



The Bulgarian Center for Not-for-Profit Law (BCNL) was founded in July 2001 and is incorporated as a public-benefit foundation in the Central Register at the Ministry of Justice. 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.

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# ***GUIDEBOOK*** ***to rights enforcement***

The current guidebook is prepared by the following team: Nadia Shebang, Marietta Dimitrova, Pavleta Aleksieva and Ivan Georgiev from the Bulgarian Center for Not-for-Profit Law (BCNL), Valentina Hristakeva from the Global Initiative on Psychiatry (GIP - Sofia), Sonya Vladimirova, Iliana Malinova, Lubka Aleksandrova and Antoaneta Andonova from the Bulgarian Association of People with Intellectual Disabilities (BAPID), Sabina Naydenova from the National Organization of Mental Health Service Users (NOMHSU).

*The present guidebook is prepared within the Next Step Programme, implemented by the Bulgarian Center for Not-for-Profit Law. The results and conclusions made in it do not reflect the opinion of the Open Society Foundations.*

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*Sofia, 2014*

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Although this Guidebook is long, it is important that you read through all of it in order to be able to understand Supported Decision Making.



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## THE NEXT STEP PROGRAM

The Next Step Program 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)<sup>1</sup>:

- Project “Article 12– the Next Step in Bulgaria”, implemented by the Bulgarian Center for Not-to-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.
- Pilot project “Paradigm shift in the context of Article 12 from UNCRPD. Searching solutions for people with mental health problems”, implemented by the Global Initiative on Psychiatry – Sofia (GIP – Sofia) in partnership with the National Organization of the Users of Mental Health Services (NOUMHS). 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 “Empowerment of people with 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.

### What is the aim of the "Next Step" program?

The aim of the program is to assist in the practical implementation of the models of supported decision making in the country by covering a minimum of 40 persons with intellectual disabilities and mental health problems. Also, the program aims to study and draw conclusions about the conditions necessary to achieve and ensure for people with these types of problems equality and full inclusion through personal exercise of human rights in five fundamental social life spheres: where and with whom to live, the right to work, property management and finance, creating personal relationships, choice of and use of health care. The program included people who are excluded from the community as a result of intellectual disability and/or mental health problem - people who are considered (some believe) unable to make decisions, to work, etc. throughout their entire life or at certain times of it (e.g. a period of psychotic episode).

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<sup>1</sup> IRIS is a Canadian nongovernmental organization developing its activity on behalf of the movement for living in 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 of thinking, inspiration and education aiming on improvement of the civic status, inclusion, human rights and welfare of persons with intellectual and other disabilities.

## **Which organizations participate in the Next Step Program?**

**The Bulgarian Center for Not-for-Profit Law (BCNL):** coordinates the Program and is responsible for the advocacy and the analytical part of the Program.

BCNL is a foundation in public benefit, founded in July 2001. **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. 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.

During the last 10 years we have been involved in the adoption of the NGO law in Bulgaria and its amendments, tax incentives for public benefit organizations and their donors, and have been pushing for the reforming the Social Assistance Act and its Implementing Regulations that have created a mechanism for contracting out public social services to NGOs. Two of our most important initiatives recently are the preparation of a Government Strategy for Support to Civil Society Organizations and the draft Law on Volunteerism.

BCNL was among the main leaders in Bulgaria for the ratification of UNCRC and participated in the preparation of the Concept for amending the national legislation concerning the legal capacity in compliance with article 12 and UNCRC standards (adopted by Council of Ministers in November 2012). BCNL was one of the members of the working group that prepared the Vision for the Deinstitutionalization of Children in Bulgaria, adopted by the government together with a 10-year Action plan funded through EU programs.

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- **Global Initiative on Psychiatry – Sofia (GIP –Sofia):** manages and implements the pilot project on SDM measures for people with mental health problems in Sofia and Blagoevgrad

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.

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- **Bulgarian Association for Persons with Intellectual Disabilities (BAPID):** manages and implements pilot project on SDM for people with intellectual disabilities in Sofia and Vidin.

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).

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- **National organization of the users of mental health services (NOUMHS):** implements the pilot project on SDM measures for people with mental health problems in Sofia and Blagoevgrad

NOUMHS is registered in 2009 in the Sofia City Court and in the Central Registrar at Ministry of Justice as a public benefit association. NOUMHS 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 NOUMHS is to unite people with mental health problems in Bulgaria, to improve their quality of life and defend their rights and interests.

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## THE AUTHORS OF THE GUIDEBOOK TO RIGHTS ENFORCEMENT

Dear friends, colleagues, readers,

In the development of this guide were involved many people who contributed to telling how to do SDM in all these pages. The knowledge and experience presented in this document are the result of our long journey in the past two years in Bulgaria approving pilot projects to support people with intellectual disabilities and mental health problems to be able to exercise their rights - to decide with whom and where to live, what and how to work, manage their funds, choose their treatment, prevent abuse. This would not be a fact, at least certainly not in this form, if we did not have the support and the faith in the values of the "Next Step" program shared by Haralan Alexandrov (anthropologist), the team of De Pasarel Bulgaria (Mirvana Syrian, Radoslava Lalcheva Freddie Wools), Vladimir Sotirov (psychiatrist), Velina Todorova (Associate to the Professor of Civil and Family Law), many parents and relatives of the people we supported. For us it is important to acknowledge the support of our donors Open Society Foundations, and especially of Tirza Leibowitz and Alison Hillman who trusted us.

We express our special thanks to Dr. Michael Bach, Institute for Research and Development on Inclusion and Society (IRIS), Canada, who was for us the greatest inspiration and guide in search of the best solutions.

And last but not least, we express our appreciation and respect for the people who trusted us and participated in the approval of measures to support decision making within each pilot project and the facilitators as part of the teams of pilot projects.

We believe that the text below will be a good basis for the creation and promotion of supported decision making as the only tool for people with mental health problems and intellectual disabilities through which to build, defend and enjoy their autonomy according to their will and preferences.

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## WHAT IS SUPPORTED DECISION MAKING?

### *Supported Decision Making*

- It is about people excluded from the community as a result of intellectual disability and/or a mental (psychosocial) problem – people considered (by someone) incapable of making decisions, working, etc. throughout their entire lives or in certain periods (e.g. in a period of a mental crisis).
- Decisions: the choice of where I live, have friends, have money and be able to spend it on whatever I choose, be able to go to the doctor and choose whom to go to and when, be able to work, etc.



Making choices on how to live – what to eat and drink, who to live with, what to spend your money on – is something that most of us take for granted while it is actually about fundamental rights. The capability of making choices determines our independence and the quality of our lives.

Some people really need support in order to make decisions. This may result from the circumstance that they have their own unique style of communication or because they need support in order to understand and digest the information necessary to make a decision.

Each of us makes major decisions seeking support, and we get it most often from people whom we trust.

- Everyone, regardless of whether he/she has disability and how serious it is, has desires, preferences and will;
- Desires, preferences and will should always be recognized and respected, regardless of the problems in communication;
- Everyone, regardless of whether he/she has a disability and how serious it is able to build relationships of trust with another person;
- Everyone, regardless of whether he/she has disability and how serious it is, at some point needs support in making decisions and receives it from people whom he/she trusts.



Supporting someone in making choices and taking decisions is actually a process indicative of how much you understand the person. Being able to provide good and worthwhile support is possible only if you work with the person and listen to whatever he/she really wants.

Providing supported decision making, based on an approach centered at the personality of the supported person, means to:

1. Listen and learn with the person;
2. Help them communicate;
3. Strive for them to guide their own lives;
4. Provide them with an opportunity to interact with other people around them and give their contribution as a citizen enjoying equal rights.

The personality centered approach can help us support someone and reserve the control to them. This tool can help us draw a detailed picture of the person's life and how they choose to live their lives.

„Supported Decision Making“ (SDM) is a system of measures aimed at ensuring that the person grasps the information, assimilates it, makes the decision and communicates it. The measures aim to support people who led by their will and preferences make decisions important for them - with whom and where to live, how to manage their finances and property, make decisions about their treatment, to be able to work, to be able to communicate with the public institutions, etc.

SDM is a combination of social interventions aimed at specific result - making decisions that have legal consequences and lead to concrete results for the person (spends his/her funds, disposes of property, enters into contracts, accepts proposals, etc.).

### ***Prerequisites for successful provision of SDM***

1. The person has to live in the community;

To implement successfully SDM, the person involved in the process of SDM, must be able to exercise control over his/her life. The way of organizing services in an institutionalized form of care (such as specialized institutions) do not allow the existence of such opportunities as the implementation of a control is vested in and entrusted to the institution - service provider. Currently in Bulgaria there is no mechanism to empower people in institutions. Moreover, even decisions on everyday issues such as how to dress, what to eat, when to sleep are fully vested in the institution.

2. To provide social support through social services that improve functioning and develop skills;
3. To make sure that the control is in the person from the beginning of the process and that he/she wishes to participate and makes it voluntarily.

### ***How do we assess that a person needs support?***

*The aim is to establish whether there is a need for SDM for a specific decision.*

Whenever a person's decision making capacity is assessed, we need to remember that:

- The capacity relates only to a specific decision;
- The capacity can change over time;
- Anyone can make an "irrational" decision and this has nothing to do with their decision making capacity.



### ***Irrational Decisions***

We should always remember that people often make irrational decisions and the lack of decision making capacity should never be used as a motive to limit the person's choice against irrational decisions.

Every time when assessing the decision making capacity of a person the following four-element test should be applied:

#### ***4 elements test:***

- 1) Understanding – the person can accept and retain the information about a particular decision;**
- 2) Assessment – the person can assess the consequences if he/she makes the decision;**
- 3) Communicating the choice - the person can communicate (objectify) his/her decision;**
- 4) Voluntariness – to be able to form the first 3 elements voluntarily.**

**If the person does not cover any of these four elements a specific social intervention can be include to support him/her to cope.**

## ***Social interventions part of the measures for SDM***

### **1) Groups of equals**

The groups of equals (or peer-support groups) include people who share a specific (similar) problem, life situation or crisis. Members of the group render each other emotional support, learn new coping methods, explore strategies for improvement of their condition and help other members to cope. The group supports the man with information, advice and encouragement. Participation in a group of equals is voluntary and does not require the investment of substantial resources. Support from equals can play vital role in the stabilization of the health condition in people with mental health problems. On the whole the support groups of equals can provide spontaneous, natural support in the community, especially where there are no developed systems of services

### **2) Consultations with a trained specialist**

These are professionals from various fields (lawyers, psychologists, financiers, etc.) who provide advice on specific issues. Consultations usually concern one particular decision with which the person cannot cope alone (e.g. in concluding a contract) or provide additional information needed for the person to make his/her own decision.

It is important that these professionals (consultants) are specially prepared for SDM and for working with the specific group of people so that they take into consideration all the factors which might have a negative effect on the real desires of the clients.

### **3) Social service**

In most of the cases, the person needs specific social support to be able to recover some of his/her skills, to improve his/her functioning and communication, to develop a capacity, improve the quality of life, etc. This is particularly relevant for people who have lived long in institutions and who have lost (or have not acquired) skills for independent decision making. In these situations it is better to offer the person support from social services. Experience shows that the use of quality social services increases the person's capacity to make decisions independently.

### **4) Mentor (Personal advisor)**

These are specially trained professionals (for example employed in a social service), who aim to support the person to gain the information necessary to understand, evaluate the outcomes and make decisions. The support that the mentor provides can be called a "support in decision making". The mentor helps the individual to gather all the information for a specific decision, to make sense of this information and put the arguments „for" or "against" making a concrete decision. The mentor does not assess; his/her role is to help people gain and understand the information so that they are able to make their own decision. This intervention is applied most successfully in people who have difficulties in establishing and maintaining relationships of trust and function badly in network.

These social interventions in 1, 2, 3 and 4 are a support that aims to make the person cope with the exercise of his/her rights. Through them, the person is able to cover and recover some of the 4 elements of the above test. Decisions are taken by the person himself/herself.

### **5) Anti-crisis plan**

An individual may have a concern that at certain times (such as in a state of psychotic crisis) his/her vision of the world and the consequences of his/her own actions/inactions is different from the one that is most important to him/her and reflects his/her best desires and preferences. Everyone suffers differently, but in some part of the people a new episode (attack) of mental disorder occurs with a state of confusion - in terms of the world or themselves. Then a good

possible intervention is to create an anti-crisis plan (preliminary declarations / powers of attorney).

The anti-crisis plan is prepared by the person himself/herself with the support of a trained professional (facilitator). In the plan the person expresses his/her will; it is possible for him/her alone to limit his/her own autonomy by giving this power to the **trustees**, selected by him/her, to make certain decisions at a particular critical time for the person.

The Plan contains:

- guidelines on and requirements for the process of decision-making in periods when the person has reduced capacity;
- who are the trustee/s and the range of issues on which they can make decisions;
- what the person wants to happen if a "triggering" event occurs;
- how to identify this "triggering" event;
- when and how power is restored to the person.

This measure has been very successful in people with mental illness or suffering from degenerative neurological disorders (such as dementia). For them the measure SDM is a "safeguard" measure so that someone may not substitute their will, without being empowered to do so, in case something happens to them that is against their will and, above all an instrument in difficult time for them when their idea about the world is totally different from what they actually know, their best wishes and preferences to be respected by the guarantees of the persons (trustees) chosen by them. Important for the success of the anti-crisis plan is the person to be in a state of remission at the time of its creation so that he/she is able to understand the consequences provided for therein. In this sense, it is necessary to provide sufficient time for its preparation so that it can be tested and, if necessary, revised.

## 6) SDM through support networks

*When the person cannot cover the 4 elements test regardless of the social interventions SDM is applied as support networks of trustees individuals:*

This is a process in which support networks (consisting usually of two to four/five people) help adult people with intellectual disabilities or mental health problems in planning their future life in the community and making decisions about their personal life, health and finance/property. The supported person chooses himself/herself the people important to him who will help him/her to include in his/her network family members, friends and advocates whom he/she believes.

Too often when we make decisions we seek the support of other people close to us - and it is because they know us and want to help us. And we also do not always choose the same people to help us – very often we use different people to help us with different things. In this sense, we must bear in mind that support networks can be dynamic and follow the natural development of the person's relationship with his/her circle.

**In order the measure to start the person must have at least one (trusted) a person who knows and can give the best interpretation (understanding) of his will, according to the specific circumstances and context.**

### ***Who is involved in the process of building support networks?***

#### ***Supported person:***

This is the person who is at the center of the process of decision making support. For the purposes of this project, a supported person is an individual who at risk or in a situation where someone else makes decision for them, regardless of their ability.

#### ***Support persons:***

Requirements to the people within the network (**support persons**) – empathize with the person, respect them and be trusted by them.

The people within the network are not professional support persons (and they do not get paid for what they do). The network can be dynamic and include different people at different points.

The support person should simultaneously:

- Have a proven trust relationship with the supported person;
- Be able to understand 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 their will and preferences and provides decision making support based on this interpretation.

#### ***Facilitator***

The facilitator has to:

1. to assist the person in preparing his/her personal profile and in building a network;
2. be "socially intelligent" i.e. to have the capacity to negotiate (to mediate the creation) effectively for the creation of complex social relationships and interactions.

The facilitator should help the person to develop his own support network. The person chooses himself/herself the people from the network and the facilitator assists him/her in this process. The facilitator may be tempted to choose the people from the support network or to build the relations between them and the supported person, but this is not part of his/her obligations.

#### ***Some key principles for SDM as a support network:***

- Ensuring the person's right to choice, respecting the person and his/her decisions, including who are the people they want to support them;
- Build a trust relationship between the person and their supporters;
- Voluntary participation of all involved in the support network;
- On the basis of a personality profile produced jointly with the person and founded on the functioning of the supported person the facilitator initially organizes the network, takes care of its stability over time and enhances the processes in it;
- Overcoming potential conflict of interest.



