

SUPPORTED DECISION MAKING

or

**how people with intellectual
disabilities or mental health
problems can live
independent lives**



The present leaflet is prepared by the Bulgarian Center for Not-for-Profit Law© under the project “Article 12 – next step”. Funding for this project provided by the Open Society Foundations.

The aim of the present leaflet is to present the fundamentals and the meaning of supported decision making concept in accordance with the ratified UN Convention of Rights of Persons with Disabilities by the Republic of Bulgaria.

In October 2012 started a pilot programme, aiming at supporting the practical application of the supported decision making models in the country by covering a minimum of 40 persons with intellectual disabilities and mental health problems. The programme consists of three interrelated projects, implemented with the expert assistance of the Canadian nongovernmental organization Institute for Research and Development on Inclusion and Society (IRIS):¹

- Pilot project “Shifting the paradigm in the context of Article 12 of the UNCRPD. Solutions searching for people with mental health problems”, implemented by the Global Initiative on Psychiatry – Sofia (GIP – Sofia) in partnership with the National Organization of Mental Health Service Users (NOMHSU). The project is aiming to test approaches for supported decision making for persons with mental health problems. The activities are implemented in Sofia and Blagoevgrad and include at least 20 persons. Duration of the project: October 2012 – September 2013.
- Pilot project “Empower people with intellectual disabilities”, implemented by the Bulgarian Association of Persons with Intellectual Disabilities (BAPID). The purpose of the project is to test approaches for supported decision making for at least 20 persons with intellectual disabilities. It is implemented in the cities of Sofia and Vidin. Duration of the project: October 2012 – September 2013.
- Project “Article 12– next step”, implemented by the Bulgarian Center for Not-for-Profit Law (BCNL). The main purpose of the project is to coordinate the activities of the partners within the programme, as well to support the preparation of adequate legal mechanisms and regulations, that can guarantee capacity of persons with intellectual disabilities and with mental health problems to enjoy their rights. Duration of the project: October 2012 – May 2014.

¹ IRIS is a Canadian nongovernmental organization developing its activity on behalf of the movement for living in the community in collaboration with other organizations, dedicated to the problems of the people with disabilities and social justice. The institute implements policy and social development researches and encourages affirmation of innovative ways of thinking, inspiration and education aiming on improvement of the civic status, inclusion, human rights and welfare of persons with intellectual and other disabilities.

WHAT DOES *SUPPORTED DECISION MAKING* MEAN?

This is the support needed to persons excluded from the community due to their intellectual disability and/or mental health problem to take decisions – people considered (by someone) incapable of making decisions, to work, etc. throughout their entire life or in certain periods (for example in a period of a mental crisis).

FOR WHAT KIND OF DECISIONS ARE WE TALKING IN FACT?



Basically, for the most important ones: the choice of place to live, to have friends, to have money which I can spend on whatever I decide, to visit a doctor and to choose whom to go to and when, to be able to work, etc.

“Supported decision making” is a process in which supporters help adult persons with mental health problems or intellectual disabilities in taking decisions for their personal lives, health, financial issues and property. The supported persons choose independently their supporters by including members of their families, friends and advocates they trust.

WHO IS INVOLVED IN THE PROCESS OF SUPPORTED DECISION MAKING ?



THE SUPPORTED PERSON:

this is the person in the center of the process of the supported decision making. For the purposes of the pilot programme, the supported person is someone who is either in a situation or in a risk someone to take decisions on his/her behalf, regardless of his/her capability to act independently.

SUPPORTERS

To be able to provide decision making support to people means:

- to be able to listen and learn together with the supported persons;
- to help them to communicate with others;
- to try to empower them to manage their own lives;
- to provide them with possibilities to interact with other people and to contribute to the community as a full-rights citizens.

Supporters are required to empathize with the persons, to respect them and to be trusted by them. The supporters are not professionals (and do not get money for what they do). The network of supporters is dynamic and in certain periods may involve different actors.

