

**Supported
decision-making:
An alternative to
guardianship**

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Executive summary

This Policy Paper has been developed by the Mental Disability Advocacy Center (MDAC), with the purpose of assisting Russian policy-makers to transform from a system of substituted decision-making for persons with intellectual and psycho-social disabilities (which includes guardianship) to one in which supported decision-making is the default model.

In section 1.2 this Policy Paper addresses the question of why it is important to switch from the guardianship system to a supported decision-making model. It highlights that Russia's national and international legal obligations call for introducing less restrictive alternatives to guardianship in the country. Current policy results in an undue restriction of the human rights of people with disabilities. Policy-makers and law-makers are encouraged to move towards a human rights based approach to disability which requires implementation of a supportive model of decision-making for people with intellectual disabilities and psycho-social disabilities.

In section 2, the Policy Paper focuses on a variety of supported decision-making systems based on respect of human rights. In order to better understand the system of supported decision-making, the Policy Paper sets out the philosophical background to models of supported decision-making and critically reflects on the assertion that autonomous decision-making and supported decision-making are not necessarily contradictory; indeed, it is argued that these models can actually be used in together, and highlights that **interdependence** is a normal method of decision-making for everyone.

The principles of supported decision making are set out in section 2.2 of the Paper, and an examination of safeguards necessary for such systems ensues in section 2.3. Briefly, the Policy Paper outlines the following principles of supported decision-making:

- the person retains their full legal capacity;
- the person himself/herself makes the decision. The role of supporters is to assist this person to reaching his/her own decisions;
- there is a relationship of trust between the person making the decision and the supporters;
- such a system must be borne of the free agreement of the adult and the supporter(s);
- there is usually a supporting group or network around the person making the decision;
- the role of supporters is to assist the person making the decision to communicate his/her intentions to others and help him/her understand the choices at hand;
- supporters are usually unpaid and could include friends, family, and/or members of the community.

To ensure that supported decision-making works correctly and effectively as an alternative to guardianship models based on substituted decision-making, a number of safeguards should be implemented to prevent and remedy abuse and neglect. These safeguards should not overprotect people with disabilities, but must respect the inherent dignity, individual autonomy – including the freedom to make one's own choices – and independence of persons. The Policy Paper underlines



that safeguards of supported decision-making should be based on Articles 12(4), 13 and 16 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which Russia signed in September 2008.¹

Finally, the Policy Paper gives best practice examples of supported decision-making systems in section 3.4. MDAC emphasises that people can be supported to make their own decisions in different ways. Supported decision-making can take various forms and support should depend on the circumstances and individual needs of each person concerned.

¹ UN Doc. A/RES/61/106 of 13 December 2006.

1. Context

1.1. Interest and expertise of MDAC

This Policy Paper is developed by the Mental Disability Advocacy Center (MDAC) with the purpose of assisting Russian policy-makers to move from a system of substituted decision-making in respect of people with intellectual or psycho-social disabilities, to one in which supported decision-making is the default model.

MDAC is committed to providing legislators with technical legal expertise on adult guardianship law reform worldwide. Since 2004 MDAC has been working in Russia and has participated in consultations on disability rights and, through a Russian attorney, has provided legal representation in several legal capacity cases in the country, including in the case of *Shtukaturov v. Russia*. Shtukaturov reached both the Russian Constitutional Court and the European Court of Human Rights. MDAC has published a series of reports analysing guardianship laws and practices in several countries around the region, including a 2007 report on Russia.²

In addition to this, MDAC has organised several capacity-building training events in Russia for civil society organisations and governmental officials. In December 2010, MDAC and Perspektiva (a Russian non-governmental organisation for people with disabilities), organised a three-day seminar on the law relating to legal capacity. Participants were mainly lawyers and came from all over Russia.

1.2. Why switch from the guardianship system to a supported decision-making system?

Article 12 of the CRPD guarantees that persons with disabilities have a right to legal capacity, which means that the law should recognise their capacity to be the bearers of rights, and their capacity to act. Capacity to bear rights means the capacity to be a potential holder of rights and obligations, while capacity to act means the capacity to exercise these rights and to enter into legal relationships. According to the background conference document on legal capacity prepared by the Office of the United Nations High Commissioner for Human Rights for the Ad Hoc Committee drafting the CRPD, “the concept of ‘legal capacity’ (...) logically presupposes the capability to be a potential holder of rights and obligations, but also entails the capacity to exercise these rights and to undertake these duties by way of one’s own conduct”.³

² See “Guardianship and Human Rights in Russia”, available in Russian and English” in the resources section of MDAC’s website www.mdac.info.