SDM through support networks is the most innovative measure, since on the one hand the person fails to cover the four elements test regardless of the social interventions that he/she is provided with, but at the same time he/she retains the power to make decisions and they to be respected. This form is a real recognition for all people that the supported person can make decisions which have consequences valid for all. SDM through networks is extremely successful in people with intellectual disabilities because for them it is a real tool for social inclusion - to be a complete and crucial part of society.

### 7) Procedure for crisis facilitation

One exception - when the following 3 conditions are present:

- there is urgency;
- there is no established support network;
- the person is in a condition which makes it difficult to communicate alone his/her own will and preferences.

The purpose is *to create an individual council* which to make specific decisions about the person. This can begin only after all other measures for supported decision making have been exhausted, but there is no result and if at least one more of the following conditions exists:

- there is an objective risk of imminent serious loss of property or an imminent risk of serious or irreversible harm to the life and health of the person or a person close to him/her (“*Serious advert affects*”);
- when the person is expressing preferences at some point, but these preferences are very much at odds with a previous will (with preliminary measures for SDM).

The procedure for crisis facilitation is applied only for the decision on the following issues:

1. choosing where the person will live, in view of the conditions and circumstances described above;
2. disposal of movable or immovable property of a certain value or
3. choosing emergency treatment.

The main task of facilitator in this case is to organize the activities of the individual council. The individual council in turn should include:

- persons who have participated in previous measures for support of the person *and/*
- persons specified in previous directions or otherwise recognized as important to the supported person, *as well as*

- persons associated with institutions which could help solve specific problems of the person with in view of the occurred situation *and*
- the person himself/herself- at the earliest possible stage.

Representatives of civil, advocacy and human rights organizations, independent members of society with active citizenship, as well as stakeholders (neighbors, representatives of condominiums, etc.) can be invited in the individual council. The role of these representatives will be both to help the gathering of information about the circumstances around the person and to ensure there is no conflict of interest or risk of violation of rights.

The facilitator observes and monitors how those involved in the council act in view of/interpret the best wishes of the person in the particular circumstances and in the specific context conforming to the following mandatory criteria:

- the interpretation is not based only on the external behavior and the condition of the person;
- all relevant circumstances are taken into account;
- all necessary efforts are made so that the person alone to make the decision;
- the circumstances related to the maintenance healthcare therapy are specifically discussed;
- past and present wishes, feelings, beliefs and values of the person are taken into consideration;
- the views of those close to the person are discussed and taken into account

The individual council makes the following decisions:

- supportive: they do not generate immediate legal consequences and are associated with providing the necessary support to the person.
- restrictive: they generate immediate legal consequences (for example – restrict a specific right of the individual to whom the measure is administered);
- administrative: only in certain cases specified by the law *where the goal is* the immediate protection from direct harm of the life, health and property of the person.

### **Safeguards**

Each measure for SDM must ensure that there is no "cover up" replacement of the will of the person and denial of the possibility to make decisions alone.

#### **General safeguards:**

➡ **Proportionality**: the support should be provided in line with the specific case and person's condition and in the necessary quantity (only for the specific decision). All other legal actions should be deemed independently performed by the person.

#### ➡ **Respecting the wishes, preferences and values of the person**

The supporting measures for decision making should necessarily be implemented and applied in compliance with the will and preferences of the person. At all times and obligatory, the will and preferences of the person are examined as the first condition. Inability of self-expression of the will and preferences in the usual way is not a prerequisite to disregard them and opportunity should be provided for them to be communicated.

➡ **Prevention of conflict of interest and undue influence**: when identifying a supporting person and implementing SDM measures, the avoidance of conflict of interest (third party benefit is not

beneficial for the person) and illegal influence (manipulating the supported person to make detrimental decisions or perform actions detrimental to the person's interests) should be ensured.

#### ➔ **SDM does not apply to the exercise of the so-called personal rights**

The personal rights cannot be restricted as a result of the support measures in any way. They are related to the personality and its identity and unique experiences - private life, freedom of conscience, religion, and participation in public life and therefore depend on the discretion of their holder. These include the right to marriage and family, reproductive rights, the right of testation, right of association, right to vote.

#### ➔ **Evaluation of decision-making capacity**

The evaluation should be deployed to understand what the functionality of the person in different areas is and it is important in the process of its preparation to involve people (not professionals) who know the person and are close to him/her.

The evaluation is done by the provider of the SDM during the preparation of the personal profile by the person himself supported by a facilitator. If necessary, other specialists (psychologist, speech therapist, psychiatrist) or a person who works or is otherwise close to the person with an intellectual disability or a mental health problem and know his/her habits, modes of communication and decision making and expression of preferences are included. The personal profile is drawn by examining how the person functions not only on the basis of a medically diagnoses.

#### ➔ **Flexibility**

Whenever the capacity of the person is changed the interventions should also be changed. They have to follow the dynamics of change in the person's condition.

#### ➔ **Participation of the person**

The involvement of the supported person at any stage should be guaranteed, which means to participate personally and express will. Advocacy opportunities must be provided for a definite circle of people (those close to the person, professionals who work with the person, including civic organizations whose activities are related to people with disabilities and / or protect their rights and interests).

### ***Communication***

Communication is an important factor in efficient support and decision making support in particular. Communication is a bilateral process – one person sends a message and another person is supposed to understand and receive it. If we want to be able to create a concrete communication channel, we may have to support the communication with words, using objects, photos, drawings, symbols or signs. To be successful, we need to focus on the person and know which method or combination of methods suits the concrete person best.

The facts show that the use of alternative and augmentative communication results in improved behavior and emotional status, improved speech, expression, comprehension and social communication (ASHA, 2006). The usage of alternative and augmentative communication leads to increased independence and involvement in everyday life. It enhances learning and education capacities, provides multisensory development and makes language more specific and hence easier to understand.

*Alternative:* a system used to replace speech.

*Augmentative:* a system used in addition to speech.

The range of alternative and augmentative communication is wide and every person needs to be assessed in order to find out which system would suit them best. Alternative and augmentative communication needs to support the communication system used by the person or suggest a new one.

There are different types of systems:

- Unaided: gestures, facial expression
- Aided: additional equipment is needed in this case; for example – pictures, computers or special communication assistance.

**What do we need to keep in mind when choosing the system?**

- The person's and family's will needs to be prioritized
- The person's development and how this can support the communication system
- The environment in which the system will be used
- How easy will it be for communication partners to comprehend the system
- The system's price
- The system's flexibility to meet the person's needs

**Think of the fastest and most effective way of communication for the person.**

## SUPPORTED DECISION MAKING ALGORITHM (PILOT PROJECTS)



### *Stage 1*

#### **Selection and Involvement of Individual Persons in the Project**

This stage contains the following steps:

1. define the criteria for involvement of individual persons (type and degree of intellectual/mental disability, residence in the community or in a resident service, availability of a family and other important circumstances relevant to the person's decision making capacity and their independent functioning) and identify concrete participants;
2. as to (fully or partly) incapacitated persons proposed to participate in the project according to the approved criteria, information should be collected if there are assigned guardians and these should be contacted; regardless of the fact that the UN Convention on the Rights of Persons with Disabilities was ratified by Bulgaria, the guardianship regime is still part of the active regulatory framework and therefore it is important to ensure guardians' assistance (as much as possible) for signing the necessary documents by the persons in order to prevent future problems in this area;
3. present an easy to read project participation consent form including pictograms, if necessary, for communication purposes to the persons to be supported; organize the signing of the forms;
4. draft a framework agreement/memorandum between the project implementing organization and the person to be supported on the set objectives, main activities to be implemented, their relationships and rights in relation to confidentiality, personal data protection, preliminary approval of project documentation and project results materials and other issues of key significance.

### *Stage 2*

#### **Selection of Facilitators**

This stage includes steps as follows:

1. clearly identify and formulate facilitators' obligations
2. identify persons to act as facilitators
3. draft a job description
4. sign a contract with the facilitator specifying relations, compensation, rights and obligations in

relation to the activities for support network establishment, confidentiality and non-disclosure of *information* about supported persons, compliance with Bulgarian legislation standards for personal data protection

5. inform facilitators about project activities including support to project participants with intellectual or mental disabilities, create a network of support persons to facilitate their active and independent participation in public life

6. the project implementing organization should ensure that, in his/her work, the facilitator will be guided by an individual approach based on respect for the disabled person's will, needs and abilities in order to support the process of self-identification and liberation from dependence. These facilitator work standards should be incorporated in the contract to be signed and their job description. Facilitator's obligations related to participation in training, team meetings, supervision, intervention, etc. also need to be envisaged conduct training of facilitators.

7. Training of facilitators.

### **Stage 3**

#### **Evaluation of the person's capacity for independent decision-making**

A) Evaluation within the SDM for people with intellectual disabilities is ensured by the SDM provider during the preparation of the personal profile by the person himself supported by a facilitator. If necessary, a psychologist, a speech therapist, a person who works with or is otherwise close to the person with an intellectual disability or autistic problems and knows his/her habits, modes of communication and decision making and expression of preferences is included.

B) Evaluation within the SDM for people with mental health problems seeks the answers to the following questions:

- General information about the client and his/her environment;
- The areas or situations in life in which the person finds it difficult to make a decision;
- The areas or situations in life in the past in which the person found it difficult to make a decision;
- The attitudes of the person to these areas or situations (does he/she find it is good to get support in this process);
- The person's resources;
- The attitudes of the environment to these difficulties of the person in the process of decision making;
- The resources of the environment;
- How can we get in touch with that person and people from his circle, whom he indicated.

The evaluation is conducted by the facilitator and the person together and if necessary, other specialists such as psychiatrists, psychologist (to assess functionality in different areas), and social worker may be included. Outside those experts it is well to include in the team a person who works or is otherwise close to the person with a mental health problem and knows his habits, modes of communication and decision making, and how he/she expresses his/her preferences. A fiduciary relationship (relationship of trust and acceptance) is necessary to exist between the person with intellectual disabilities or mental health problems and the person who knows him/her. It is therefore important to have in the team a person with whom there is an established relationship of trust.

## **Stage 4**

### **Determining the measure for SDM**

At this stage, all available information about the person has been collected and together with him/her the appropriate measure for SDM is determined. It is important to note that for different people, different interventions can be appropriate. They are provided according to the specific needs of the person, and they are also based on his/her will.

#### **A) Establishment of the Support Network – Identification of Potential Support Persons for the Individuals Involved in the Project – steps:**

1. with the assistance of a facilitator, the individual participating in the project identifies the people who are important to them and with whom they have a relationship of trust. The facilitator's role is to support the identification of support persons and the establishment of the support network. As a rule, the facilitator should not participate in the support network. Exceptions are possible in cases of hypotheses when there are no other possibilities for identification of support persons and for a certain period of time during which the supported person can create relationships of trust with other people
2. when potential support persons are identified only among the staff or family of the person to be supported, the establishment of the network may start with their involvement and gradually expand by involving other people
3. organize regular meetings of the supported person, support persons and the facilitator.

The support network: once established, the functions can be distributed – one support person is responsible for the bank, another has other functions, but the facilitator continues to support the whole network.

#### **Development of a Personal Plan**

This includes steps as follows:

1. organize a meeting with the supported person, identified support persons and the facilitator
2. develop a personal plan by the supported person with the assistance of the support persons and the facilitator where the supported person should identify their dreams and objectives; short-term and long-term objectives; realistic and unrealistic objectives; whose support they can rely on when implementing individual activities and objectives; which community players (administrative bodies, business representatives, etc.) will be addressed to accomplish this vision
3. organize regular meetings of the supported person, the support persons and the facilitator.

The active role is in the beginning – the first six months, after those contacts are maintained once a month; for the planning – weekly meetings with the network to develop the plan and start implementing it.

#### **Implementation of the Personal Plan**

This includes steps as follows:

1. the supported person, with the assistance of network people, implements the activities related to the accomplishment of their personal plan objectives by independently undertaking legal actions in line with their will, choice and preferences
2. organize regular meetings of the supported person, the support persons and the facilitator
3. discuss and summarize the effect of this implementation on the supported person's quality of life
4. document project activities with materials, photographs, video camera, etc.

- B) Development of an anti-crisis plan with the person (see above)
- C) Procedure for crisis facilitation (see above)

One of the most serious challenges will be the initial involvement of individuals in the project. Some examples of resolutions include as follows:

#### 1. Rose who lives in a residential service

Problems: these people often do not have relatives or friends who are important to them or can support them and often are disconnected with their families or are disinterested in maintaining these connections.

The existence of a network of self-advocates here would be a major advantage. A group of people from this network could visit the person at the institution. It would be good if this group includes previously institutionalized people currently living in the community. In addition, it is also important for the group to include a facilitator who will give them support and certainty during this visit – in relation to both ongoing processes and their unimpeded exit of the institution. When a group of self-advocates visits institutionalized people, it can have a stronger impact on them and help them identify themselves. After the visit, the emotions provoked in each participant can be processed within the group.

#### 2. Yavor who lives in a family

They meet simultaneously with the person and the family, they ask them where they would like to meet; the aim is to tell about the person's destiny and most of all have him tell his story; the aim is to identify key people, next they will ask for their opinion, look for other relatives or friends he says are important and will contact them.

Another possible option is for the facilitator to support the family to invite the people who are not part of the family.

#### 3. Trendafil who lives alone

A contact with the Social Assistance Directorate can be made – they can talk to the person and ask them if they want to be contacted, we can also ask the person; it would be good if self-advocates go there; neighbor volunteers may get involved – the facilitator contacts them (as a first step) and then they work on expansion.

#### 4. Lilia who lives in a family but their relationships are tense

Resistance from the family, they are very likely that they do not allow team members in, resistance from the person themselves because of the bad relations; no outside contacts; an established traumatic dependence between the person and the family and it will be terminated; a deal should be offered – one team which will work with the person and another team should be set up for interaction with the family; the intervention should be launched simultaneously; the organization of relatives can be involved in order to help; one facilitator; this will be the most difficult case; contacts outside the family will be looked for; if she accesses a service, it is a good sign because it means that we already have a kind of a network; for the family – supported decision making too.

## INFORMATION COLLECTION MECHANISM

*Procedures for collection, processing and storage of information about persons participating in the pilot projects*

### ***Procedure 1***

#### **Compile a record for each person with intellectual disability or mental health problem who has agreed to participate in the project**

This procedure includes steps as follows:

- provide to the person the respective project participation consent form; ensure their consent through signature or other alternative methods, including the collection of declarations for inclusion in the program from persons who are identified as supporters.
- provide and sign a contract/framework agreement for project participation and documentation of project results
- collect the necessary information about the person's lifestyle (in the community or in a specialized institution), health condition, diagnosis, history, family, social contacts and other project relevant facts. The information can be collected through questionnaire forms, interviews and other forms specified by the project implementing organization and compliant with the specifics of the target group
- compile a hard-copy and an electronic record (file) of the person containing the aforementioned documents and other data about the person of relevance to the pilot project
- archive and store the record (file) at the administration of the pilot project implementing organization and comply with all legislative requirements and internal rules for personal data collection, processing and storage
- these activities are implemented by the facilitator and (a) professional(s) identified by the Manager of the project implementing organization; only the facilitator will have access to the information.

### ***Procedure 2 (when the person does not want his/her identity to be disclosed to third parties)***

#### **Compile a mock file for each person with intellectual/mental disability who has agreed to participate in the project for the purposes of communication and documentation of project results**

This procedure aims to ensure that project results will not be communicated and documented using involved persons' real identities in order to guarantee confidentiality and personal data protection. It includes steps as follows:

- a) create an alias for each person with intellectual/mental disability who has agreed to participate in the project
- b) compile a mock file for each person using their aliases to collect and process electronic documents and data related to project implementation
- c) communicate project data and results only based on mock files and comply with the right to refer only to persons' aliases
- d) only the facilitator has access to the mock files; the facilitator is the only person who has information about the correspondence between persons' real files as per Procedure 1 and persons' mock files

Access to the real records of the persons with intellectual/mental disabilities participating in the project will be granted to the facilitator and the person in charge of personal data protection as per active legislation.

