed the law places responsibility for the decisions made in the context of the support agreement on **the decision-maker alone**. This issue is crucial in cases of undesirable outcomes for third parties or for the decision-maker him/herself. According to these definitions, both the supporters and third parties are exempt from all legal liability for the decisions. It should be noted that in British Columbia, under

the Representation Act, this holds true even if it is the supporter that makes the decision and not the individual with a disability, because the supporter is authorized to make decisions on behalf of the individual, based on their previous wishes, values and beliefs.

6.5 Legal requirements for the supporters

In most countries and states, upon the signing of the supported decision-making agreement, supporters are obligated to act in good faith and with integrity, not exceed their authority under the agreement, to act in a loyal manner towards the decision-maker, to avoid a conflict of interest, to safeguard the privacy of the decision-maker's personal information, to use the form of communication that will enable the decision-maker to understand and help him/her in making decisions, to take the decision-maker's wishes and present and past preferences into account as much as possible, and not to exert undue influence on the decision-maker, etc. In several countries and states, the role of supporter is unpaid, and the supporter is prohibited from using their role for personal gain or benefit. As mentioned above, in Victoria, for example (Powers of Attorney Act, 2014), the appointment of a supporter may be revoked if, in the course of the appointment, the supporter becomes the decision-maker's paid personal caregiver, or provider of health, personal care or residential services to the decision maker.

These requirements are generally written into the agreement itself, in the "code of conduct", or in the "code of ethics", and they form part of the legal requirements or the pilot program requirements from the supporters. In such cases, if the supporter does not act in accordance with the principles established by the agreement, the support agreement can be terminated, a complaint may be filed against him or her, charges may be pressed against him/her, or reimbursement of monies demanded from him/her.

In several countries and states and in some of the pilot programs, supporters have additional areas of responsibility, or are restricted in their actions. For example, in British Columbia, supporters need to document the decisions and actions that they take for the decision-maker. In the Latvian pilot program, supporters were required to report actions performed as part of their role, both for supervision purposes and for the purposes of research and assessment of the pilot program (I. Leimane-Veldmeijere, personal communication, 12.2.20). In Sweden, the supporter is not required to act in a manner that goes against their conscience, and the supporter may inform the decision-maker that s/he cannot support the decision-maker in such instances, for example, if the decision-maker asks the supporter to provide support that involves illegal actions (Tolub, 2015).

6.6 Aspects of life included in support arrangements and the restrictions on them

Each country and state define the areas in which supporters can assist the decision-maker. The three main areas are personal matters (such as where to live, education and training, and choosing services), medical or health matters, and financial matters. The agreement generally specifies in which areas the supporter is authorized to assist the decision-maker. The level of detail varies from simply stating a general area to specifying topics within that area.

In the countries and states reviewed no restrictions exist for providing support on **personal matters**. On medical and financial matters, however, several countries and states restrict the authority of supporters, set additional requirements for the appointment of supporters in these areas, or use legal means to restrict the authority of supporters in those areas.

With respect to **medical matters,** in Victoria (https://www.publicadvocate.vic.gov.au), a medical supporter is appointed to deal only with these matters, while the other supporters are prohibited from assisting in this area. The medical supporter and the supporter designated for mental health issues have additional authorities, such as the authority to represent the interests of the decision-maker regarding medical treatment even if the individual's medical condition does not enable him/her to make decisions. In the New York pilot program, the decision-maker must sign a power of attorney for the supporter if s/he wishes to receive support on health matters from him or her. In British Columbia, a distinction is made between routine medical care issues as opposed to exceptional medical care issues, such as lifesaving treatment or treatment that includes physical restrictions. A decision supporter, under Section 7 of the Act, can only deal with routine medical care issues.