³ http://www2.ohchr.org/SPdocs/CRPD/DGD21102009/OHCHR_BP_Legal_Capacity.doc (Executive summary).

Furthermore, the Parliamentary Assembly of the Council of Europe – which includes representatives of the Russian Duma – unanimously adopted a Resolution in 2009 calling on “states to guarantee that people with disabilities retain and exercise legal capacity on an equal basis with other members of society”,⁴ by “ensuring that their right to make decisions is not limited or substituted by others, that measures concerning them are individually tailored to their needs and that they may be supported in their decision making by a support person”. The Resolution goes on to say that “people placed under guardianship [should] not [be] deprived of their fundamental rights (not least the rights to own property, to work, to a family life, to marry, to vote, to form and join associations, to bring legal proceedings and to draw up a will), and, where they need external assistance so as to exercise those rights, that they [should be] afforded appropriate support, without their wishes or intentions being superseded”. The Parliamentary Assembly also encourages States to provide “sufficient safeguards against abuse of people under guardianship notably through establishing mechanisms for periodic review of guardians’ actions and ensuring that legislation mandates compulsory, regular and meaningful reviews of guardianship, in which the person concerned is fully involved and has adequate legal representation.”

Legal capacity is a form of legal recognition which provides the basis for all people to make decisions about their lives. In many States around the world, including the Russian Federation, people with intellectual disabilities and people with psycho-social disabilities are often denied full legal capacity and are placed under guardianship, resulting in the restriction or denial of many of their fundamental human rights. In MDAC’s second Policy Paper, we analyzed the Russian legal capacity system. In that document we pointed out that a person’s rights to decide where to live, to liberty, to correspondence, to political participation, to work, to marry and found a family, to consent to somatic and mental health treatments, and to access justice are fully removed if the person concerned is placed under the guardianship of a substitute decision-maker.

Alongside this, MDAC’s first Policy Paper on legislative measures required to achieve compliance with the European Court of Human Rights’ *Shtukaturov* judgment⁵ highlighted the need for legal capacity law reform in Russia, reforms which are also required following the the judgment of the Russian Constitutional Court in a related case,⁶ recommendations of the UN Human Rights Committee,⁷ Russia’s commitment to guarantee the human rights of all people, as demonstrated by its September 2008 signature of the UN Convention on the Rights of Persons with Disabilities (CRPD).

Article 12 of the CRPD represents a so-called ‘paradigm shift’ in addressing legal capacity. This paradigm shift requires recognition of the principle “that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (CRPD Article 12 (2)). This means that States must not deny legal capacity to people with intellectual or psycho-social disabilities, but instead, must, “provide access by persons with disabilities to the support they may require in exercising their legal capacity” (CRPD Article 12 (3)).

The undue deprivation of human rights of people with disabilities, and Russia’s national and international legal obligations call for introducing less restrictive alternatives to guardianship in the country.

⁴ Resolution 1642 (2009) of the Parliamentary Assembly of the Council of Europe, “Access to rights for people with disabilities and their full and active participation in society”, 26 January 2009.

⁵ *Shtukaturov v. Russia*, Application no. 44009/05, judgment 27 March 2008.

⁶ Constitutional Court of the Russian Federation. Judgment no. 4-P of 27 February 2009.

⁷ UN Doc. CCPR/C/RUS/CO/6 of 24 November 2009.

2. Supported decision-making

MDAC's second Policy Paper was designed to support the formulation of new legislation in Russia that would meet the requirements of international law and ensure that the rights of persons who need support in exercising their legal capacity are protected, respected and fulfilled. Policy Paper 4 focuses on supported decision-making systems based on respect for the human rights of people with intellectual and psycho-social disabilities.

2.1. The philosophical background to supported decision-making

Everybody needs support from others in making important as well as less important decisions concerning different areas of life. Indeed this is obvious; we all need the knowledge and expertise of people around us because we do not have all the talents and skills which are relevant to make every kind of decision possible in life. For example, if Masha wants to buy a car she may ask the car salesman about the engineering, a car mechanic about the crash-test scores, her friends about the brand, and her partner about the functionality and her financial advisor about the cost. Masha can accept or reject all of these people's advice. However, there is another significant principle behind this form of trust- and support-based decision-making system: the principle that people have the right to take risks and make decisions which may turn out to be "wrong", or ones which they later regret. The type and amount of assistance which we all, as individuals, need when making decisions and choices can be different, but in reality we all make choices and decisions based on the supported decision-making model.