THE SUPPORTERS SHOULD SIMULTANEOUSLY:

- have a proven trust relationship with the supported person;
- be able to understand the communication forms and interpret rationally and logically the person's will and preferences and apply the interpretation in specific decision making situations;
- be committed to the person's well-being, be able to interpret his/her will and preferences and provides decision making support based on this interpretation.

FACILITATOR

The facilitator has two main tasks:

- to support the person in the process of establishing the network
- to assist the supporters to respect and consider the choices of the supported person, to provide him/her with support, to help him/her in building perspective and dreams.

EVALUATION OF THE DECISION MAKING CAPACITY OF THE PERSON – MEASUREMENT FOR THE NECESSITY OF SUPPORTED DECISION MAKING



During evaluation process of the decision making capacity of a person should be always considered, that:

- the evaluation concerns the decision making capacity for certain decision, and not of the person as a whole;
- capacity can vary in time;
- everyone can make “irrational” decision and this

has nothing to do with decision making capacity.

Each time when evaluation of the decision making capacity is made, two questions should be answered:

- Is there a brain functioning problem?
- If yes, does it make the person incapable of independent decision making for a certain situation?

In order to assess the decision making capacity, tests on the level of functioning should be conducted, according to which a person is incapable of decision making if he/she cannot:

- understand information regarding a certain decision;
- perceive/ keep information;
- adequately use and assess the information as part of this decision making process;
- communicate the decision (by whatever mean)

Some key principles of supported decision making:

- The supported person is in the center and is the most important – his/her right to choose, the respect towards his/hers decisions including who will be his/hers supporter/s, are guaranteed;
- Trusted relationship between the supported person and his/hers supporters is needed;
- Participation in the support network is voluntary;
- The facilitator organizes the start up of the network and is responsible for its sustainable development in time;
- Avoiding conflict of interests between supported persons and supporters.

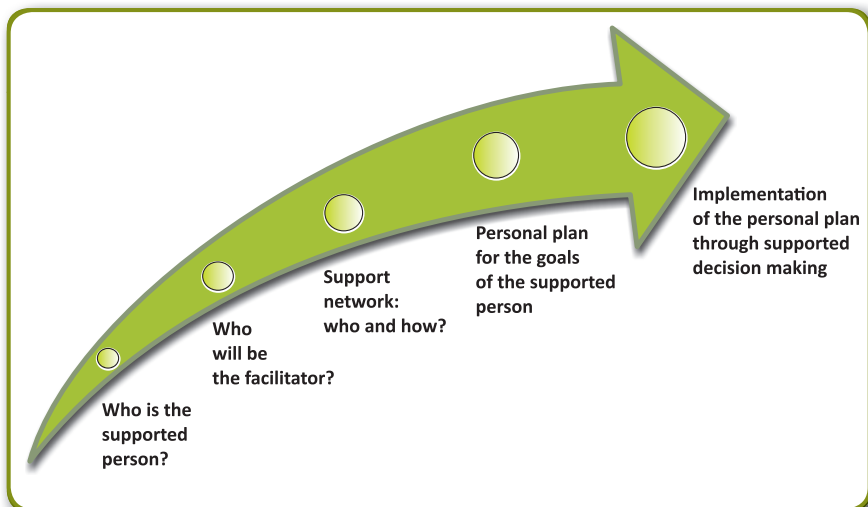
ALGORITHM FOR SUPPORTED DECISION MAKING



Within the pilot programme a system (algorithm) of certain stages was developed. Each stage consist of minimum necessary steps, that should be undertaken for the real application of supported decision making approaches in respect to persons with

mental health problems and intellectual disabilities. Each of the stages is provided with the necessary documentation that guarantees the compliance with the current Bulgarian legislation.