Financial matters are dealt with differently in different countries states. In Victoria (https://www.publicadvocate.vic.gov.au) and in British Columbia (Representation Agreement Act, 1996) a distinction is made between routine financial decisions and significant financial decisions, which decision-making supporters are not permitted to deal with. A significant financial decision in Victoria might be an investment of more than 10,000 Australian dollars, a real estate transaction, obtaining loans, and providing guarantees, etc. In British Columbia, the law requires, appointing a monitor to supervise the activity of supporters appointed to deal with routine financial matters, or alternatively, two or more supporters must be appointed who then need to work together on financial matters (except in cases where the supporter is the spouse of the decision-maker).

There are also differences between the countries and states when it comes to the supporter's authority to request personal information for the decision-maker, such as their medical file or information from the bank, as well as differences in the supporter's authority to assist in carrying out the decisions. In several countries and states, such as Victoria, the support agreement is sufficient proof to access financial information for the individual (OPA, 2020). In other countries and states, such as Texas (TCDD, 2018; Texas Appleseed & AARP, 2017), as part of the supported decision-making agreement, the decision-maker must also to sign a confidentiality relief form to allow the supporter to obtain personal information for him/her, including medical and financial information, as well as school records, information that is protected by Texas confidentiality laws. In several countries and states, the decision-maker needs to sign a general or specific power of attorney for the supporter to be able to obtain personal information about the individual and act on their behalf in interactions with other parties, such as government services or health care providers in order to carry out decisions. Sweden is an example of such a country (Tolub, 2015).

6.7 Use of additional legal tools

The assumption in most countries is that there are likely to be people around the individual with a disability who have the authority to support the individual or make decisions for the individual in various areas of life, whether as part of a supported decision-making agreement or in addition to it. A combination of support and other tools were designed to preserve the individual's autonomy as much as possible and to enable individuals incapable of making decisions in certain areas to preserve their autonomy to make decisions in other areas. In most countries and states with supported decision-making legislation in place, an attempt is made to facilitate a continuum from full independence in making decisions, to support (official or unofficial) in making decisions, to substitute decision-making (making decisions on the individual's behalf). This continuum is created using various legal means, including supported decision-making, which creates a balance between preserving the autonomy of an individual with a disability or at least minimize limiting their autonomy, and protecting the individual from harm or exploitation by others. Some countries and states expressly require judges to consider these means before deciding to appoint full guardianship for an individual with a disability.

Texas is an example of a state in which the law requires other supports as part of supported decision-making (Texas Appleseed & AARP, 2017; Theodorou, 2018). Legislative amendments on guardianship in the state refer to official and unofficial "supports and services", including unofficial supports such as laundry or food preparation services, and official supports such as Enduring Power of Attorney, medical power of attorney and a joint bank

account[7]. Ireland (Tolub, 2014) allows an Enduring Power of Attorney for financial matters, and the new Assisted Decision-Making Act addresses an Enduring Power of Attorney in the other areas of life as well. In Texas, Victoria and Sweden, reference is made to case managers, personal budget managers or individualized plan managers as a possible type of support in making decisions in certain areas, primarily when it comes to choosing services and financial management.

On the other hand, there are countries and states in which the law specifies substitute decision-making practices that limit the ability of the individual to make decisions for him/herself in certain areas. For example: the law in Ireland stipulates two restrictive means: codecision-making and representation in making decisions. Swedish law stipulates two additional alternatives that are more restrictive than supported decision-making: partial guardianship (forvaltare) and trusteeship (godman). These require an appointment by the court and deal mainly with financial or medical matters. Trusteeship is less restrictive with respect to the decision-maker's legal capacity than partial guardianship[8] (Tolub, 2014). In British Columbia, the law dealing with supported decision-making mentions two main means: an agreement under Section 7 of the Act enables supporting an individual with a disability to make decisions, and to make decisions for the individual in certain situations, while Section 9 of the Act grants the supporter appointed in such an agreement wider authority to make decisions for the individual (Representation Agreement Act, 1996).

6.8 Third parties' legal obligation to honor the agreement, legal liability, and other aspects

In several of the pilot programs, difficulties arose in implementing the decisions with third parties, such as banks or medical services, since the status of the support agreement was not regulated by law. For example, in the Victoria pilot program, difficulty arose in implementing decisions because employees of other organizations did not recognize the supporter status and did not always honor decisions made as part of the support agreement (Burgen, 2016).