The United Nations Handbook on the CRPD states that

[s]upported decision-making can take many forms. Those assisting a person may communicate the individual's intentions to others or help him/her understand the choices at hand. They may help others to realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity.⁸

The concept of supported decision-making contains two components which arise from Article 12 of the CRPD:

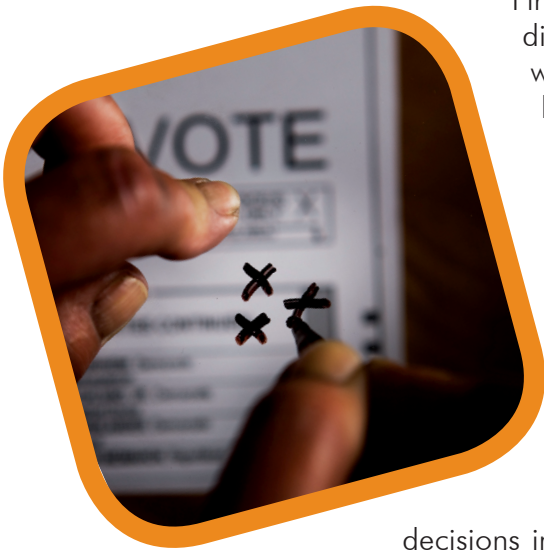
- Everyone has the right to make their own decisions – known as autonomous decision-making; and,
- Everyone has the right to receive adequate support to do so – known as supported decision-making.

⁸ See <http://www.un.org/disabilities/default.asp?id=242>.

Autonomous decision-making and supported decision-making are not contradictory; they can be used in interaction. In most people's lives, interdependence between people is how decisions get made.

2.2. The principles of supported decision-making

Article 12 of the CRPD necessitates that guardianship systems should be replaced by systems of alternatives, including, in particular, methods of supported decision-making.



Firstly, supported decision-making is borne of the social model of disability, according to which the "problem" is not in the person with disabilities, but in societies which create various barriers hindering the full and effective participation of people with disabilities in society on an equal basis with others.

While in the guardianship system an adult's legal capacity is restricted or denied, supported decision-making means that the person retains full legal capacity.

In the guardianship system an adult's decision-making is substituted: it is the guardian who makes decisions on behalf of the adult with disabilities and in his or her 'best interests'. Supported decision-making means that the adult himself/herself makes the decision. Instead of making decisions in the name of the adult, supporters assist the person to reach and communicate his/her own decisions.

While the guardianship system is based on a relationship of paternalistic subordination, where guardians 'know what is good' for the adult, the core principle of supported decision-making is a relationship of trust between the person with disabilities and supporters.

In guardianship systems, guardians are appointed by a court or other authority, and can be either a social welfare centre or the guardianship authority. Supported decision-making, on the other hand, is based on the free agreement of the adult and supporters. In other words, supported decision-making consists of a voluntary relationship between the adult and his or her supporters.

In guardianship systems a person usually has one or, at most, two guardians, while in supported decision-making systems a broader support group or network can be recognised.

The role of the guardian is to act on behalf of the adult. In certain situations the guardian can make decisions without taking into account – or even in direct contradiction to – the adult's wishes. In other situations the guardian is obliged to take into consideration the wishes and will of the person placed under guardianship. Guardianship systems often lack appropriate safeguards to ensure that decisions of a guardian coincide with the adult's wishes. Usually there are no complaints

mechanisms for adults with disabilities to challenge the decisions of their appointed guardians. In supported decision-making, the role of supporters is to enable the supported person to make his/her decisions and on the basis of informed choice. Supporters assist the adult to communicate his/her intentions to others and help him/her understand the choices at hand. They are facilitators of the supported person's decision-making process. As such, they must respect the person's wishes, preferences, and interests.

While professional guardians are paid for their job, in supported decision-making systems supporters should be independent from service-delivery professionals. They are usually unpaid and could include friends, family, or members of the local community.