The facilitator is the only person who has information about the correspondence between persons' real files and their mock files and aliases.

Public communication and documentation of project results takes place based on persons' mock file data and aliases, unless the persons express their explicit will to be identified with their real names and histories.

The support persons do not have information about the correspondence between supported persons' mock and real files.

The support persons do not have any right to access archived files and are not authorized to make public statements or provide information about project implementation

### *Consent solicitation – option 1*

To solicit project participation consent:

1) we need to find a person with whom the person to be supported has a relationship of trust who should support them make the choices below

2) what should consent cover – agree to participate in a new planning process, build a vision, communicate the vision to the facilitator, take part in studies, the issue of public communication is important (movies, the Consultative Council), interviews.

Support network members also need to grant their consent.

### ***Challenging cases:***

- for example, severe mental retardation which makes it difficult for the person to communicate their will – Lila is unable to communicate in any other way but through her mother and sister, the facilitator contacts the mother and the sister, talks to both of them, asks certain questions about what would be more important for Lilia; knowledge is gained based on the telling of specific experience; the facilitator assesses if this is an adequate interpretation of will;
- when the person has a severe mental crisis and is unable to give informed consent to be included in SDM it is best to wait and not make any decision until the crisis passes. Meanwhile, it is good to examine whether the person uses social or health services that support him/her to overcome the crisis.
- as a result of a history of documented abuse, and sometimes because of distinctive paranoid symptoms a strong distrust of signing any documents may be strongly manifested in people with mental health problems. In such cases it is necessary to invest enough time to build a relationship of trust between the facilitator and the person, and only then to proceed to the signing of the consent for inclusion in the project.
- in crisis facilitation the consent can be obtained only at a later stage, when the crisis event is under control and the person is able to make decisions regarding the inclusion in the SDM.

*Cases like stories*

**Person's name and age:**

**Verification code:**

**Brief background:**

Place of birth, diagnosis, places of previous and current residence, education, professional qualification, employment, past and current occupations

**Family relationships:**

**Incapacitation and ability circumstances:**

**Problems:**

**Solutions:**

**Task distribution and timeframe:**

**Documents and materials:**

# PILOT PROJECT FOR SUPPORTED DECISION MAKING FOR PEOPLE WITH INTELLECTUAL DISABILITIES

## (“EMPOWERING PEOPLE WITH INTELLECTUAL DISABILITIES” PROJECT)



### **Step by step toward supported decision making by people with intellectual disabilities and/or autistic spectrum disorders**

1. Establish two management committees from BAPID local branch offices (Sofia – Autism Association; Vidin – RSSPID) and development and implementation of pilot local projects
2. Select and hire facilitators – two for Vidin and Sofia each
3. Conduct training of facilitators, committee members and volunteers
4. Establish a local support council
5. Conduct information meetings for people with intellectual disabilities/autistic disorders and their families
6. Identify direct beneficiaries and develop personal profiles jointly with them
7. Build support networks for 16–20 persons with intellectual disabilities and/or autistic disorders
8. Develop personal life plans for 16 persons with intellectual disabilities and/or autistic disorders
9. Develop materials and a Guidebook to Supported Decision Making in an easy to read format.

### ***Roles of the leading local organization and selected facilitators for process launch and support***

1. Invite persons and families to participate
2. Provide information about the project to interested persons
3. Identify potential participants, participant selection process:
  - Identify the number of persons to be invited at the launch;
  - Invite persons and families to participate;
  - Meeting in person with the family and the included person;
  - Share information;
  - Those who express willingness to participate, will need to sign a participation consent form.

***From this point on the facilitator is in charge of the process***

1. Support people involved in the project develop a personal profile
2. Establish and foster support networks
3. Support the development of a personal life plan:
  - dreams
  - objectives
  - desires
  - strengths
  - needs
  - local capacity for plan implementation
  - necessary resources
  - key decisions that will need to be made

Support the networks in the implementation of personal plans

**Personal life plan design and development steps**

***Step 1. Organize a first meeting:***

- Done by the participant
- Done with the support of the facilitator

Build relationships of trust between them. The facilitator talks to the planning person and probably to his family and/or other people they live with or take care of them at the residential social service facility.

***Step 2. Develop a personal profile:***

The process is supported by the facilitator. It takes place during several meetings. The meeting venue is determined by the person.

A comprehensive list of life areas is composed – place of residence, education, labor, health, property, free time. It is composed by the planning person with the support of the facilitator. Its preliminary composition guarantees that the person has control over its content and is actively involved in its composition. This will make it possible for them to present the things that are important for them at the first meeting.

It is advisable to develop the profile based on the person's key life areas – at home, school, job, free time; personal history – life milestones, changes, health issues, nice experiences, sad memories; relationships – people they spend most time with during the day, people they love but do not see often, friends, supporters, people they turn to for help and advice; emotional needs – what they do, what they like, what they dislike. Success is contingent on participants' personal empathy.

***Step 3. Organize a planning meeting:***

The planning person, the facilitator and the family and/or other people they live with or take care of them at the residential social service facility determine collectively who will be invited to the first

meeting, when and where. The important people and the place are selected by the person. The time of the meeting is also important. The facilitator should be ready to schedule the meeting even outside working hours or on weekends.

The invitation can be submitted in writing or on the phone. The invitation should be always on behalf of the person and, if possible, he/she should hand it in person.

#### ***Step 4. Building a vision of the future:***

Summarize and synthesize profile information.

At the first planned meeting, the person describes how they see the future: where they will live, with whom they want to live, where they want to work, where and who they want to spend their free time with, what places they want to visit, whose help he would like to have and with what, etc.

**Important question: Reality and vision of the future?** – some space needs to be opened so that the person can express their dreams, and broad and inspiring vision can be built later on.

The support network, together with the person, looks for new opportunities to enable them to test a part of the vision in conformity with their skills, abilities and preferences.

#### ***Step 5. Follow-up meetings for action plan development:***

The personal life plan is the engine for changing the person's life. Not all planned activities can be implemented as envisaged, but at following meetings they can be streamlined and modified. Not all support network participants stay the same, some changes can be expected there too. Dealing with bureaucratic institutions may be impossible without support and assistance from many people outside the network – the local support council, parents' organization, self-advocacy organization. How many life areas and long-term objectives need to be included in the plan is a strictly individual matter. Following the development of the personal profile and the organization of the first two or three meetings of the support network, the facilitator's role transforms from someone "leading" to someone "coordinating" the process and tracking the progress. To track the progress, another network member can also be involved based on the person's preference.

It is important that the "planning group" really becomes a "support network" and meetings take place whenever the person needs support to make a decision or perform an action that is difficult for them from a life point of view.

Once actual results from planning are seen, this prepares the ground for new activities related to new objectives.

The aim is, with time, to make the informal resources of the support network more diverse and its members, together with the planning person, realize the power of the process and the opportunities and rights it gives to the disabled person.

# ANNEXES

## ANNEX 1

### CONSENT FORM FOR PARTICIPATION IN A SUPPORTED DECISION MAKING PILOT PROJECT (name of the GIP/BAPID project)

I, the undersigned....., Personal ID No....., address....., acting with the consent of the guardian....., Personal ID No....., hereby agree to



participate as a supported person in a pilot project for supported decision making aiming to establish a network to support me in the decision making process in my day-to-day life, by respecting my preferences and personal choices and my right to exercise my rights through personal actions.



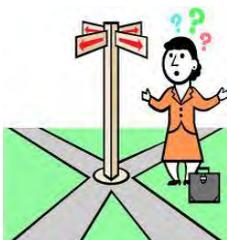
I hereby agree to take part in project stages as follows:



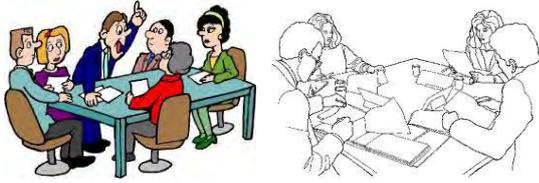
Identification of the circle of persons in the community whom I trust, are important to me and who could take part in my support network. In case no such persons are available, I hereby agree to be supported, with the cooperation of the facilitator, in establishing such relationships of trust.



Participation in the process of development of my personal plan, with the cooperation of the identified support persons, in order to formulate a vision on what I would like to and could achieve, (identification of realistic short-term and long-term objectives with the involvement of which support persons), formulation of difficult moments and challenges and development of coping strategies.



Maintenance of a contact and communication with the facilitator and participation in procedures and meetings organized by the facilitator.



Participation in project related research on possible approaches and measures for implementing supported decision making and the actual impact of supported decision making on the quality of my life.

1. Documentation of project stages and results through:

camera recording	NO	YES
		
participation in interviews	NO	YES
		
presentation of results and information on	NO	YES
		
my participation before individual councils set up under the project photographs	NO	YES
 		

2. Use of my personal data in view of implementing project activities and in line with Bulgarian legislation.

3. Public communication of project results.

The in-principle consent for documentation granted herein may be withdrawn by me, at my own discretion, after receiving information about specific documentation related materials.

I hereby agree that the overall summarized experience in relation to my personal involvement in the project can be used for motivating future changes in Bulgarian legislation in relation to the adoption of supported decision making and amending the regimes of guardianship in order to ensure the adequate enforcement of Art.12 of the UN Convention on the Rights of Persons with Disabilities.



Regardless of the fact that the person ..... is incapacitated and in line with Art.12 of the UN Convention on the Rights of Persons with Disabilities, prior to putting my signature as a guardian as per active Bulgarian legislation, this consent form was presented to ..... (supported person) in an accessible and easy-to-read format and I hereby confirm that the participation of the person ..... in the project complies with his/her desire and choice, thereby supported by me.

An easy-to-read format version is an inseparable part of this consent form.

Date.....

Signature:

1.....(supported person)



2.....(guardian)



Note: In case the person, due to a disability, is unable to sign the form, his/her volition will be certified through a right hand thumb mark and the signatures of two witnesses with disclosed identities.

**CONSENT FORM FOR PARTICIPATION IN A SUPPORTED DECISION MAKING PILOT PROJECT (name of project and organization Pilot Project *BAPID*)**

I, the undersigned....., Personal ID No....., address....., hereby agree to participate as a support person in a pilot project for supported decision making aiming to establish a network to support ..... (supported person), who is a ..... of mine in the decision making process in his/her day-to-day life, by respecting his/her preferences and personal choices, his/her right to exercise their rights through personal actions and act in their best interest.

I hereby agree to take part in project stages as follows:

- Identification of other persons who could get involved in the support network of .....
- Participation in the process of development of a personal plan of the supported person whose network I make part of, with the cooperation of the other identified support persons and the facilitator in order to formulate a vision on what the person would like to and could achieve, (identification of realistic short-term and long-term objectives with the involvement of which support persons), formulation of difficult moments and challenges and development of coping strategies;
- Maintenance of a contact and communication with the facilitator and participation in procedures and meetings organized by the facilitator;
- Participation in the work of the various councils established under the project, if necessary;
- Sharing of experience;
- Participation in project related research on possible approaches and measures for implementing supported decision making and the actual impact of supported decision making on the quality of disabled peoples' lives;
- Documentation of project stages and results through:

camera recording:	NO	YES
participation in interviews:	NO	YES
presentation of results and information on my participation before individual councils set up under the project:	NO	YES
photographs:	NO	YES

- Public communication of project results.

The in-principle consent for documentation granted herein may be withdrawn by me, at my own discretion, after receiving information about specific documentation related materials.

I hereby agree that the overall summarized experience in relation to my personal involvement in the project can be used for motivating future changes in Bulgarian legislation in relation to the adoption of supported decision making and amending the regimes of guardianship in order to ensure the adequate enforcement of Art.12 of the UN Convention on the Rights of Persons with Disabilities.

Date.....

Signature:

Note: In case the person, due to a disability, is unable to sign the form, his/her volition will be certified through a right hand thumb mark and the signatures of two witnesses with disclosed identities.

**CONSENT FORM FOR PARTICIPATION IN A SUPPORTED DECISION MAKING PILOT PROJECT (name of project and organization Pilot Project *BAPID*)**

I, the undersigned....., Personal ID No....., address....., hereby agree to participate as a supported person in a pilot project for supported decision making aiming to establish a network to support me in the decision making process in my day-to-day life, by respecting my preferences and personal choices and my right to exercise my rights through personal actions.

I hereby agree to take part in project stages as follows:

- Identification of the circle of persons in the community whom I trust, are important to me and who could take part in my support network. In case no such persons are available, I hereby agree to be supported, with the cooperation of the facilitator, in establishing such relationships of trust.
- Participation in the process of development of my personal plan, with the cooperation of the identified support persons, in order to formulate a vision on what I would like to and could achieve, (identification of realistic short-term and long-term objectives with the involvement of which support persons), formulation of difficult moments and challenges and development of coping strategies.
- Maintenance of a contact and communication with the facilitator and participation in procedures and meetings organized by the facilitator.
- Participation in project related research on possible approaches and measures for implementing supported decision making and the actual impact of supported decision making on the quality of my life.
- Documentation of project stages and results through:

camera recording:	NO	YES
participation in interviews:	NO	YES
presentation of results and information on my participation before individual councils set up under the project:	NO	YES
photographs:	NO	YES

- Use of my personal data in view of implementing project activities and in line with Bulgarian legislation.
- Public communication of project results.

The in-principle consent for documentation granted herein may be withdrawn by me, at my own discretion, after receiving information about specific documentation related materials.

I hereby agree that the overall summarized experience in relation to my personal involvement in the project can be used for motivating future changes in Bulgarian legislation in relation to the adoption of supported decision making and amending the regimes of guardianship in order to ensure the adequate enforcement of Art.12 of the UN Convention on the Rights of Persons with Disabilities.

An easy-to-read format version is an inseparable part of this consent form.

Date..... Signature:

Note: In case the person, due to a disability, is unable to sign the form, his/her volition will be certified through a right hand thumb mark and the signatures of two witnesses with disclosed identities.

## ANNEX 2: QUESTIONS THROUGH WHICH THE FACILITATOR CAN ASSIST THE PLANNING PERSON IN PERSONAL PROFILE DEVELOPMENT

### (Option 1)

(This questionnaire could help identify the planning person's socially significant people)



1. Where do you live?



2. Who do you live with?



3. Which of these people do you do anything with?

- talking;



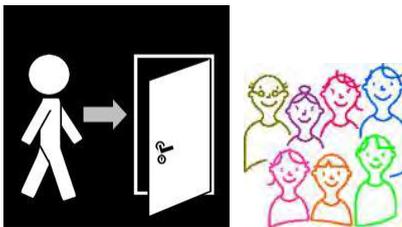
- cooking;



- getting help (in cooking, eating, showering.....);



- walking; **going out**.....



- Who do you help at home (at the protected house, at the institution.....)?
- How do you like helping?
- What do you do to help?
- Who do you like spending your free time with?
- What do you do after you go back from the DC, from work, from school?
- Who do you do it with?
- What do you do in your free time? (drawing, singing, dancing, walking, watching TV, going out for a coffee, etc.?)



- What do you do on weekends? With whom?

- Over the past month, have you:

- been visiting anyone (On your own? With someone else? With whom?)



- gone out for a coffee (On your own? With someone else? With whom?)



- been to the cinema (On your own? With someone else? With whom?)



- done some sport (On your own? With someone else? With whom?)



- been to a hospital, medical center (On your own? With someone else? With whom?)



- been to the bank (On your own? With someone else? With whom?)



- gone to the ATM (On your own? With someone else? With whom?)