Main stages:

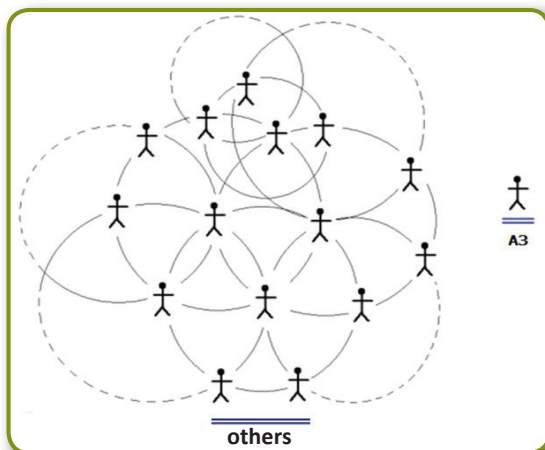


PROJECT “SHIFTING THE PARADIGM IN THE CONTEXT OF ARTICLE 12 OF THE UNCRPD.

SEARCHING FOR SOLUTIONS FOR PEOPLE WITH MENTAL HEALTH PROBLEMS”

Have you ever asked yourself how does the world look like from the point of view of a person with mental health problem?

In most cases, the picture is as follows:



With the years passing by, the mental health problems often become the reason for the person to narrow his/ hers contacts, so that the circle of supporters and friends steadily decreases: very often he/she becomes isolated from the social network.

How does isolation effect the lives of people with mental health problems?

Same as in the life of the other people: it deepens their problems.

People with mental health problems, living in isolation, feel misunderstood and vulnerable, they receive very limited feedback on questions such as who they are, what they can, what is the result from their actions and this additionally worsen their social orientation. They do not have enough support and confidence in decision making. All these on top of the problems caused by their mental disorders, makes their life more difficult and confused.

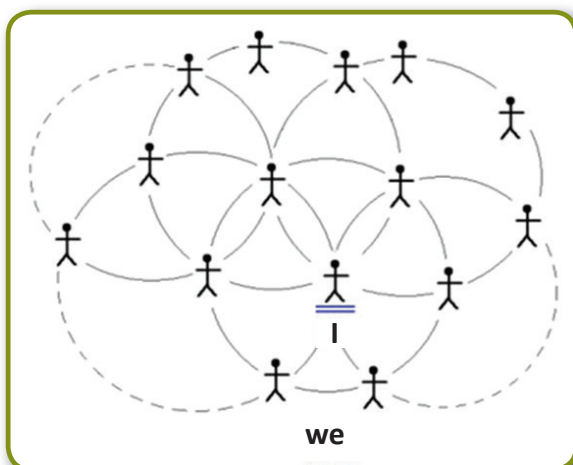


Within the present pilot project, actively supported by trained specialist (facilitator), the supported person makes the following first steps:

- Extends the circle of people who love and support him/her;
- Receives support in determining the important personal goals and works together for achieving them;
- Receives support in all life domains: home, circle of friends, work, health, education, finance, shopping, etc. They trust their supporters' opinion for the issues, in which they do not feel confident to make independent decision;
- Listens and pays attention to the given feedback – with their support the person can recognize the symptoms of the upcoming mental crises and to take actions to avoid/prevent it;
- Participates in group for mutual support, sharing the experience with other people living with the same problems. He/she can become part of the support network of another participant in this group or to meet among these participants people who can become part of his/her own network.

As a result of these steps, the person builds sustainable connections and creates close relationships: he/she becomes surrounded by a support network, similar to the informal networks we all have.