2.3. Safeguards to supported decision-making systems

To ensure supported decision-making works correctly and effectively in place of substituted decision-making under guardianship, a number of safeguards should be put in place to prevent and remedy any forms of physical, emotional or financial abuse, or neglect, that may occur. Such safeguards should not overprotect people with disabilities, but should respect the inherent dignity, individual autonomy (including the freedom to make one's own choices), and independence of persons, as required by Article 4(a), a general principle of the CRPD.

When setting up safeguards for systems of supported decision-making, Articles 12(4), 13 and 16 of the CRPD should be considered.

Article 12 – Equal recognition before the law

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

Article 12(4) refers to safeguards which:

- a. are appropriate
- b. are effective
- c. prevent abuse

- d. ensure that “measures” (including support) which relate to the exercise of legal capacity
 - i. respect the rights, will and preferences of the person
 - ii. are free from conflict of interest and undue influence
 - iii. are proportional and tailored to the person’s circumstances
 - iv. apply for the shortest time possible
 - v. are subject to regular review by a competent, independent and impartial authority or judicial body, and
- e. are proportional to the degree to which such measures affect the person’s rights and interests.

People with disabilities, just like people without disabilities, are not a homogenous group. Everyone is different, yet entitled to the same rights. The preamble of the CRPD recognizes the “diversity of persons with disabilities”,⁹ and highlights the “need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support”.¹⁰

As noted above, “disability is an evolving concept and [...] results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”.¹¹ At the same time it is also evident that people with disabilities need different types and degrees of support, so any such assistance must be tailored to a person’s individual circumstances.

Whatever type of support is required by a person with disabilities, the supported adult’s rights, will and preferences should be respected.

A person with disabilities may need the same type or degree of support in his/her day-to-day decisions such as choosing what to eat, where to spend the weekend and what to wear. There are also situations where the type or degree of support needed may be different or greater because of the nature of the choice itself, such as choices about serious healthcare issues or other emergency situations. In both cases, either regarding day-to-day decisions or decisions based which require a higher degree of support, any support given should apply for the shortest time possible. Only in those cases where people with disabilities require highly intensive support should measures be taken related to the exercise of legal capacity, which must be subject to regular review by a competent, independent and impartial authority or judicial body. It should be noted that highly intensive support does not mean substituted decision-making in any case.

⁹ CRPD perambulatory paragraph (i).

¹⁰ CRPD perambulatory paragraph (j).

¹¹ CRPD perambulatory paragraph (e).

Article 13 – Access to justice

1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.
2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

Article 13 contains the safeguards necessary in remedying any kind of abuse and neglect related to the process of supported decision-making.

Article 16 – Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.
2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.
3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.
4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

Article 16 outlines safeguards necessary to protect disabled persons against exploitation, violence and abuse in many fields, including in respect of any assistance which may be given in supported decision-making systems. Article 16 highlights not only the importance of appropriate legislative, administrative, social, educational and other measures of protection, but effective monitoring and promotion of recovery services as well.

2.4. Supported decision-making in practice

People can be supported to make their own decisions in different ways. Supported decision-making can take various forms and support should depend on each person's circumstances and individual needs.

2.4.1. Swedish mental health service user-run support

Skåne is the most southern province of Sweden. ¹² The province has a system of personal ombudsmen/women. Most of the personal ombudsmen/women in Skåne are employed by PO-Skåne, which is an independent NGO run by a mental health user organisation called the Swedish National Association for Social and Mental Health (RSMH), and a family organisation called the Schizophrenia Fellowship Association (IFS). Only local groups of RSMH and IFS can be members of PO-Skåne. The organization is 100% mental health service user-controlled and personal ombudsmen/women work according to the client's guidelines. Examples of these guidelines include:

- Personal ombudsmen/women do not work Monday to Friday office hours like most other services. The week has seven days and with 24 hours in each day so personal ombudsmen/women must be prepared to work at all these various hours. Not only are their clients' problems not concentrated to office hours but it is also easier or more appropriate to contact some people at evenings and weekends. Personal ombudsmen/women have a 40 hour working week and work according to flexible hours every week according to the wishes of their clients.
- Personal ombudsmen/women do not have an office because an office is a sign of power. Personal ombudsmen/women work from their own home with the help of a telephone and the internet and they meet clients in their homes or at neutral places in town.

¹² See: www.po-skane.org.