- been to a shop (On your own? With someone else? With whom?)



13. Which of the above people do you like talking to? (if people with whom they do things are specified)

14. Which of them do you trust? (Who do you think protects you from bad experiences?)



15. Have you invited anyone to come visit you? Who?

16. Has he/she come for a visit?

17. Who do you talk on the phone with? If more than one, please list all of them.



18. Do you meet groups of people outside your home? (outside the DC, PH or other social service)?



19. Which of your belongings do you like and value the most (watch/clock, telephone, computer, ring, favorite toy, etc.....)?



20. In whose charge would you leave them?

21. Do you have a boyfriend/girlfriend? What is his/her name?



22. If you need someone to help you (take you somewhere, fix you something broken), who do you go to? Who helps you...?

23. Whose advice would you seek – on a haircut, an enrollment in a course, a choice of a social service, buying something? Whom would you ask?



## QUESTIONS THROUGH WHICH THE FACILITATOR CAN ASSIST THE PLANNING PERSON IN PERSONAL PROFILE DEVELOPMENT

### (Option 2)

(Suitable for a second meeting for personal profile development)

1. What do you imagine you want to do next year?



2. Which of the things you do currently would you like to change? (Currently you do ... this, this and that.....)

3. What would you prefer doing for a living? What do you want to do for a living?



4. Where do you want to live? With whom? Now you are living with ..... Is there any other place that you like better? Or any other people you like living with better?

5. What kind of a home do you prefer? (currently living in an apartment, a house, in a city, in a village.....)



6. What do you like doing the best?

7. What other knowledge do you need to be able to do what you want? What do you think you should learn to work as a car mechanic?

(We specify the job and for every job chosen by the young person we have a set of visual aids – pictures including all characteristic activities, tools, typical clothing, etc. for each job)

8. Do you need any special help to be able to do what you like?

9. Do you want me to read, tell, explain, show you online, and take you to a place where other people do this?

10. Is there anything in particular that you think impedes you from doing the things you like?

**QUESTIONS THROUGH WHICH THE FACILITATOR CAN ASSIST THE PLANNING PERSON IN PERSONAL PROFILE DEVELOPMENT**

**(Option 3)**

**Let's prepare my personal profile**



**Name**



**Where do I live and who do I live with?**



**Phone number**



**Email**



**Date of birth**



**What do I like doing in my free time:**

- interests -


- hobby - (walks, listening to music, watching movies .....)



**Past and/or current jobs**

**(labor activities I am involved in – at the Day Center; CRSI.....):**



**Milestones  
of my life:**



**Nice experiences:**



**Sad memories:**



**Who are the people helping me:**

- **At home (wash, cook, clean.....):**



- **Going to work or to the DC, CRSI:**

- **In my free time:**



- **Other people important to me:**



- **Who do I like inviting for a visit:**

- **Who do I like go visiting:**



**I need support**



**Do you have any disabilities?**

Yes  No



**What disabilities do I have?**



**Do I need any support during training?**

Yes  No

**What kind of support?**

**Do I need any support at work?**

Yes  No

**What kind of support?**

**Do I need any support during shopping?**

Yes  No

**What kind of support?**

**Do I need any support when I am at home?**

Yes No

**What kind of support?**

**Let's write about what I want to do:**



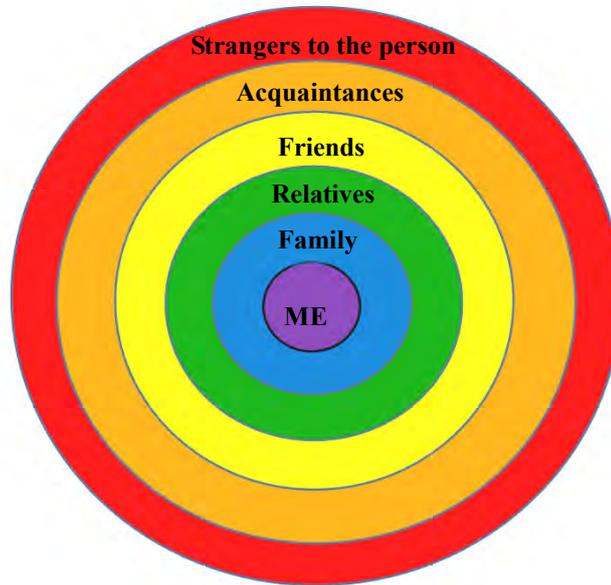
## QUESTIONNAIRE

for selection of volunteers to take part in project “.....”

1. Name, surname, family name.....
2. Address:.....
3. Phone:.....
4. Email:.....
- .....
5. Age:.....
6. Family status:.....
7. Education, subject:.....
8. Where do you currently work/study?.....
9. Have you participated in volunteer campaigns?.....
10. Do you have any experience in working with disabled people?.....
  - Yes (specify).....
  - No
11. Do you have any disabled relatives/friends?.....
12. What motivates you to take part in the project?.....
- .....
- .....
13. Would you go together with a disabled person:
  - to the cinema.....
  - to the theater.....
  - to have a coffee.....
  - to a walk in the park.....
  - to a concert.....
  - to a sports event.....
  - to any other place (specify).....
14. Would you invite a disabled person to visit your home? Would your family accept them?.....
- .....
15. How does your day go:
  - During the week.....
  - .....
  - On weekends.....
- .....
16. What do you like doing in your free time?.....
- .....
17. How much of your free time would you spend on the disabled person with whom you will maintain friendly relationships under the project?
  - Weekly.....
  - Monthly.....
18. When will it be the most convenient time for you to meet the disabled person?
  - On week days.....
  - On weekends.....
19. Would you continue maintaining a contact with the disabled person beyond the end of the project?.....
- .....
20. Do you have any concerns or requirements in relation to the project (specify) .....
- .....

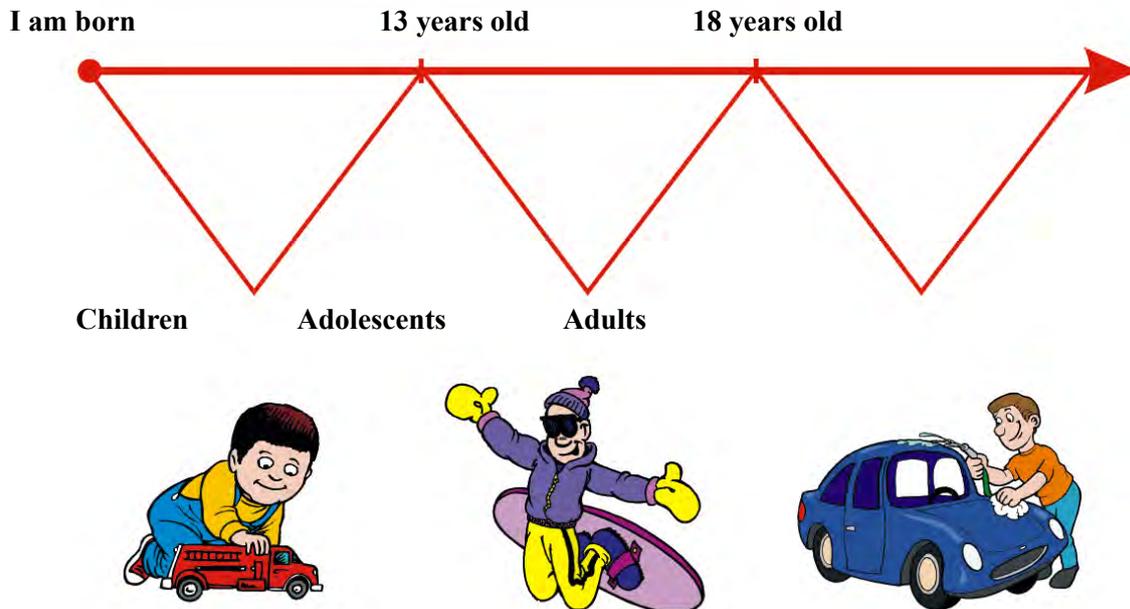
ANNEX 4

Circles for visualization of social relationships



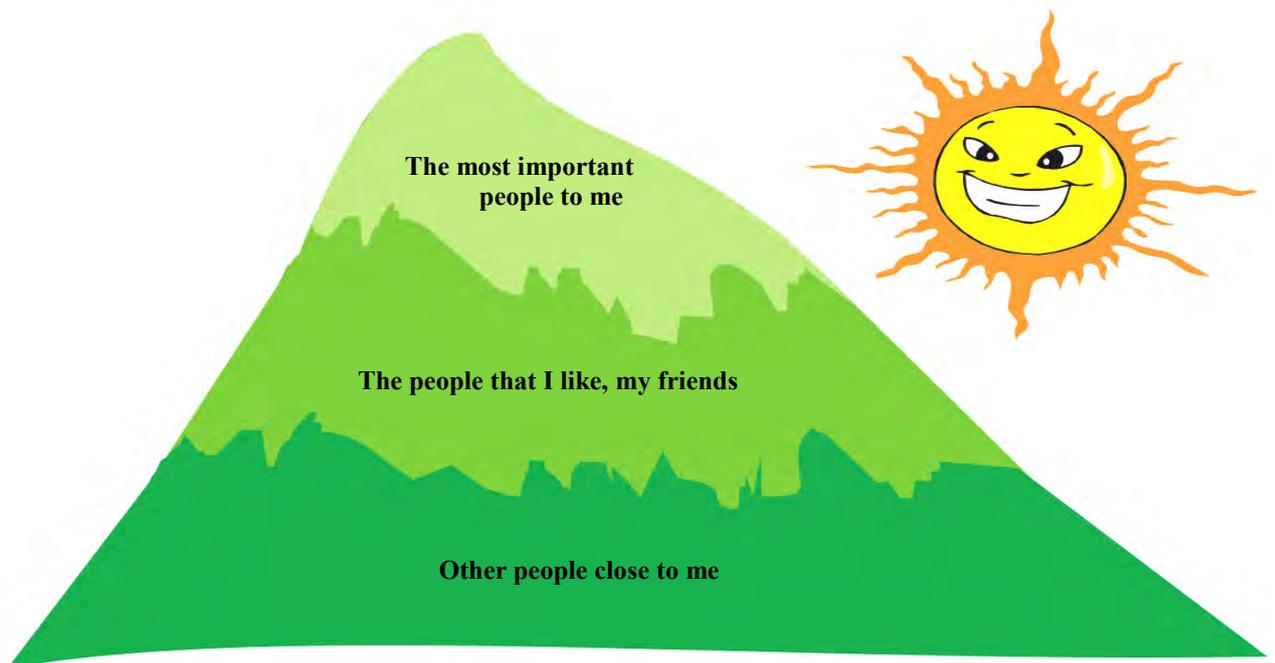
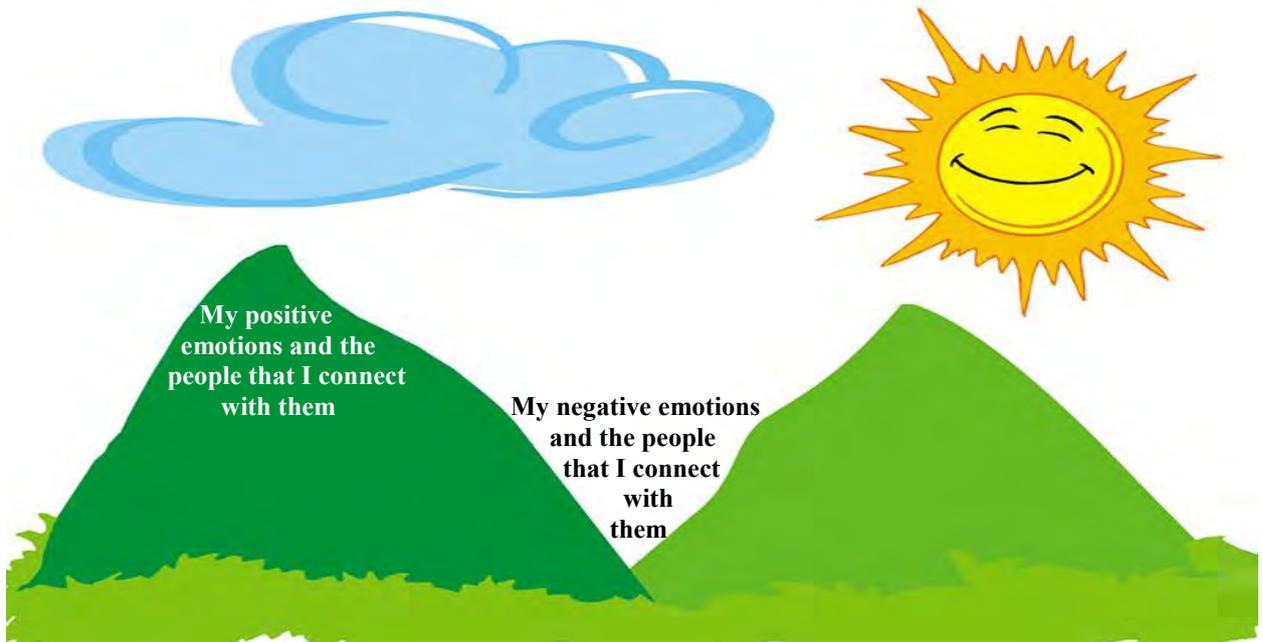
ANNEX 5

Visualization – periods in life



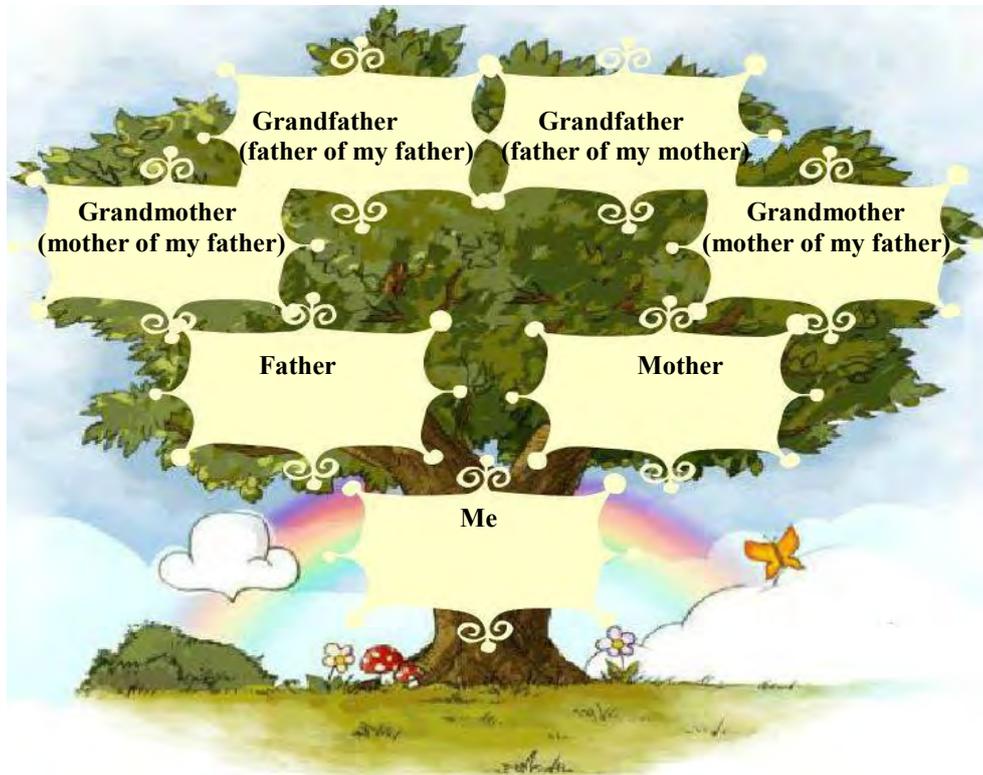
ANNEX 6

Projection of feelings and emotions



ANNEX 7

Family tree



ANNEX 8

Table about the people around me

Me			
Close friends	Acquaintances	Colleagues	People I don't like

**ANNEX 9**

**SUPPORT FOR THE SUPPORT NETWORK**

You have already understood the important things about supported decision making!