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[7] An amendment to the Act includes a list of recognized supports in order to consolidate all the services that were "dispersed" among the various laws in a single place, thereby helping to make attorneys and judges aware of the alternatives to guardianship that exist.

[8] For more details on these two roles and on the differences between them, see: https://rfs.se/wp-content/uploads/2018/08/Rollkoll_EN_2015-12-21.pdf

In several pilot programs, the program staff or the supporter were assisted by other organizations in realizing the support in interactions with a third party. For example: in Victoria, program staff were assisted by advocacy organizations for individuals with disabilities in interactions with other organizations, such as service providers, to carry out the decisions of individuals with disabilities (Burgen, 2016). In Latvia, the program coordinator was sometimes obliged to explain the supported decision-making arrangement to a third party so that the latter would recognize the supporter's standing in carrying out their duties (I. Leimane-Veldmeijere, personal communication, 12.2.20). In countries in which legal recognition of supported decision-making agreements exists, the law requires that a third party recognize the support agreement and the supporter's authority and provides instructions on how to work with a third-party. In several countries and states, the agreement obliges other parties (such as physicians, service providers, banks, etc.) to honor the agreement upon receiving a copy. This is the case in British Columbia, in Texas (TCDD, 2018; Theodorou, 2018) and it is planned in Massachusetts (Bill S.2490[9]). In British Columbia, a third party can use the help of the monitor (the supporter's supervisor on financial matters) to communicate with the supporter if a difficulty arises or to receive additional explanation about the decision-maker's wishes. In several countries states it is necessary to use additional legal tools when carrying out decisions with a third party. In Sweden, for example, the decision-maker needs to sign a power of attorney for the supporter. In most cases, this is a specific power of attorney on behalf of an individual with a disability for dealings with agencies such as social services, health care providers and the courts (Tolub, 2015).

In countries with legislation of supported decision-making, it is stipulated that organizations or persons constituting a third-party shall not be liable (professional, civil or criminal liability) for actions taken in good faith, when relying on an agreement presented to them, and will allow a supporter to perform their duties and help the person in the decision-making process during interactions with them. In Sweden, the law defends the decision-maker from a third party if it becomes clear that, to protect their privacy and confidentiality in the support process, the third party must not be informed of the fact that the decision-maker is assisted by a supporter. In addition, all the decision-maker's personal documents are always kept by the decision-maker and not by the supporter (Series, 2015).

[9] https://malegislature.gov/Bills/191/S2490

7. Safeguards and supervision

Protection and supervision mechanisms are designed first and foremost to **prevent** harm exploitation or neglect of decision-makers, and **to provide a proper response** if such situations occur or are suspected of having occurred. There is little practical experience; consequently, information about safeguards and supervision is scant. Safeguards exist that are built into the legislation or into the pilot programs. These include, for example, **the presence of witnesses** to the signing of the support agreement, **mechanisms for filing complaints**, and the existence of an **obligation to report** harm or neglect caused to a person with a disability. In addition to the safeguards, several countries and pilot programs also employ **proactive supervision.** Naturally, the one does not necessarily preclude the other, and the legislation and pilot programs employ a variety of safeguards or supervision tools. All legislation and pilot programs have at least one safeguard, and in most cases, several.

There is a significant difference between supported decision-making under legislation and supported decision-making as part of a pilot program. In pilot programs, there is much more supervision as they are run by an organization that closely monitors the program's participants in order to learn from the experience and improve the support arrangement practices. Moreover, pilot programs almost always also include training, supervision, support and monitoring of the supporters, which is not always the case in supported decision-making outside a pilot program. On the other hand, safeguards and supervision mechanisms provided by legislation have legal validity that is lacking in the pilot programs.