- Personal ombudsmen/women work primarily according to a 'relation-model'. As many clients are suspicious or hostile, or hard to reach because for other reasons, personal ombudsmen/women have to go out and find them where they are. Personal ombudsmen/women reach the client through several steps: 1. Making contact. 2. Developing communication. 3. Establishing a relationship. 4. Starting a dialogue. 5. Getting instructions from the client. Each of these steps can take a long time to realise and, in some cases, simply making contact can take several months.
- There are no bureaucratic or formal procedures to get a personal ombudsman/woman from PO-Skåne.
- Personal ombudsmen/women should be able to support clients in all kind of matters. According to PO-Skåne's experience the clients' first priorities are usually not housing or employment, but existential matters ("Why should I live?", "Why has my life become the life of a mental patient?", "Do I have any hope for change?"). Personal ombudsmen/women must also be able to spend a lot of time listening and talking with their client about these kinds of issues.
- Personal ombudsmen/women should be skilled to be able to effectively argue for their client's rights in front of various state authorities or in court. All personal ombudsmen/women of PO-Skåne have an academic degree from the university or similar equivalent education. Most of them are trained social workers.
- The client should have the right to be anonymous to the authorities. If a client does not want his/her personal ombudsman/woman to tell anybody that he or she has a personal ombudsman/woman then this must be respected. PO-Skåne receives money from the community for the services they provide, but the contract specifies that personal ombudsmen/women can withhold information including the names of their clients to the community.



2.4.2. Circles Network

Circles Network is a UK national voluntary organisation formed in 1994. Circles Network's aims are to build inclusive communities where everyone can belong regardless of ability, background or culture, and meaningfully contribute – with appropriate support for children, young people and adults – to the aims and well-being of the community.

The idea of a circle of support was developed in Canada and spread fairly quickly through North America and began in the mid 1980s in the United Kingdom.¹³ A circle of support, sometimes called a circle of friends, is a group of people who meet together on a regular basis to help somebody accomplish their personal goals in life. The circle acts as a community around that person (the 'focus person') who, for one reason or another, is unable to achieve what they want in life on their own

¹³ See: <http://www.circlesnetwork.org.uk>.

and decides to ask others for help. The focus person is in charge, both in deciding who to invite to be in the circle, and also of the direction that the circle's energy is employed, although a facilitator is normally chosen from within the circle to take care of the work required to keep it running.

The members of the circle, who may include family, friends and other community members, are not usually paid to be there. They are involved because they care enough about the focus person to give their time and energy to helping that person overcome obstacles and increase the options which are open to them. Although the focus person's goals are the primary drive in everything the circle does, the relationship is not just one way. The circle members will all have diverse gifts and interests, and new opportunities and possibilities may appear which had not even been considered before the forming of the circle. Because of this, an important function of the circle is to regularly re-visit the plans from which they are working and to ensure that they are staying true to the goals that the focus person really wishes to achieve.

The circle is not a service or tool to be applied to a certain group of people. Circles are about seeing people as individuals who feel they need support in order to take more control over their own lives. A properly facilitated circle is empowering to all of the individuals involved and, unlike many service systems, does not reinforce dependence.

The work of circles of support is based on the values of inclusion, and through facilitating the setting up of circles of support, support has been provided for many hundreds of people with disabilities across the UK.

3. Conclusion

Supported decision-making recognises the individual autonomy and inherent dignity of a person with an intellectual disability or psycho-social disability. Supported decision-making respects the freedom of such a person to make their own choices. Supported decision-making acknowledges the independence of persons with disabilities.

In this Policy Paper MDAC has examined the way in which supported decision-making is both philosophically grounded and normatively required by international human rights law and backed up by evidence of good practice from other countries. A support system with adequate safeguards must, as a matter of priority, replace the system of substituted decision-making which is, in itself, a violation of international human rights law, and facilitates the deprivation of a range of other human rights. Instead of removing legal capacity of persons with intellectual disabilities and people with psycho-social disabilities, appropriate and effective support should be provided for these people.

MDAC believes that legal capacity law reform is a vital part of ensuring that people with intellectual disabilities and people with psycho-social disabilities enjoy the full range of human rights on an equal basis with others in all aspects of life.



For additional information contact:

Mental Disability Advocacy Center
(MDAC)

H-1051 Budapest

Hercegprímás utca 11, Hungary

Telephone: +36 1 413 2730

Fax: +36 1 413 2739

Email: mdac@mdac.info

Website: www.mdac.info

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