Now is the time to discuss all parts and develop the plan!

Together, we will review the framework/tool you can turn to when making decisions. The tool includes all things important to supported decision making. It will help everyone:

- Work together when a decision needs to be made
- Make sure that the person is at the center of the decision
- Feel listened to and respected
- Get used to make decisions together as we practice
- Make valuable and meaningful decisions by having EVERYONE participate.

Assume responsibility for the decision making process by having everyone sharing the responsibility.

While somewhat formal, our hope is that you will be able to use the tool for practicing decision making and starting making decisions collectively.

With time, the process you developed by utilizing the tool will improve! The constant use of the tool should lead to a process so natural and practical that the tool will no longer be needed! It all depends on practice! Think of the tool as support which will help you initiate a powerful process! It depends on the group how much time it will take for this process to become natural.

Use the tool for any kind of decisions. Practice together.

**THIS TOOL WILL:**

- Provide the support the person may need to exercise their decision making right
- Put the person rather than other people at the center of the decision making process
- Distribute the responsibility between the person and their support persons
- Promote independence
- Develop relationships and connections (communication) between the person and the people they trust.

**HERE IS YOUR TOOL FOR SUPPORTED DECISION MAKING!**

MY PLAN	Options	Pros / Cons	Risks?	Agree-ment/ Disagreement	Working together	Who, what and why?	Resour-ces and informa-tion	Let's do it!

## **WHAT SHOULD EACH SESSION INCLUDE OR DISCUSS?**

### **WHAT DECISION NEEDS TO BE MADE?**

**Put down the decisions you will discuss together in the provided space.**

#### **OPTIONS:**

Write down all possible methods which you can achieve together through brainstorming. What are some actions you can try in order to assist the achievement of the results?

During the brainstorming, everyone should keep in mind what is important for the person, what kind of person they are, how they communicate.

The more options you identify, the bigger the odds for success!

Mark each option with “1, 2, 3” or “a, b, c” for future use.

Collect information and seek advice inside and outside the group (when necessary).

#### **PROS/CONS**

Write down the pros and cons for each option (1, 2, 3 or a, b, c).

This will take time – brainstorming and then sharing your ideas based on your relationships and connections.

#### **RISKS**

Everyone uses this opportunity to express their fears or hesitations in relation to each option by weighing the pros and cons and assessing the level of risk (see the reflection circle). This is done to make sure everyone can express their concerns and share the responsibility for the risk as a member of the team.

Determine if this is a manageable risk or if there is a risk at all, consider every option. Write down all risks and all your thoughts.

#### **DISAGREEMENT/AGREEMENT?**

Having heard everything, now is the time to choose the most convenient option. Go through what you have written so far.

Determine how you are going to do that.

- Consensus
- Present the options to the planning person and have them choose which one they will try
- Other
- What happens if there is disagreement? Now that you have all the information is the time to work on disagreement.
- Now is the time to get to an action that will help everyone work on results.
- Write down how you are going to make a decision and what decision was made to show that everyone made a commitment.

#### **WORKING TOGETHER**

What does it take? How are we going to work together? Highlight the steps you will need to fill to achieve a result/decision.

#### **WHO, WHAT AND WHY?**

For each step, determine who will do what. Mention why this person was nominated (so that the same person does not do everything) to support the person in achieving a result.

Talk about why each person was nominated for a certain part of the result/decision. Write it down.

Mark a completion schedule.

Nominate a person to collect/share information upon receipt. Talk about and write down how the information will be shared.

## **RESOURCES AND INFORMATION**

Will you need additional information and resources? Put this down here. How will they be accessible?

Indicate who will collect the information starting when.

## **LET'S DO IT!**

Once all parts are in place, set them going. The choice has been made... now we are working on the decision. Encouraging words are an idea!

## **LET'S THINK TOGETHER!**

**How do things work out? Evaluate the results – see if things work out.**

**(Reasons to celebrate, challenges, successes, dilemmas, positive things are included here.)**

### **Let's think together!**

What else can we try? **Or** let's celebrate together?

Look at what happened. Is this what you want? If no, why not?

What have you tried?

What have you learned?

What are you happy about?

What are you concerned about?

## **CONSIDERATIONS and OVERVIEW**

Write these here – address your other options when you seek to try something else. Start using the tool again for the next option – start by filling in the Working Together section and move forward.

Or write down how you will celebrate your success together if things happen as planned. Celebrating your success does not only give an impetus, it also strengthens the team.

## **NEXT DECISION?**

**Use the tool again!**

**Practice together.**

Now practice using the tool. Use the sample scenario below!

### **SCENARIO**

*Ivo:* I don't want to work in the work group any more.

*Lena:* Why not? This is your job. You don't have any support at home during the day. This is a way to do what you need to. Sometimes life is not fair. Many people take up jobs they don't like.

*Ivo:* I don't want to go. I'm going back to bed. I don't feel well.

*Lena:* It's not healthy for you to spend half day in bed.

*Ivo:* But I don't want to go to the group.

*Lena:* Shall we bring your support network together so we can help?

*Ivo:* I don't want to go. There are too many people. It's too noisy. All I do is sitting in the activity room all day long. Sometimes I shred papers for recycling. I hate this job.

*Lena:* If you agree to the meeting, we can ask your support network to come and we can talk about this.

Ivo: OK.

Support network meeting:

Lena: Ivo said he did not want to work in the group any more.

Ivo: I don't like it there. It's too noisy. Too many people.

Tsvetan: But you must do something during the day. You can't just sit in your house all day long, all week long. And you don't have any staff at home to help you during the day.

Ivo: I don't want to go there anymore. I've been going for a long time.

Lena: Yes, Ivo has been attending this group for 14 years.

Tsvetan: But what are you going to do then, Ivo?

MY PLAN	Options	Pros / Cons	Risks?	Agree-ment/ Disagree-ment	Working together	Who, what and why?	Resour-ces and informa-tion	Let's do it!

### THINGS TO REMEMBER ABOUT SUPPORTED DECISION MAKING

- It is about values, relationships and process development.
- It is based on every person's right to decision making support.
- It is a lifelong process. A process which takes practice.
- It will/must develop differently for the different people.
- It can be used for all decisions.

### THINGS TO REMEMBER ABOUT SUPPORTED DECISION MAKING

The process you are going to use within your support network will change just like you change.

This process will change to fit the different abilities, skills and methods of communication. In supported decision making, if the process is consistent, there is no such thing as "bad decision". Results might be challenging, but not the decision or the process.

### THINGS TO REMEMBER ABOUT SUPPORTED DECISION MAKING

- The hardest part of the supported decision making process for your support persons is "sticking to the different".
- Supported decision making is not easy! It is a challenge for everyone committed to learning, growing and changing. Practice, work together ... and remember to celebrate!
- Together you can make great things happen!

## ANNEX 10

### TERMS OF REFERENCE AND SCOPE OF SERVICES

#### FACILITATOR OF SUPPORTED DECISION MAKING BY PEOPLE WITH INTELLECTUAL DISABILITIES AND/OR AUTISTIC PROBLEMS

##### I. GENERAL TERMS

###### 1.1. Project “Empowering People with Intellectual Challenges”

The project “Empowering People with Intellectual Challenges” aims to:

- Provide direct support to supported decision making
- Implement advocacy activities for changing attitudes and regulatory framework
- Provide effective and efficient mechanisms for supporting people with intellectual challenges so that they can exercise their rights according to their will
- Make decisions based on concrete results
- Empower people with intellectual challenges.

The project “ **Empowering People with Intellectual Challenges**” is funded by the Open Society Foundation in Switzerland and is implemented and administered by BAPID and the associations RSSPID, Vidin, and Autism Association – BAPID members.

**1.2.** The project “ **Empowering People with Intellectual Challenges**” is implemented as per the Contract between the Foundation Open Society Institute, Switzerland, and BAPID signed on 1 October 2012.

Key target groups of the project include:

- Persons with intellectual disabilities at risk of incapacitation or already incapacitated
- Persons with autistic problems at risk of incapacitation or already incapacitated.

###### **Project activities include:**

1. Develop an operational plan
2. Set up two management committees by the associations RSSPID, Vidin, and Autism Association – members of BAPID Sofia and design and implement local pilot projects
3. Select and hire facilitators – two for Vidin and Sofia each
4. Train the facilitators
5. Establish a Local Consultative Council
6. Hold information meetings for people with intellectual disabilities and/or autistic problems and their families
7. Identify direct beneficiaries and prepare personal profiles jointly with them
8. Build support networks for 16–20 persons with intellectual disabilities and/or autistic problems
9. Develop personal life plans for 16 persons with intellectual disabilities and/or autistic problems
10. Elaborate materials and a user friendly format of a supported decision making guidebook.

## II. GOAL

The goal is to support the implementation of the project “**Empowering People with Intellectual Challenges**” of BAPID by hiring a facilitator who, through organization of the supported decision making process, support to the individual support networks, informing local community about disabled people’s rights, establishment of Local Consultative Councils will create conditions for changing the attitude that people with intellectual disabilities are unable to have their own vision of their own lives and have the right to exercise their rights according to their will.

## III. SCOPE OF WORK

In line with the objectives, requirements and characteristics of activities envisaged in the project “**Empowering of People with Intellectual Challenges**”, the facilitator will:

1. Develop a schedule and a plan of activities, together with the other members of the local management committee for each activity they take part in;
2. Based on an analysis and research, as per the need, provide consultations in groups and one-on-one including through fieldwork, home visits and provision of project related training and information materials;
3. Provide information about the nature of supported decision making by people with intellectual disabilities and/or autistic problems and building a support network to implement the process – to these people, their families and friends and the community;
4. Organize the establishment of a Local Consultative Council, take part in it and support its activities by taking care of practical details;
5. Provide consultations to enhance project participants’ and their families’ knowledge and awareness of their rights and responsibilities;
6. Select program’s clients, together with the Local Management Committee;
7. Provide project participation consent forms to disabled people and their parents/ guardians;
8. Assist with the development of a personal profile by each person they are in charge of;
9. Carry out mobile work within project activities they take part in;
10. Participate in regular meetings with disabled people involved in the project, assist the formation of individual support networks;
11. Act as a liaison person for a definite number of people (3–4);
12. Take care of practical details in relation to meetings of support networks (venue, invitations, materials, etc.) in consultation with participants;
13. Conduct the first two or three meetings and participate in the development of a final version of the personal life plan;
14. Meet with the person, four months after the development of the personal life plan, to describe their attitude and feelings in relation to the implementation of the plan;
15. Ensure respect of people’s ethnic background, religious beliefs and culture in all situations;
16. Motivate and support the network to continue its meetings in cases of necessity as stated by the disabled person;
17. Provide support to support networks upon request;
18. Take part in the implementation of activities for promotion and discussion of project services, including through development of information materials about the nature of supported decision making;
19. Cooperate with the Local Management Committee throughout the project;

21. Provide technical preparation of training at the local level at the request of the project manager;
22. Take part in the development of a Guidebook to Supported Decision Making and its distribution to support networks;
23. Prepare an interim and a final report on project progress by 31 May and 30 September 2013;
24. Prepare financial reports of project funds as per Bulgarian legislation – May and September.

In the implementation of tasks, the consultant shall:

- comply with the ethical code and principles of social work with children, families and communities;
- participate in project team meetings and provide assistance;
- collect, keep and maintain documentation on the implementation of assigned tasks and the activities of support networks set up by them;
- participate in project related training organized by BAPID;
- provide support to support networks;
- signal identified risks to competent authorities and provide assistance in case work.

The conditions (premises where activities take place, office supplies, equipment, etc.) for the implementation of activities will be provided by BAPID and the respective associations in Vidin (RSSPID) and Sofia (Autism Association).

#### **IV. EXPECTED RESULTS**

1. Information materials elaborated and distributed;
2. Disabled people, their families and friends and the community informed about the objectives of supported decision making;
3. Meetings with project beneficiaries planned and held, personal profiles developed and support networks for each of them set up – at least 4 persons for a period of eight months;
4. Support networks supported (4 groups) for a period of seven months;
5. A Local Consultative Council set up;
6. Participation in a Local Management Committee;
7. Proposals for possible changes in the regulatory framework drafted.

#### **V. QUALIFICATION REQUIREMENTS AND EVALUATION BASIS**

##### **5.1. Applicants' profile**

Facilitators should meet education, competency and expertise criteria as follows:

##### **5.2. Key requirements**

- be natural persons;
- have university education – a professional bachelor's, bachelor's or humanitarian master's degree;
- have professional experience in working with people with intellectual disabilities and/or autistic problems of at least 2 years;
- be familiar with the regulatory framework in the area of social work, education, healthcare, employment, disabled persons' rights;
- be computer literate;
- are not convicted of an intentional crime of a general nature;
- are not public, district or municipal administration employees;
- have teamwork skills.

### **5.3. Specific requirements**

*Advantage will be given to applicants who:*

- have hands-on experience in the implementation of projects in the field of social activities, healthcare, education and/or social inclusion of persons with intellectual disabilities and their families.

### **5.4. Skills**

- Believe in disabled persons' strengths and abilities;
- Be fond of process based work;
- Be able to show respect for others;
- Be resourceful and flexible;
- Be persevering and persistent;
- Know how to listen;
- Be able to act independently by:
  - letting others make conclusions;
  - not interpreting;
  - asking questions, not controlling;
  - enabling people to make a plan without controlling its content.

## **VI. TASK IMPLEMENTATION DURATION**

The facilitator shall start working immediately after the signing of the contract which is expected to be 2 January 2013. Contract services will be provided for a period of nine months.

The consultant will receive a monthly remuneration, within ten days from the submission and approval of a report (joint for the two facilitators for the respective region – Vidin, Sofia). No advance payment is envisaged.

Travel and per diem expenses, if any, will be paid separately following approval by the Executive Director of BAPID.

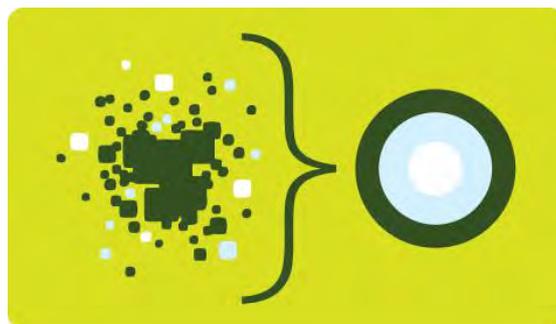
## **VII. FACILITATOR'S REPORTING OBLIGATIONS**

The facilitator will cooperate closely with the Manager under the Contract. He/she will prepare monthly reports on activities implemented by him/her during the past month in Bulgarian language and will submit them to the Manager under the Contract for consideration and approval. In the middle and at the end of the project, the two facilitators from the respective regions will prepare a final report on activity results based on an analysis and recommendations for process improvement as well as enclosed materials – photos, recordings, posters, etc. descriptive of the entire process.

## **VIII. THE TERMS OF REFERENCE WILL BE AN INSEPARABLE PART OF THE CIVIL CONTRACT AT THE TIME OF ITS SIGNING**

## PILOT PROJECT FOR SUPPORTED DECISION MAKING FOR PERSONS WITH MENTAL DISABILITIES

### (PROJECT “PARADIGM SHIFT IN THE CONTEXT OF ART. 12 OF THE UNCRPD. LOOKING FOR SOLUTIONS FOR PEOPLE WITH MENTAL PROBLEMS”)



#### **Methodology for supported decision making for people with mental health problems**

**Supported decision making for people with mental health problems:** organization on an ongoing (continuous) or situational (limited in time, rendered when necessary) support to allow a person with a severe and lasting mental health problems to exercise effectively his/her civil rights.