7.1 Safeguards

The legislation and pilot programs in the countries and states reviewed have a variety of built-in safeguards. These include the obligation to have **witnesses** to the signing of the support agreement; **regular engagement of another party** in the support relationship (who can be a second supporter, or a facilitator or coordinator); **restrictions on the areas of the support or their scope**, especially when it comes to support on financial matters; a **code of ethics** or ethical guidelines for supporters (for example: avoidance of a conflict of interest); **the obligation to report** if harm, exploitation or neglect of decision-makers is suspected; **mechanisms for filing and investigating complaints**; and **filing the support agreement in an agreements repository**.

The following is a brief description of the main safeguard mechanisms:

7.1.1 Witnesses to the signing of the support agreement

A key control component of the support agreement is the mandatory presence of witnesses to the signing of the support agreement by the decision-maker and their supporters. This obligation applies wherever support is provided based on a signed agreement. This holds true especially in countries that have systematic legislation on supported decision-making, but also in several of the pilot programs reviewed. In addition to the mandatory presence of witnesses, there are also generally **authorizations or restrictions as to who can serve as a witness**. In Victoria, for example, the individual must sign the support agreement form in the presence of two witnesses (OPA, 2018). To appoint a medical support person, the support agreement form must be signed in front of two witnesses. One of the witnesses must be a certified physician or a person authorized to witness an affidavit under oath, while the supporter must sign in front of a witness who is over the age of 18 (OPA, 2017). In British Columbia, the law mandates the signature of two witnesses attesting to the fact that the decision-maker did indeed sign the agreement. The law also specifies who cannot serve as a witness. For example: the supporter him/herself, family members of the supporter or a minor (The Representation Agreement Act, 1996).

7.1.2 Regular involvement of an additional party

As mentioned above, in various countries and states and pilot programs, an additional party is meaningfully involved in the support arrangement, and this involvement is also used to safeguard the support arrangement and its implementation, and in effect acts as a form of supervision. Sometimes such supervision is intentional, and sometimes it is a consequence of the way the pilot program is operated.

Additional persons involved in the arrangement and in the support relationship can include, for example: **one or more additional supporters**. Sometimes there are different supporters for different areas of life. In most cases, the appointment of an additional supporter is based on the wish of the decision-maker, but there are cases, as in Victoria, in which this is required by law. In several countries and states, and especially in pilot programs, there is a **facilitator or coordinator** who supervises the implementation of the agreement between the decision-makers and the supporters, and who can note problems that arise. In the Victorian Medical Treatment Planning and Decision Act, 2016, in addition to a medical support person, an additional professional must be appointed who can attest to the fact that the individual received appropriate and practical support for decisions regarding medical procedures (Bigby & Douglas, 2020). In the New York pilot program, for example, a **mentor** is also appointed to oversee the facilitator in their work with the decision-maker and the supporters and to serve as an additional means of supervision for the implementation of the support agreement.

7.1.3 Restrictions on the areas or scope of the support

The legislation in the various countries and states reflects different types of restrictions, especially in the case of support on financial matters. Very often, the support is restricted to financial actions up to a specific amount, and sometimes it is restricted to personal matters and cannot include financial or health matters (additional restrictions are detailed in section 6.6 above: Areas of life included in support arrangements and the restrictions applied to them).

7.1.4 Code of ethics or ethical guidelines for supporters

A code of ethics or ethical guidelines for supporters are common practice in systematic legislation as well as in pilot programs. Supporters are required to act in accordance with a clearly defined code of ethics or within a defined ethical framework. An example of this is their duty to act in good faith and to avoid conflict of interest.

7.1.5 Mandatory reporting

The obligation to report applies if harm, exploitation, or neglect of decision-makers is suspected. In most cases, this obligation applies to any third party who encounters the support arrangement or to supporters and other parties involved in the support arrangement. In British Columbia, for example, the monitor is obligated to report and file a complaint if exploitation of the decision-maker is suspected (https://www.nidus.ca). The complaint is filed with the Public Guardian, who is obligated to check it, investigate, and take any steps required. The law in Texas, and the text of the agreement itself, makes it clear that any person who receives a copy of the agreement or is aware of the agreement's existence and believes that the decision-maker is a victim of exploitation, neglect, or abuse on the part of the supporter, is obligated to report this to the Department of Family and Protective Services via the Department's hotline or website (TCDD, 2018).