The person becomes included again in the community network and the world for him/her looks like this:

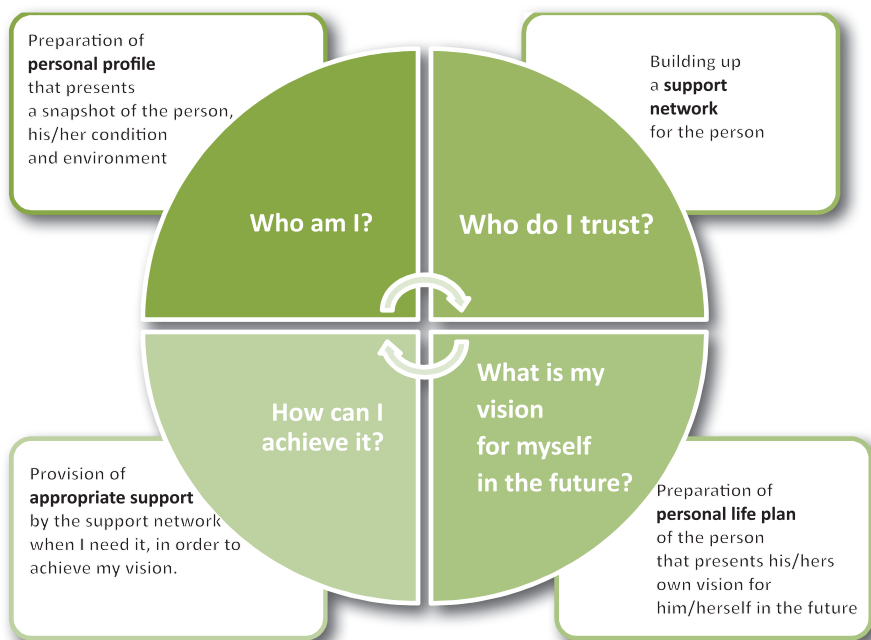


PROJECT “EMPOWER PEOPLE WITH INTELLECTUAL DISABILITIES”

**Step by step toward supported
decision making for people
with intellectual disabilities
and/or autistic problems**



The grounds of the pilot approach for supported decision making for people with intellectual disabilities and autistic problems are the answers of the following questions:



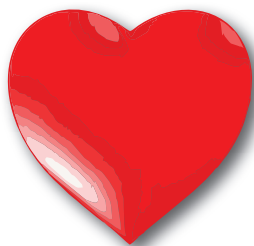
How do we create a personal profile?

The process of developing a personal profile includes preparation of a detailed list of the person's life domains – place to live, education, labour, health, property, free time, based on which during the regular meetings and with the assistance of the facilitator, the person identifies the important things for him/herself:

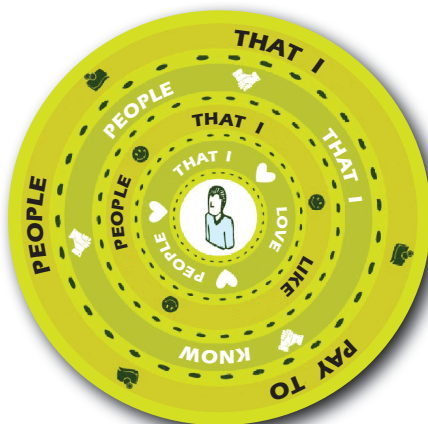


- key life events: changes, health problems, positive experience, sad memories;

- relationships with the people around – loved ones, friends, supporters, people he/she turns to for help and advice;



- emotional needs.



Personal life plan – a “driver” for change in life

The purpose is to gradually increase the non formal resources of the supporting network and its members, along with the supported person, to realize the strength of the process, the opportunities and the rights that this process provides to the person with disability.

PROJECT

"ARTICLE 12 – NEXT STEP"



The role of this project in the programme is in three main dimensions:

- advocacy – by supporting the elaboration of new legal mechanisms, providing disabled people with the opportunity to act independently and enjoy their rights
- research – by studying the attitude change of the various groups of people involved in the programme (professionals and experts, supported persons, supporters, etc.)
- coordination – by collecting and storing information on the results from the testing of supported decision making

PLANNED PROJECT ACTIVITIES



CHALLENGES FOR BULGARIA

BACKGROUND:

On December 13, 2006 the United Nations adopted the Convention on the Rights of Persons with Disabilities (CRDP).