*Supported decision making (SDM) is a service, although currently available under a project. Accordingly, the person who uses it is a client.*

The aim of supported decision making (SDM) is to support people who have difficulties to make decisions in certain situations (in deteriorated mental health) or in certain areas of their life (when they have to manage their property). The main objective of the support is both to compensate the deficit of decision making capacity and to help person to create alone a safety mechanism to prevent making decisions that are contrary to his/her personal preferences and interests.

#### **Who needs supported decision making?**

The main characteristics which the client of SDM must meet are:

1. Someone else makes decisions for him/her (irrespective of whether there is a legal basis for this)
2. There is a risk someone else to make decisions for him/her

The probability/risk of this to happen to people with psychiatric diagnosis is higher in the following cases:

- If they are in a serious protracted conflict with their environment (family, neighbors, institutions) or manifest a tendency for conflict (provocative) behavior;
- In the presence of a certain character and course of psychosocial problems: serious symptoms of major impact on psychosocial functioning, recurring crises with a noticeable deterioration in the functioning and incomplete remissions between them lasting and deep damage to cognitive and psychosocial functioning not including:
  - If there is serious neglect caring for themselves and their homes;
  - If there is serious social isolation / lack of support network;
  - If they demonstrate dependent / passive behavior: a tendency to uncritically accepting of one's prescriptions;
  - If there is history of abuse of property.

## Algorithm for SDM

SDM is applied in four basic steps:

- i. Establishing criteria and inclusion of client.
- ii. Evaluation
- iii. Organization / preparation of the support
- iv. Implementation of the support measures

### I. DETERMINING THE CRITERIA AND INCLUSION OF CLIENTS.

At this stage the scope of the service (territorial) is determined, the information needed for potential clients to form a willingness to participate and determine the criteria for inclusion in the project is prepared.

#### 1. Preparing a strategy for dissemination of information.

An important moment for the program's success is the strategy for dissemination of related information. This process may include: preparation and distribution of a brochure, presentation to groups of people with mental health problems, presentation to professionals in this area. Presentation in social networks and websites.

There are three main channels through which clients are included in the program:

- Self - referral: potential clients can learn about the service and seek contact to take advantage of it.
- Referral: potential clients can be referred by different specialists, relatives, neighbors who have learned about the service.
- Indication: people who could benefit from the service can be indicated and their problems - described - by a variety of professionals or citizens who have learned about the service (including the family members of these people).

Based on the information gathered a preliminary assessment is made:

- Is this person likely to benefit from using the service?
- How could he/she accept the proposal to take advantage of?
- Who and how contact him/her?

Paper trail: a list of potential clients and some information about each one of them (name, problems, resources, are they referred by someone, etc.)

#### 2. Establishing initial contact with a potential client.

The main tasks at this stage are two:

- Check the original assessment that this person can benefit from the service;
- Start building a relationship of trust with him/her.

Building a relationship of trust with the client is crucial for the success of SDM and that is why it is necessary to invest enough time and effort to fulfill this condition. Often, despite all efforts (sufficient number of meetings, existing necessity for SDM), a potential client may refuse the use of the service. In this case it is better to withdraw, but to keep in touch with the client. In most cases, the client gets in touch alone when a risk event occurs for him. In this sense, a part of the work is done (the person knows that he/she can seek support and know where to get it).

Conversation with the prospective client. Written materials can be used to acquaint the client with the service and its purposes. Prior arrangements can be made - for example, if the client wants to think for a few days a new appointment is arranged, etc. In conversation, it is worth addressing the following issues:

- Presentation of the facilitator: name, position, role.
- Presentation of the service: nature, goals, organization.
- Why this particular person?
  - How have we learned about him/her? By whom?
  - What have we learned?
  - Why do we think that the service is suitable for him/her particularly?
- What are the benefits of using the service?
  - What do we offer? How can it meet the needs of the client? Which needs?
  - What is expected of the client?
  - What will the entire process be like.

Paper trail: a description of the meeting and the gathered information.

**Important!** Experience shows that people involved in the program often confuse SDM with various services they are familiar with or have used to date. This leads to confusing the role of the facilitator with that of the person in charge of the case or the social worker. It is important that the facilitator is well prepared to deal with the challenge to take this role and try to solve alone the problems about client.

### 3. Signing an informed consent for inclusion in the project.

At this stage, the informed consent can be signed. If this is impossible because of the risk of withdrawal of the client this can wait and can be proceeded to the next stage. In this sense, the signing of a declaration of informed consent can be considered as written reflection of the existence of a relationship of trust between the facilitator and the client. An option to the declaration at this stage may be an application for inclusion in the program.

## II. EVALUATION

Evaluation helps to understand:

- In general whom we are working with;
- The areas or situations in life in which the person finds it difficult to make decision now;
- The areas or situations in life in the past in which the person found it difficult to make a decision;;
- The attitudes of the person to these areas or situations (does he/she find it is good to get support in this process);
- The person's resources;
- The attitudes of the environment to these difficulties of the person in the process of decision making;
- The attitudes of the environment to the implementation of any measure in the form of SDM;

- The resources of the environment;
- How can we get in touch with this person and with people from his environment whom he/she has indicated;
- General information about the client and his/her environment;
- The areas or situations in life in which the person finds it difficult to make a decision;

**More specifically:**

<b>We ask (ourselves)</b>	
What kind of person is sitting in front of us (a bird's eye view)	<ul style="list-style-type: none"> <li>• What is his/her name?</li> <li>• How old is he/she?</li> <li>• Where and with whom does he/she live?</li> <li>• What does he/she do?</li> <li>• What mental disorder does he/she suffer from?</li> <li>• Is he/she in treatment, how?</li> <li>• Etc..</li> </ul>
Difficult areas or situations in life now	<p>How does he/she copes with:</p> <ul style="list-style-type: none"> <li>• money and their spending;</li> <li>• management of other movable and immovable property (including the ID card);</li> <li>• relations with various institutions and organizations (including government and municipal ones);</li> <li>• caring for his/her physical, dental and mental health (identification of new complaints as a reason to visit a doctor, complying with a prescribed treatment, follow-up, etc.);</li> <li>• caring for the living environment, appearance and personal hygiene;</li> <li>• his/her own emotions (aggressive, euphoric, depressive) and attempts to react to them;</li> <li>• creation and maintenance of satisfactory relationships with other people (intimate, friendly, collegial, work, etc.);</li> <li>• the need for dependence and fear of abandonment;</li> <li>• symptoms of mental disorder, and the periods of their exacerbation (crises);</li> <li>• and so on, depending on the circumstances</li> </ul>
Difficult areas or situations in life in the past	<ul style="list-style-type: none"> <li>• How did he cope with the situations above in the specified areas in the past?</li> <li>• Did he/she have problems and if so - what kind of?</li> <li>• How did he/she deal with these difficulties?</li> </ul>
Attitudes of the person (does he/she want support?)	<ul style="list-style-type: none"> <li>• Does he/she think there are difficulties making good enough decisions related to any of the evaluated areas? Which ones? How serious and how lasting are these difficulties?</li> <li>• Does he/she agree that there is a problem if confronted with facts or observations or encouraged to think in this direction?</li> <li>• How does he/she explain the problem - what is the reason? To what extent does he/she connects it with him/her? To what extent are the explanations plausible?</li> <li>• Does he/she think than something can be done to improve the situation? Does he/she think that he/she alone can do something or does he/she transfer the decisions entirely outside himself/herself?</li> <li>• What does he/she think can be done? What should h/she do? What should someone else do? Who?</li> <li>• Is he/she willing to think about any of the measures for SDM? Which one/s?</li> </ul>
The person's resources	<ul style="list-style-type: none"> <li>• Critical thinking about the problem (the mental disorder)</li> <li>• Readiness to comply with a drug or other therapy (as prescribed by the doctor)</li> <li>• To what extent does he/she control his/her symptoms?</li> <li>• Cognitive functioning: thinking, memory, attention</li> </ul>

	<ul style="list-style-type: none"> <li>• To what extent does he/she control his/her impulses?</li> <li>• Can he/she predispose people to himself/herself (consciously or unconsciously)? Can he/she set people against him/her (consciously or unconsciously)? To what extent does he/she exhibit these qualities?</li> <li>• Is he/she ready to cooperate for implementation a measure for SDM?</li> </ul>
Attitudes of the environment to these difficulties of the person in the process of decision making	<ul style="list-style-type: none"> <li>• Do the people of his/her environment believe that the person has difficulty in making decisions in some situations or areas of his/her life? Which ones? What difficulties? For how long? Are they lasting? Are they subject to change? Can the difficulties be resolved (by themselves, over time) or someone has to intervene? Who? How?</li> <li>• To what extent are the people from the environment want to control the decisions made by the person? What are their arguments? Are they willing to change their attitude?</li> <li>• To what extent are their arguments related to their own safety (immediately or in the future, in any further deterioration such as when they will have to hospitalize the person) and well-being? To what extent are they related to the safety and welfare of the person? In what way? In general, what do they fear, what risks do they see?</li> <li>• Within what limits do they tend to recognize the right of the person to choose? In what areas of life?</li> </ul>
The attitudes of the environment to SDM	<ul style="list-style-type: none"> <li>• What do they think about the measures for SDM?</li> <li>• What are their concerns or complains?</li> <li>• Are they willing to cooperate in the implementation of some of the measures?</li> </ul>
The resources of the environment	<ul style="list-style-type: none"> <li>• Are there patient and benevolent doctors (as a minimum - GPs and psychiatrist, may be others depending on the health problems of the client)</li> <li>• Does he/she have somebody to rely on outside the nuclear family? For what? How fast can he/she get support? What are the limitations?</li> </ul>
Contact information	<ul style="list-style-type: none"> <li>• Demographic data <ul style="list-style-type: none"> <li>✓ Name:</li> <li>✓ Years:</li> <li>✓ Marital status:</li> <li>✓ Close people (name/relationship):</li> </ul> </li> <li>• Contact information <ul style="list-style-type: none"> <li>✓ Personal address:</li> <li>✓ Telephone</li> <li>✓ Close people's address:</li> <li>✓ Close people's telephone:</li> </ul> </li> </ul>
<b>Assessment</b>	<ul style="list-style-type: none"> <li>• The person has difficulty making good enough decisions in a situation ... in the area of...</li> <li>• At these moments is happening ...</li> <li>• The difficulties are due to ... The person himself/herself explains them as a result of ...</li> <li>• The people of his/her environment believe that the person has difficulties in... they explain them as a consequence of ...</li> <li>• The views of the person, the people from his/her environment and the personal advocate affirm the understanding that ... the measure can be to his/her advantage</li> </ul>

These questions are evaluated with the implementation of the approach to the dynamic interview. It can be held in the office, at the client's home or at another location convenient for the client – a cafe, a park; the prerequisite is the environment to provide enough peace and privacy for one or more meetings lasting 40-60 minutes.

Sometimes, in order to identify the personal resources of the client in terms of his/her capacity to make decisions and the difficulties that he/she may have in different areas related to the nature of his/her illness, the evaluation team can include other specialists such as a social worker, clinical psychologist, and psychiatrist. The inclusion of such professionals and the benefits of this are discussed with the client his/her consent is sought. The results of initial evaluations are provided to the client and discussed with him/her and the people close to him with whom he/she has built relationships of trust.

**Important!** Evaluation in the process of facilitation is not intended to determine the deficits of the client and does not make any predictions about the way he/she is suffering from his disorder. The only purpose for which it is done is to identify the problems and resources in terms of decision making capacity and to offer adequate support measures.

*Paper trail:*

- Information card of the client (personal data)
- Client's profile: formulation of the difficulties of the client to use the available
- Signed "declaration of informed consent" by the client.
- Minutes of the meetings
- Photos, recordings (audio/video)

### **III. PREPARATION / ORGANIZATION OF SUPPORT**

It is advisable to have one person who takes the responsibility for the support's organizations. In this program we call him/her a facilitator for lack of a better name to describe his/her role. Generally the facilitator:

- Evaluates the situation of the person who has difficulty making decisions
- Comes to a description of the situation and the difficulties (stocktaking), which he/she shares with the person and the people close to him/her
- Agrees with them on the implementation of any measures
- Prepare an action plan which specifies who participated in the implementation of the measure, how, when, etc.
- Maintains continuous contact with the person with difficulties in making decisions
- Liaises with the people involved and urges them to act if necessary
- Monitors the update of the plan, etc.

One facilitator can work with 4 or more people, according to the intensity of work and the complexity of the situations of the clients. Based on the original evaluation the facilitator together with the client and if necessary - together with another person with whom the client has built relationships of trust - plan the specific support measures. They generally can be grouped into three categories according to the clients' attitudes in terms of his/her decision-making capacity.

People involved in SDM can be very different, both in terms of the support they need, and in terms of their disorder. Under the pilot project, the people involved in it can be grouped as follows:

1. People who want to cope with the instances of risky behavior, but realize that it is difficult to do so. They are critical of some chronic symptoms and do not want to have a crisis again. They need support to learn to cope better with the behavior that puts them in situations of risk and in which someone else controls their lives and make decisions for them.
2. They are ambivalent: it is the most common attitude. Some of the clients may be critical to certain symptoms or behaviors and not critical to others; critical thinking may change over time (in both

directions), or with the development of the disorder (in crisis critical thinking diminishes. These interventions rely on a relatively stable healthy part in the client seeking assistance during remission or at times when the trend towards denial is weak, and that can pursue cooperation in such periods.

In both cases described above, the facilitator seeks to maintain contact and work with the client in respect of the proposed measures for SDM. If there is a crisis, it is better to wait for it to pass by helping to support the treatment and rehabilitation if necessary.

In order the planned measures to be effective it is essential that the person is in a relatively stable condition and is critical to it.

3. Part of the people have no desire to fight the signs of risky behavior; it can bring them comfort (in the case of mania) or they are not critical to it (in the case of paranoia or hoarding).

These people hardly seek help on their own. Often these are people living alone, with extremely low quality of life. They have lost the majority of their assets, are not included in the social support and healthcare systems. Most often they are referred to the program by public institutions due to signal/number of signals from neighbors or citizens.

They demonstrate the objective risk of imminent serious loss of property or an imminent risk of serious or irreversible damage to the life and health of the person or someone close to him/her ("Serious advert affects");

In this case it is more appropriate to think of a combination of supportive, restrictive and administrative measures.

#### **Support measures:**

Support measures have three main tasks:

- to help the person to compensate a deficiency in his/her in decision-making capacity
- to help the person to develop the capacity for independent decision-making
- to develop the capacity to support within the immediate environment of the person

When providing support measures, we should try to work for the achievement of the three objectives of the measures .

When we talk about support, we need to distinguish the following two categories of support:

"Support in the process of decision making". This is informal help which people use constantly in their life - for example, consulting with friends and acquaintances on various issues.

"Supported decision making" is a process that has important legal consequences. In it the measures help the supported person in the planning of his/her future life in the community and making decisions about his/her personal life, health and finance/property.

The measures may be offered independently depending on the need for support and the wishes of the person and in combination (for example, in a group of equals and preparation of anti-crisis plan). They must also be consistent with the personality characteristics of the person and his/her preferences (there are people who cannot benefit from the support of a group and prefer to use the support of a personal advisor).

When in the community where the person lives, there is no resource for support it may be necessary the facilitator to do advocacy activity for organizing such a resource.

## **I. Support groups of equals**

Usually the groups of equals are organized and managed by people with mental health problems, they are informal and open to anyone who wants to join . They provide natural support of the person in the process of decision making.

Groups of equals are one of the cheapest and effective support mechanisms . it is necessary to invest in the support of organizations of people with mental health problems to create regular meetings of groups of equals. The groups of equals are an appropriate support measure for all who wish to make use of it.