7.1.6 Mechanism for receiving and investigating complaints

There are two principal ways to receive complaints about a support arrangement drafted in specific legislation. One is **receipt of complaints by a general official body** dealing with the protection of the rights of individuals with disabilities or another official body, such as the Administrator General (Public Guardian). Another way is to set up a **designated complaint system** for supported decision-making. In Ireland, for example, a special hotline is being set up for the supported decision-making service. Once the service is launched, subject to the final authorization of the bill, it is also expected to include supervision of supporters, handling of complaints, and investigation, as necessary (MHC, 2020).

Receipt of complaints in pilot programs is different, because all of the programs reviewed include regular contact between the decision-maker and the program staff which supervises the supporters. One exception was

the Latvian pilot program, where a special complaints system was set up for the program's participants. Each participant received a card with the contact details of the program coordinator responsible for their supporter and of the program director. If necessary, a card in plain language (i.e., simplified and accessible) was provided (I. Leimane-Veldmeijere, personal communication, 12.2.2020).

7.1.7 Filing the support agreement with a government office and maintaining a repository of agreements

This tool requires a central government office to keep track of the supported decision-making agreements. In Ireland a repository for filing support agreements is currently being set up as part of the Government Decision Support Service, and in British Columbia, the non-profit organization Nidus[10] created a registry for filing support agreements.

7.2 Proactive tracking and supervision

In several of the pilot programs reviewed, as well as in British Columbia, which has systematic legislation, it is the duty of the supporter to **record and report** all actions taken as part of the support. Such recording can be used for **proactive supervision** by the program, by the monitor, in the case of British Columbia, or by state authorities.

In British Columbia, supporters for financial matters are required to record all their actions and to produce these records and other relevant documents upon demand when requested to do so by the monitor. Proactive supervision is conducted by the monitor, a person chosen and appointed by the decision maker as part of the support agreement (Glen, 2015). If the monitor thinks that the supporters are not doing their job properly, or are exploiting the individual in any way, he or she is obliged by law to file a complaint to the Public Guardian (Representation Agreement Act, 1996)

In the Latvian pilot program, the supporters were required to accurately record each action performed as part of the support, both for research of the pilot, and for proactive supervision by the coordinator, a program staff officer responsible for several supporters. The coordinators interviewed the decision-makers and compared what they said with the reports recorded by the supporters. The reporting by the supporters, as well as proactive supervision, is intended to continue in the future official supported decision-making mechanism in Latvia (I. Leimane-Veldmeijere, personal communication, 12.2.2020).

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[10] Nidus is a nonprofit organization in British Columbia, specializing in representation agreements. The organization was founded by citizens and organizations pressing for legislation on representation agreements. For more information, see: https://www.nidus.ca/home-2/about-us

8. Optimal support in decision-making – preliminary insights

The review of the countries and pilot programs did not find a formal or informal definition of what constitutes **optimal** support in decision-making. However, broad consensus exists about the nature of supported decision-making and its components, the operating principles and the ethical framework for the supporter's actions and the support relationship. This chapter presents insights about the components of optimal support in decision making, based on the experience of the countries and pilot programs reviewed here. First it addresses the question of who is the optimal supporter - a family member, a volunteer or a paid professional?

8.1 Who is the optimal supporter?

A discussion of optimal support addresses the question of who the optimal supporter is, and whether a close relationship with the decision-maker impacts the quality of the support action. In other words, **what is required of an optimal supporter, and is the optimal supporter a close supporter, a volunteer supporter, or in fact, a paid supporter?**

Close supporters (family members): given that the support relationship can be intensive, highly demanding, and ongoing, and requires a trusting relationship and deep acquaintance between the decision-maker and the supporter, there are times when family members or friends are the appropriate and natural candidates to serve as supporters. This, if they operate within the framework of supporting the decision-making and do not actually make the decisions for their family member.