On December 23, 2010 the European Union joined CRDP.

On January 26, 2012 Bulgaria ratified CRDP.

Art.12 of the Convention requires legal reform of the guardianship and custody instituts and the possibility that substituted decision making for people with intellectual disabilities and mental health problems will be replaced by supported decision making models. According to the concept of art. 12 people with disabilities can and should be allowed to exercise their personal rights independently meaning that the will of the person cannot be substituted by the will of another person (guardian, custodian, advocate, etc.).

The regulation of supported decision-making in Bulgaria should guarantee the accurate application of the CRPD principles for protection of the rights of people with disabilities and their best interests. This requires legal reform of the current Bulgarian legislation. And not only. It is necessary to adopt and apply a holistic approach for reviewing the current legislation on guardianship and custody but also implementation of governmental policy that envisages capacity building trainings on the Convention and the provision of adequate financial resources needed for the



new measures. It is also important to change our own attitude – to accept and respect the choices made by people with different disabilities nonetheless they might be not able to communicate like us.

THE BULGARIAN CENTER FOR NOT-FOR-PROFIT LAW (BCNL)
was founded in July 2001 and is registered in the Central Register at the Ministry of Justice as a public-benefit foundation.

BCNL is an affiliate of the International Center for Not-to Profit Law (ICNL) headquartered in Washington D.C. and is a local partner of the European Center for Not-to-Profit Law based in Budapest. BCNL's mission is to provide support for the drafting and implementation of legislation and policies aiming to advance civil society, civil participation and good governance in Bulgaria.

CONTACTS

BULGARIA, Sofia 1000, 6 Dobrudza Str, fl.1

Tel./Fax: +359 2 981-66-17, 988-81-66

info@bcnl.org

www.bcnl.org, www.equalrights.bcnl.org

GLOBAL INITIATIVE ON PSYCHIATRY – SOFIA (GIP –SOFIA)
is registered in Bulgaria in December 2004, as public benefit foundation.

GIP – Sofia as part of Federation GIP, shares common mission and values and works for the achievement of one main goal: promoting human, ethic and effective mental health care throughout the world. We firmly believe that every person should have the opportunity to realize his full potential, despite personal vulnerabilities or life circumstances.

CONTACTS

BULGARIA, Sofia 1000, 1 Malyovitsa Str, fl.2

Tel.: + 359 2 987-78-75; Fax: 980-93-68

sofia@gip-global.org

www.gip-global.org

BULGARIAN ASSOCIATION FOR PERSONS WITH INTELLECTUAL DISABILITIES (BAPID) is a national representative organization of persons with intellectual disabilities in Bulgaria, whose members are people with intellectual disabilities, their friends and families. The mission of BAPID is to defend human rights and dignity of people with intellectual disabilities and to fight against their discrimination.

BAPID is a member of the International and European Network of Nongovernmental Organizations for People with Intellectual Disabilities Inclusion (Inclusion International and Inclusion Europe).

CONTACTS:

BULGARIA, Sofia 1000, 10 Lavele Str, fl. 4

Tel.: + 359 2 417 44 19; Fax: 416 09 56

bapid@bapid.com

www.bapid.com

NATIONAL ORGANIZATION OF MENTAL HEALTH SERVICE USERS (NOMHSU) is registered in 2009 in the Sofia City Court and in the Central Registrar at Ministry of Justice as a public benefit association.

NOMHSU is an association of people with mental health problems, managed by a Managing Board, nominated among its members. The organization is a member of the World Network of Users and Survivors of Psychiatry (WNUSP). The mission of NOMHSU is to unite people with mental health problems in Bulgaria, to improve their quality of life and defend their rights and interests.

CONTACTS

BULGARIA, Sofia 1000, Malyovitsa Str, fl.2

Tel.: + 359 888 902737

yellowbgsubmarine@abv.bg