In the process of implementation of the pilot program were established two support groups of equals (in Blagoevgrad and Sofia). Coordinator of this process is the National Organization of Users of Mental Health Services, which is a key partner organization in the program.

Some of the key features of the group of equals are described below.

### **1. Aims of the group**

The support group of equals in this program has the following aims:

- 1) To create an environment in which people with mental health problems to be able to speak freely about the specific problems they face.
- 2) To create new acquaintances and contribute to building a support network among the people involved in the program.
- 3) The members build relationships of trust among them which will facilitate the easier inclusion of new members from the target group.

### **2. Organization**

- 1) The group meets weekly on the same day of the week and at a time announced in advance.
- 2) Participation in the group is voluntary, it is open to everyone eligible for participation.
- 3) The participants are required to comply with the rules of the group (in implementation).
- 4) The group leader is committed to select and train a participant in the group who could replace him/her in the event of illness or other urgent reason he/she cannot conduct any of the weekly meetings. The deputy leads the group on a voluntary basis without a fee.
- 5) In the event of illness or other cause leading to prolonged inability of the group leader to perform his/her duties, his/her deputy becomes the group leader.
- 6) For any organizational problems which he/she cannot solve alone, the group leader from Blagoevgrad turns for advice to the group leader from Sofia, and he/she in turn asks for advice the Project Coordinator from the Global Initiative in Psychiatry –Sofia.

### **3. Roles in the group**

#### **1) The role of the group leader:**

- To provide an environment of mutual respect and hearing
- To help the participants to stick to the topic under discussion
- To stimulate the activity of speaking (e.g. by sharing their experiences on the topic under discussion or asking questions to specific participants who have experiential familiarity with it, etc.)
- To keep the balance in the speaking of individual participants - to prevent taking the floor by some talkative people

#### **2) The role of the participants:**

- To create an environment of understanding, trust and support in the group

- To share their views and personal experiences on the discussed topics
- To share in the group their experiences and problems in the process of testing of supported decision making

3) The role of the other participants in the group:

- To create an environment of understanding, trust and support in the
- To share their views and personal experiences on the discussed topics
- To broaden the social contacts of the participants.

## II. Consultation with a trained specialist

This measure aims at specialized support of the person in terms of making a single decision that has legal consequences (e.g. signing a contract, real property transaction, etc.).

The professionals can be from various fields (lawyers, psychologists, financiers, etc.) who provide advice on specific issues. The consultations ensure the need for additional information so that the person can make his/her own decision.

It is important that these professionals (consultants) are specially prepared for SDM and for working with the specific group of people in order to take into account all the factors which might have a negative effect on the actual wishes of the clients.

**Example:** Vanya is a woman of 42 years who lives with her mother and has a 19 year old daughter. For 20 years Vanya has been diagnosed with bipolar affective disorder. During the illness she has had multiple hospitalizations, some of them forced. Currently she is on a maintenance treatment, she is critical to her disorder. She is able to take care of her daughter and works part time in an advertising agency.

Vanya has decided to enter into a second marriage with a man who knows about her disorder. She knows that she has a reduced decision-making capacity in times of crisis and feels insecure in relation to any misuse of her property by her future husband during these periods. Vanya has heard about SDM program during a presentation by the project team which she was invited to attend by an acquaintance also with a mental health problem. She turns for assistance to a facilitator.

Solution: Vanya has a functioning support network, which helps her to cope with risky behavior during a crisis. Vanya is referred to a specialist lawyer who consulted her regarding her doubts about the property and, together with her made a pre- nuptial agreement. Vanya has is no need for other support measures and manages to make the decision alone after this consultation.

## III. Social Service

In some of the cases, the person needs specific social support to be able to recover some of his/her skills to improve his/her functioning and communication, to develop a capacity, improve the quality of life, etc. This is particularly relevant for people who have lived long in institutions and have lost (or have not acquired) skills for independent decision making. In these situations it is better to offer the person support from a social service. Experience shows that the use of quality social services increases the person's capacity to make decisions alone.

Some of the areas in which social services can be very effective in relation to creating skills for decision-making are:

- acquisition of skills for recognition and control of the symptoms of mental health problems;
- recovery of lost social skills;
- acquisition of new social competencies;
- acquisition of skills for searching and keeping a job;
- restoration of suspended social/ health insurance rights;
- provision of minimum income (if there is no such) to enhance the quality of life and other capacity related skills;
- encouragement of the establishment of a social network that can render support in the future.

The role of the facilitator in this process is to refer the person to the service. If necessary, he/she can liaise with person in charge of the case of the person and to include him/her in the discussion of possible support measures. The reason for the involvement of the person in charge of the case is that very often he/she is one of the few trusted individuals with whom the person has a relationship. The facilitator should endeavor together with the person and the person in charge of the case to expand the support network by expanding the opportunities for social contacts.

**Important!** In this intervention the greatest risk is the person to confuse the roles of the facilitator and the person in charge of the case. This is particularly relevant when the social service is provided "in the field" and both professionals visit the person at his/her home or at a neutral location . It is important that both specialist are aware of the limits of their roles and try to communicate these relationships with the person. However, when the person is in unstable mental health state he/she cannot tell the difference and does not want to accept the role of the facilitator which would be more unknown than the professional roles he/she has seen so far. In this case it is better to invest in establishing a long-term relationships of trust with the facilitator and he to intervene when the client is ready to take advantage of SDM and when there is need for intervention regarding a specific problem. The person in charge of the case can refer the person to the facilitator when a problem or a need arises.

**Example:** Michail is the first child of two children in the family and has a younger brother. It is not known whether he has worked; he has been ill for more than 30 years. He currently lives with his brother who also has a mental disorder. He is not married, has no children. Michail is not under restricted legal capacity.

The two brothers live in a home which was sold to their uncle for a paltry sum in 2009 against the duty to take care of them - an obligation that the uncle does not comply with. Their female cousin takes care of the brothers. The uncle often threatens Michail and his brother that he would drive them out of the house where they live.

Michael and his brother used the social service "active care" for 2 years. The person in charge of their case has referred them to the program for SDM because of the risk Michael and his brother to lose their home.

Currently Michael has not achieved complete remission and his behavior has somewhat disorganized nature. The facilitator is trying to establish contact with the brothers and has held several meetings during which it became clear that the brothers do not recognize the importance of the service. They are afraid to initiate steps to resolve the conflict and to benefit from some of the measures. However they communicate clearly the desire to remain in the house and realize the risk of loss. Solution: The person in charge of the case and the facilitator together with the brothers discussed different possibilities for interventions and made a plan for the organization of the existing resources. The person in charge of the case who has a trustee relationship with the brothers worked to motivate Michail to start a treatment and to reach remission. Meanwhile he/she monitored the occurrence of circumstances related to the property. The facilitator initiated meetings with the cousin and the uncle along with the two brothers and the person in charge of the case during which they discussed the issues concerning their home. An agreement was reached and work has begun on creating a supportive network where the cousin takes the responsibility for maintaining the property, to avoid future such conflict .

The use of social services can be crucial to the success of SDM, as this is where the condition of the person is monitored regularly and measures for his/her support in everyday life are taken when the resources are not available in the environment. Social workers in social services can be a good source of information if problems arise and the starting point for referring clients to the SDM.

#### IV. Mentor (personal advisor)

These are specially trained professionals (for example employed in a social service), who aim to support the person to gain the information necessary to understand, evaluate the outcomes and make decisions. The support that the mentor provides can be called a "support in decision making". The mentor helps the individual to gather all the information for a specific decision, to make sense of this information and put the arguments "for" or "against" making a concrete decision. The mentor does not assess or consult the person; his/her role is to help people understand the information so that they are able to make their own decision. This intervention is applied most successfully for people who have difficulty establishing and maintaining relationships of trust and function badly in network.

The mentor can be any professional who has a relationship of trust with the person and works with him/her to resolve specific issues. The mentor often works "in the field", i.e. the place where the person lives. He is often "available" 24 hours and knows the history of the person and his/her difficulties associated with decision making. The mentor is socially competent, knows the social security and health care systems and can organize resources for support in a particular situation. He/she does not evaluate the decisions of the person but helps him fulfill his desires.

**Example:** Violeta is a 36 years old woman who has suffered from schizophrenia for over 30 years . She lives with her father, who is in a wheelchair. In times of a crisis Violeta often leaves her home and disappears for days. During these periods Violeta is vulnerable in relation to decision making which later she regrets. Such decisions are, for example to sell her ID card for 10 levs, or to sign a contract with a mobile operator for which she owes large amounts.

The father threatens to put Violeta under restricted legal capacity, something she fears.

Violeta has been referred to the program by the Social Support Department where she sought help to resolve the problem with the mobile operator.

**Solution:** Violeta does not want to participate in a support group of equals and does not wish to benefit from social services. She is suspicious of signing contracts because there is a history of serious abuse. She was able to build a relationship of trust, however, with a personal advisor who helped her solve various problems in daily life. Violeta turned to him when there was a doubt about a possible act of abuse, and when she suspected that a decision would have negative consequences. As a result, Violeta was able to annul the contract with the service provider. The father keeps her ID card and Violeta has a copy of it for identification when necessary.

The social interventions pointed in 1,2,3 and 4 are a support whose aim is to make the person cope with the exercise of his/her rights. Through them, the person is able to cover and recover some of the deficits with respect to decision making. Decisions are taken by the person himself/herself.

#### V. Anti-crisis plan

It is possible that an individual may have a concern that at certain times (such as in a state of psychotic crisis) his/her vision of the world and the consequences of his/her own actions/inactions is different from that which is most important to him/her and reflects his/her best desires and preferences. Everyone suffers differently, but for some part of the people a new episode (attack) of mental disorder occurs with a state of confusion - in terms of the world or themselves. Then a good possible intervention is to create an anti-crisis plan (preliminary declarations / powers of attorney)

The anti-crisis plan is prepared by the person himself/herself with the support of a trained professional (facilitator). In the plan the person expresses his/her will; it is possible for him/her alone to limit their autonomy by giving this power to the trustees, selected by him/her.

The Plan contains:

- guidelines on and requirements for the process of decision-making in periods when the person has reduced capacity;
- who are the trustee/s and the range of issues on which they can make decisions;

- what the person wants to happen if a "triggering" event occurs;
- how to identify this "triggering" event;
- when and how power is restored to the person.

The preparation of a crisis plan is carried out by the person himself/herself together with a facilitator and the process goes through several stages:

Making a crisis plan in general	Usually it requires several meetings. These meetings can cover days or more often weeks - performing some ancillary tasks such as meetings with specialists takes longer. It can be said that on average the making of a crisis plan takes about ten days. Within these few meetings the facilitator is able to get acquainted with the person to some extent - to get to know each other, to win the trust and his/her sympathy (or not to do it) to like him/her, in turn, and finally separate. In the context of these relations the facilitator communicates what is important to know about the crisis plan; the person makes the final decision whether to use our service; information that is necessary is collected and organized in a certain way; t how to continue the contact in the future is negotiated and how the person will use the plan. These relations, as all human relationships have their internal logic of development, and this logic is interwoven with the efficient performance of the primary task.
What does a crisis plan include	Any information that the clients identify as important for the people who may be around them at a time of serious episode of mental disorder can be entered In a crisis plan. Overall, the plan includes the following information: <ul style="list-style-type: none"> <li>• Name and address</li> <li>• Information about the diagnosis and the specificity of the mental crisis</li> <li>• Information about available somatic diseases and known allergies</li> <li>• What medications the client is currently taking or has stopped taking during the episode</li> <li>• Some guidelines for professionals who can care for him in this condition</li> <li>• Possible agreements and arrangements with institutions on the placement for treatment</li> <li>• Other practical issues concerning the management of the household, the bills, etc.</li> <li>• Information about the person whom the client pointed as a trustee - which means to be informed in case of such severe episode • Contact information of the GP, treating psychiatrist, the person in charge of the case and others.</li> </ul>
Sequence of the work	It can be described as a series of several stages.
Stage 1	Introduction
Stage 2	Interview to gather information for the crisis plan.
Stage 3	Setting the crisis plan including meetings with people from the client's environment
Stage 4	Completion of the crisis plan. Planning the use and negotiating follow through.
Sage 1 Introduction	The purpose of this session is to meet each other. Primarily to get the client acquainted with the idea of a crisis plan - in more detail than he/she has understood so far from our information campaign. With more interest to his/her specific questions and fears. With more individualization of our response. Let's try to respond to the fears of the person before us to increase the probability to come back again. Let him/her learn more about us as people (with the idea to like us) to motivate him/her to come back. To learn more about him/her as a person – not so much about to the

	course of his illness at this stage. If we decide that the contact is going well we can ask the client to fill in in advance the form for a first meeting with the facilitator for preparation of a crisis plan. However at this stage it is important to comment on what will happen with the information gathered about the client, and how this information will be stored. In this regard, it is important to sign a declaration of consent for storage of personal data
Stage 2 Interviewing	At this stage we collect the information needed to create a crisis plan. The areas that we are interested in are listed generally in the form for the first meeting in the crisis plan itself. Below in the next section, we focus a little on the process of information gathering.
Stage 3 Setting the crisis plan	During the next meeting the facilitator discusses with the client his experience to date and the likelihood of a new crisis situation. During this situation the client's wishes about what to be written in the crisis plan and how to do so in the clearest way is clarified.
	Then the facilitator in collaboration with the client, prepares a crisis plan. An important part of the crisis plan is choosing the person/people to whom the client can trust for the period when there is a reduced decision-making capacity (during a psychotic episode). For brevity we call this person "trustee". In addition to the trustee chosen to be notified during the crisis (this can be a friend, a family member, a neighbor or even a specialist) this plan should be consulted with various professionals. What help can these people render to the holder of a crisis plan could be considered again.
Meetings with people from the person's environment	<ul style="list-style-type: none"> <li>• The purpose of these meetings is to collect additional information (such information which the clients themselves often find it difficult to provide) and inform them of this new service - a crisis plan. In practice, this means a further consultation among the people, and the most significant among them are: <ul style="list-style-type: none"> <li>• The personal GP;</li> <li>• The treating psychiatrist</li> <li>• The trustee/s chosen/ by the client;</li> <li>• The person in charge of the case and others.</li> </ul> </li> <li>• It is advisable the consumer to attend these meetings.</li> <li>• Organizing meetings in itself can be difficult, the involvement of another participant makes them even more difficult. They can sometimes attend the meeting with the trustee.</li> </ul>
Stage4 Completing the crisis plan	The objectives of this stage are related to the finalization of the crisis plan, its signing by the client and the trustee/s and planning its use, negotiating the follow up.
At this meeting it can become clear that...	<ul style="list-style-type: none"> <li>• The client does not like something in the text (more things than he/she is willing to allow are said, for example) or there is a discrepancy in the information (suddenly he/she decide that something is not true or is not just as he/she said it)</li> <li>• The person thinks of something additional that he/she insist to be incorporated into a crisis plan.</li> <li>• Sometimes we ourselves may need more information, etc</li> </ul>
	All this clearly shows how important is this information to be carefully organized so as to be presented in a manner acceptable to the person. The clearest signal of consent is the signature that the client puts under his/her crisis plan.
Follow up	Follow up means to find out whether the client will meet us again to see if the crisis plan is helpful and whether anything in the content needs to be change. In fact, we can also agree on meetings to be made whenever the situation of the client changes and which requires a change in the content of the plan such as:

	<ul style="list-style-type: none"> <li>• Change in drug and/or other therapy</li> <li>• Change of the treating physicians or other important people mentioned in the crisis plan</li> <li>• Any other change that should be reflected in the crisis plan</li> </ul> <p>The principle of deciding whether to have a meeting depends on the task: we can agree to meet if there is a change in the treatment or in life, we can also arrange to meet at certain periods of time to discuss together how things are going and whether the crisis map is doing its job.</p>
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#### Annexes to stage2

1. Defining warning signals of the client	Questionnaire for warning signals (Annex 2)
2. Defining the acuteness of the warning signals	Acuteness of warning signals (Annex 3)
3. Preparation and signing of n agreement	Agreement (Annex 4)
4. Training in the filling in of the evaluation list of warning signals	Evaluation list of warning signals (Annex 5)
5. Preparation of a crisis plan	Sample crisis plan (Annex 6)

This measure has been very successful in people with mental illness or suffering from degenerative neurological disorders (such as dementia). For them the measure SDM is a "safeguard" measure so that someone may not substitute their will, without being empowered to do so, in case something happens to them that is against their will and, above all an instrument in difficult time for them when their idea about the world is totally different from what they actually know, their best wishes and preferences to be respected by the guarantees of the persons (trustees) chosen by them. Important for the success of the anti-crisis plan is the person to be in a state of remission at the time of its creation so that he/she is able to understand the consequences provided for therein. In this sense, it is necessary to provide sufficient time for its preparation so that it can be tested and, if necessary, revised.