Volunteer supporters: volunteer supporters can provide a solution that is suitable if the decision-maker does not have a family member or a person that belongs to their natural circle of support who can serve as their supporter. This might be the case when the circle of support is very small or when the family has reservations about supported decision-making or are opposed to it and prefer guardianship. Volunteer supporters need to establish a deep acquaintance and a trusting relationship with the decision-maker if the support is to be optimal. Furthermore, given that the role of the supporter is often intensive and time consuming, volunteer supporters must be committed and available to fill the demanding role and persevere over time if their support is to be optimal.

Paid supporters: The advantage of paid support is that it defines a clear commitment of the supporter to a defined role and code of conduct. Usually, the employment is through an organization that regulates the support and deals with various aspects of the supporter's work, such as insurance coverage and defining of a code of

ethics. Paid supporters, like volunteer supporters, need to get to know the decision-maker well and to establish a trusting relationship between them to provide support, and especially, optimal support.

The practical experience in the countries and the pilot programs reviewed indicates that because of the unique nature of the support relationship, there is no single answer to this question, and different types of supporters have different advantages for decision-makers. However, any supporter - close, volunteer or paid - must be committed to the idea of equality and to the right of the individual to make decisions about their life, must have good interpersonal communication skills, must be capable of establishing a relationship of trust between him/herself and the decision-maker, and must operate within a defined ethical framework (Burgen, 2016; Morrissey, 2012; Series, 2015; Simmons & Gooding, 2017).

8.2 What constitutes optimal support in making decisions?

The review of the countries and pilot programs, shows that optimal support in a supported decision-making arrangement includes several essential components:

Preserving the decision-maker's autonomy and encouraging self-determination. The first and possibly foremost characteristic of optimal support is providing the decision-makers the support they need to preserve their autonomy. Moreover, the aim of optimal support is to empower decision-makers, to afford them greater independence and self-determination.

The supporter's commitment to the idea of equality. The supporter's commitment to the decision-makers' right to make decisions about their lives, and his/her commitment to act according to the decision-makers' wishes and preferences is a prerequisite for optimal support. Seeing the decision-maker as an equal party to the supported decision-making agreement is another prerequisite for optimal support.

Supporting decisions that incur reasonable risk[11]. One of the recurring questions is: what is the degree of risk that decision-makers should be allowed to take, and what is the supporter's duty if decision-makers want to do something that constitutes a risk for them and that has real potential to harm them or their well-being. Optimal support in making decisions backs the decision-maker even when s/he makes a decision that puts him/her at risk, provided that the risk is reasonable. If the risk has the potential to cause real harm to the decision-maker, it is the supporter's duty to warn him or her. The supporter is not obligated to continue to support the decision-

[11] This applies mostly to persons with an intellectual disability, though this issue could also be applicable to decision-makers with other disabilities.

maker if his or her decisions are causing him/her real harm or go against the supporter's values and ethics. For example: if the decision-maker asks for assistance in illegal actions or threatens suicide.

Developing decision-making skills. Many people with intellectual disabilities lack "decision readiness", i.e., a basic understanding and experience of what decision-making is. Often their education, living arrangements, work, and leisure as well as other aspects of their lives are extremely structured and their opportunities for making any decision are very limited. Therefore, their experience and understanding of decision-making is very limited (Bigby et al., 2017). To optimize support in making decisions, the readiness of the individual to make decisions must be examined, and time and effort spent on developing such skills, as necessary.

In-depth acquaintance and establishing a trusting relationship. Optimal support in making decisions requires the supporter's **in-depth acquaintance** with the decision-maker, which allows the supporter to provide support in making decisions even to people with limited abilities to communicate, such as people with a significant intellectual disability. In-depth acquaintance allows the supporter to become familiar with the way the individual communicates, even if it is very limited, and to successfully support the individual in carrying out his or her wishes and decisions. Furthermore, it enables the supporter to act as an intermediary between the individual's wishes and decisions and other people (Bigby C., personal communication, March 2020)[12]. Optimal support in making decisions also requires **a relationship of trust** between the decision-maker and the supporter and is often perceived as the key to successful support. In most cases, such trust is gained from previous, in-depth acquaintance, such as when supporters are family members or friends (or even former or current caregivers). Sometimes, such relationships of trust need to be built during the initial entry into the supported decision-making process, as in the case of a volunteer or paid supporter, where the supporter and the decision-maker were not previously acquainted.

Interpersonal communication and accessibility to information. An important component for providing optimal support in making decisions is the ability of the supporter to understand how the individual communicates and to make information accessible to him/her. It is the supporter's duty to explain information that the decision-maker needs in order to make decisions, and at the same time, be able to mediate and explain the decision maker's wishes, preferences, and decisions to a third party. This applies especially in cases where the decision-maker's ways of communicating are very limited and complex.

[12] Professor Christine Bigby is a lecturer at La Trobe University, Victoria, Australia. She conducts research on people with intellectual disabilities and heads the Living with Disability Research Centre. Professor Bigby is one of the creators of the La Trobe model of support practices in the making of decisions.

Support in implementing decisions made. Supported decision-making is not a single action, but a process that requires ongoing support. Support does not stop at one point of this or that decision but is a series of many choices and considerations that need to be made and addressed along the way, as well as after the decision is made. Experience around the world indicates that optimal support in making decisions accompanies the individual in implementing and realizing those decisions. In other words, implementation, and realization of the decisions, and of the subsequent decisions that need to be made during the implementation of the original decisions are integral to optimal support in decision making. Optimal support is support that can be implemented and provided within the supporter's authority as prescribed by law, by the support agreement and by an ethical framework.

Support based on a clearly defined ethical framework. Apart from building safeguards and supervision into the legislation or into the pilot program, **optimal support operates within a defined ethical scope**. At times, a code of ethics is defined for the supporter's activity, especially in cases where systematic legislation is in place or a long-running service exists. An ethical framework requires, first and foremost, that the decision-maker be interested in such a service and be cooperative. Furthermore, such an ethical framework obliges the supporters **to act in accordance with the law, in good faith, loyally, avoid undue influence on the decision maker, avoid a conflict of interest, and avoid exploiting the support relationship**. However, it is agreed that the supporter cannot be expected to act in a manner that goes against their conscience or is unlawful.

Defining the duration of the support. Many support agreements are limited in time but are subject to renewal. Signing an agreement that is time limited generally enables the decision-maker and the supporter to review the arrangement, to determine how well-suited it is to them, and to ensure that it meets the decision-maker's needs. This practice also serves as a reminder to the decision maker and the supporter that this is an agreement between two parties and not a lifelong arrangement, and that necessary controls and safeguards must be in place, such as signing the renewed agreement in the presence of witnesses. However, as mentioned above, optimal support requires an in-depth acquaintance and a relationship of trust, which often takes time to cultivate.

9. Summary and conclusions

This review presents some of the latest knowledge, experience, and insights on supported decision-making around the world, as a basis for drafting practices in Israel. The review is the first in-depth examination of the applied experience in supported decision-making around the world, as well as various aspects of safeguards and supervision of supported decision-making arrangements. The review places special emphasis on the definition of optimal support in making decisions as a basis for creating criteria to supervise supported decision-making in the future. A distinction is made between a supported decision-making arrangement based on a court order (the 'legal channel') and a supported decision-making arrangement based on an agreement between a decision-maker and their supporter or supporters (the 'agreement channel'). The agreement channel is standard practice in most countries and is currently being examined in Israel with a view to its adoption both in practice and in legislation.

The review of the countries, states and pilot programs found that no comprehensive model exists for safeguards and supervision of supported decision-making arrangements, and that reference to these two issues is very limited. However, the experience provided a range of practices that deal with safeguards and supervision.

The review of the countries, states and pilot programs also found no comprehensive definition for optimal support in making decisions. Preliminary insights on the components of optimal support were presented, based on the practical experience in this area in the countries, states and the pilot programs reviewed.

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