#### VI. Building support networks

This includes several tasks:	<ul style="list-style-type: none"> <li>• To motivate the client to participate in the building of such a network and to use it;</li> <li>• To assist the client in building a support network;</li> <li>• To support the functioning of support networks in the initial stages of its existence.</li> </ul>
To be able to effectively use the service, the clients customers must:	<ul style="list-style-type: none"> <li>• Understand the service and the role of the parties involved - support network, supporting social worker, his/hers;</li> <li>• Be willing to work actively within a certain period of time which may be long and - and to really make it;</li> <li>• The clients can renew and improve existing relationships with at least two people who agree to play the role of supporters and can maintain these relationships over a long period of time.</li> <li>• Clients who do not meet these basic conditions cannot benefit from the service and may be referred to the use of protective measures (still under development)</li> </ul>

The essence of support	The facilitator will assist in the organization of several persons designated by the client and motivated to participate forming a support network or group. The supported person chooses alone the people who will help him/her, including in the network / the group family members, friends and advocates whom he/she believes. The main support provided by the group is emotional, although practical one may also be provided. We can talk about network if the supporters do not keep an intensive and regular contact with each other (including all meeting the client) but choose to have more individual meetings with him/her to discuss issues and provide support. A group implies a relatively regular contact of all members who get together and provide support. The experience of the application of the model will show whether this distinction makes sense.
The organization of this support goes through several stages:	<ol style="list-style-type: none"> <li>1. Assessment of whether the client can benefit from using the service/evaluation of the needs and resources of the client.</li> <li>2. Planning and agreeing on actions necessary to build a support network / group.</li> <li>3. Gathering the participants in a support network / group.</li> <li>4. Creating a personal level of support and assigning the roles of the supporters in it. In practice, creating a personal level may precede the gathering of the participants or the two processes can overlap and occur more or less in parallel influencing each other - the inclusion of a new wish in the personal plan requires the search for new supporter figure or the existence of any person whom the supported trusts that makes it possible to think about achieving a certain goal.</li> <li>5. Supporting and empowering clients to use supportive network / group.</li> <li>6. Supporting the functioning of the supporting network / group.</li> <li>7. Assessment of the achieved, planning and negotiating new actions if needed.</li> <li>8. Gradual withdrawal of the active involvement of the supporting social worker.</li> <li>9. Completion of the work of the supporting social worker / supporters; continue to operate without this source of support.</li> </ol>
Organizing the support:	
1. Assessment of the needs and resources of the client:	<ul style="list-style-type: none"> <li>• What does he want to accomplish? What goals can be formulated?</li> <li>• Who thinks can help him/her in achieving the goals? <ul style="list-style-type: none"> <li>✓ Family members, close or extended?</li> <li>✓ Friends and acquaintances?</li> <li>✓ Colleagues (current and former), classmates, fellow students?</li> <li>Other?</li> </ul> </li> <li>• Why has not this support network formed alone so far? <ul style="list-style-type: none"> <li>✓ What are the obstacles?</li> <li>✓ What is the relationship with these people? How did it happen that such a relationship has developed?</li> <li>✓ What are the barriers associated with the people form the environment? What do they want from him / her? Why do they avoid him/her? Are there tensions and conflicts in the relationships with potential members of a support network?</li> <li>✓ What are the obstacles associated with the client himself/herself?</li> </ul> </li> </ul> <p>These issues are examined with the application of the approach of the dynamic interview. It can be held in the office, at the client's home or at another location convenient for the client – a cafe, a park; a prerequisite is the environment to provide enough peace and privacy for 40 - 60 minutes.</p>

<p>2. Planning and negotiating actions necessary to build a supportive network /group.</p>	<p>Planning and negotiating go together because they can hardly be done once and for all - the planning of a certain stage goes with negotiating how the roles will be assigned in its implementation.</p> <ul style="list-style-type: none"> <li>• Planning is done in terms of specific people, steps, and situations.</li> <li>• The client provides information and recommends how to approach one or another person</li> <li>• Allocation of the roles between the supporting social worker and the client: who will do what in this process.</li> </ul> <p>Whenever possible, the facilitator encourages and urges the client to establish contact with potential members of a supportive network / group alone and tries to support him/her in this process or at least to involve him/her as a partner and participant, rather than to do this instead of him/her.</p>
<p>3. Gathering the participants in a support network /group.</p>	<p>In practice, this means receiving the consent of several people mentioned by the client to assist him/her in achieving his/her set of objectives. Such assistance may relate to the achievement of immediate, short-term goals, but it is better if it is a permanent readiness to provide diverse support. How intensively and regularly will these people communicate with each other (will they be a network or group) is a matter of further clarification. The gathering includes a series of steps:</p> <p>A. Establishing a contact with potential members of support networks and creating initial relationship:</p> <ul style="list-style-type: none"> <li>• These are the people chosen by the customer to form a supporting network / group;</li> <li>• They can already play a real role in the life of the client, but he / she may want this role to change (for example, those people to take more responsibility or their functions to change);</li> <li>• They may be do not play a role at the moment, but the client wants to attract them;</li> <li>• Accordingly, these people may have very different ideas about the relationship with the client compared to his / her expectations for them and willingness to participate.</li> <li>• This requires applying varying degrees of directness to different people.</li> </ul> <p>B. Informing potential participants about:</p> <ul style="list-style-type: none"> <li>• The service, its goals and values, the role of the supporting social worker for the role expected of them (generally);</li> <li>• The practice of placing under restricted capacity in our country and its outcome; ideas for changing this practice and the legal framework for these changes;</li> <li>• The characteristics of mental disorder: course, prognosis, positive and negative symptoms, functioning;</li> <li>• The current understanding of the treatment of mental disorders;</li> <li>• The current understanding of the role of psychosocial factors in the course of mental disorder and the recovery thereof;</li> <li>• The amount and nature of information will be measured according to each specific potential supporter;</li> <li>• Informing may be oral, using written or multimedia materials.</li> </ul> <p>C. Sending an Invitation to join the support network / group.</p> <ul style="list-style-type: none"> <li>• These people can only be invited or asked if they agree to;</li> <li>• Invitations are different: once to speak with the supporting social worker, to understand what it is about; to tell more about their</li> </ul>

	<p>relationship with the client (from their perspective); to consider whether they would like to commit to anything; to commit to something</p> <p>D. Negotiations (bargaining)</p> <ul style="list-style-type: none"> <li>• Some of the invitees can respond willingly, but most likely they will have different concerns; with those who do not refuse categorically contact can be extended by negotiation in order to be persuaded to join.</li> <li>• Perhaps these negotiations will include elements of persuasion, awakening/provoking interest (seduction), manipulation, bargaining and other strategies to involve;</li> <li>• A key element of negotiations is searching, identifying and clear indication of the benefits which the prospective supporter can derive from their role (probably this benefit will be more emotional or moral than material);</li> <li>• A categorical refusal by a prospective supporter is absolutely respected and he/she is no longer bothered.</li> </ul> <p>E. Advocacy for the client.</p> <ul style="list-style-type: none"> <li>• In some cases some pressure may be exerted on the potential supporters; an example of such cases may be the special position of the person toward the client (he/she is a guardian or custodian at the time), especially intensity conflict in the relationships (when, in the opinion of the supporting social worker, the client's interests are harmed), lack of other resources (the people who can potentially provide support are very few) and others.</li> <li>• Advocacy is important when the client for some reason finds it difficult to defend his/her interests alone; the purpose of advocacy is not deepening the conflict but its solution or reducing the tension.</li> <li>• Advocacy is always preceded by careful negotiation with the client and is done with his/her express consent.</li> </ul> <p>F. Mediation in conflict relations</p> <ul style="list-style-type: none"> <li>• The willingness of all parties to enter into a process of seeking solution advantageous for all involved is examined; this means that those involved are willing to give up some part of their claims and disagreements,</li> <li>• Their readiness to accept the supporting facilitator as leading this process and to agree to the restrictions and rules of the procedure proposed by him is examined. A model of mediation involves six steps: <ul style="list-style-type: none"> <li>✓ Explanation of the process and application of basic rules;</li> <li>✓ Hearing the stories of conflict and summary versions of both parties;</li> <li>✓ Identification of the painful topics and their discussion;</li> <li>✓ Both parties understand better the position of the other party and express their feelings;</li> <li>✓ Brain storming of ideas and evaluation of possible solutions that benefit both parties;</li> <li>✓ Signing of voluntary agreements and arranging follow-up meetings.</li> <li>✓</li> </ul> </li> </ul>
<p>4. Creating a personal plan of the supported and assigning the roles of the supporters in it.</p>	<p>A. This can be done in one or more group meetings of all involved.</p> <ul style="list-style-type: none"> <li>• The meeting may take place after the script of "case conference" (case conference);</li> <li>• This means an agenda with the stated purpose of the meeting, defining of the roles of the participants, discussing problems and conflicting</li> </ul>

	<p>issues following a certain procedure of speaking, formulation of the results of the meeting.</p> <p>B. Supporters may not want to gather and work as a group; then they can provide support without having close relations. In this case, the facilitator evaluates (for each supporter):</p> <ul style="list-style-type: none"> <li>• the willingness of the potential members to participate in the solution of specific problems;</li> <li>• the willingness of the potential members to commit to rendering short term or long term support to the client</li> <li>• the parameters and limits of their participation</li> <li>• the support they may need themselves to render support to the client</li> </ul>
<p>5. Rendering support and empowering the client to use the support network / group</p>	<p>The clients can have a variety of difficulties to remain in the network/ group build to support them. Surely some of the problems may be beyond the competence of the facilitator (as worsening of the psychosocial functioning to the extent that requires medical intervention).The facilitator endeavors to retain or even strengthen their motivation to use this service by...</p> <ul style="list-style-type: none"> <li>• Encouraging and inspiring hope that the efforts are worth it;</li> <li>• Supporting and encouraging the client to develop the skills to express and assert his/her will and interests (to behave assertively);</li> <li>• Returning to reality if the client develops unrealistic expectations or fears;</li> <li>• Holding the strong negative emotions of the client;</li> <li>• Discussing current problems with the functioning of the supporting network / group, etc.</li> </ul>
<p>6. Rendering support for the operation of the supporting network / group.</p>	<ul style="list-style-type: none"> <li>• "Ideological" support: training the supporting network/ group in the performance of its primary function - to respect the wishes of the client and to support him / her t in decision-making, rather than to seek and impose decisions for him / her. The training is not formal or structured and occurs in the context of specific events or tasks within the work meetings and consultations; the supporting social worker expresses an opinion or informs hoping to change the attitudes of the representatives of the supporting network on certain issues.</li> <li>• Logistic support: practical help in organizing and conducting meetings. This may be linked to setting a time of the meeting convenient to all, deciding the place of the meeting, conducting the meeting, reaching decisions, etc.</li> <li>• Emotional (moral) support: encouraging and urging people to continue.</li> <li>• Coordination of the network / group functioning: fulfilling the role of a connecting agent between the different participants, maintaining contact with everyone and encouraging them to seek each other out.</li> <li>• Mediation: Intervention in conflicts, reducing tensions and seeking mutually acceptable solutions.</li> <li>• Crisis intervention: supporting the network / group to act in case of deterioration of the psychosocial functioning of the client when the communication with him / her may be difficult or even be interrupted.</li> <li>• Following up whether the decisions are implemented: the supporting social worker follows the execution of the made decisions, reminds or prompts they to be perform, offers assistance in case of difficulties, urges the search for help in the network / group.</li> <li>• Maintaining a sense of integrity of the network / group: the supporting social worker remembers the work task of the network / group and then recalls it when needed.</li> </ul>

	<ul style="list-style-type: none"> <li>Searching for a leader who over time will to replace the supporting social worker. This may be the client himself/herself, but may be someone else on the network / group. It depends on the nature and characteristics of the psychosocial difficulties of the client</li> </ul>
7. Assessment of the achieved, planning and negotiating new actions if needed.	<p>This is stocktaking which the facilitator can do with the client or with the client and his / her support network / group. The point is to determine whether any changes - if there are not forgotten or newly occurred needs, if there are any grievances, whether the people involved are happy and ready to continue.</p> <ul style="list-style-type: none"> <li>How the created support network / group can be regarded as being able to exist without the support of the supporting social worker;</li> <li>To what extent have been achieved the specific objectives that the client wants to achieve;</li> <li>Whether the client is satisfied.</li> <li></li> </ul>
8. Gradual withdrawal of the facilitator from active participation.	<p>At this stage it is impossible to predict what time will be required for an average networks / groups to cease to need the support of the supporting social worker for its functioning. Most likely, this time will be different in different cases.</p> <ul style="list-style-type: none"> <li>Gradual transfer of the parts of tasks or whole tasks to other participants in the network / group. Although initially this may be accompanied by failures and setbacks that direction should be followed.</li> <li>Discuss the upcoming release of the facilitator from network / group. Delegating aspects of his/her role to different participants: clarifying, motivation, training (if necessary), giving feedback, encouragement. The facilitator may indicate a specific date by which he/she will withdraw. The withdrawal may be associated with the completion of the funding period or finding a suitable figure to replace the facilitator.</li> <li>Open space to discuss feelings that the withdrawal creates: anxiety, anger, sadness.</li> <li>Farewell to the members of the network / group.</li> <li></li> </ul>
9. Completion of the work of the facilitator.	<p>/The support network continues to operate without this source of support/. The facilitator may maintain some irregular contact with the client and the network / group for some time. It is important to make clear, however, that this contact is up to a certain time.</p>

## VII. Procedure crisis facilitation

One exception - when the following 3 conditions are present:

- there is urgency;
- there is no established support network;
- the person is in a condition which makes it difficult to communicate alone his/her own will and preferences.

The purpose is *to create an individual council* which to make specific decisions about the person. This can begin only after all other measures for supported decision making have been exhausted, but there is no result and if at least one more of the following conditions exists:

- ✓ there is an objective risk of imminent serious loss of property or an imminent risk of serious or irreversible harm to the life and health of the person or a person close to him/her (“*Serious advert affects*”));
- ✓ when the person is expressing preferences at some point, but these preferences are very much at odds with a previous will (with preliminary measures for SDM).

The procedure for crisis facilitation is applied only for the decision on the following issues:

1. choosing where the person will live, in view of the conditions and circumstances described above;
2. disposal of movable or immovable property of a certain value or
3. choosing emergency treatment.

The main task of facilitator in this case is to organize the activities of the individual council. The individual council in turn should include:

- persons who have participated in previous measures for support of the person *and/*
- persons specified in previous directions or otherwise recognized as important to the supported person, *as well as*
- persons associated with institutions which could help solve specific problems of the person with in view of the occurred situation *and*
- the person himself/herself- at the earliest possible stage.

Representatives of civil, advocacy and human rights organizations, independent members of society with active citizenship, as well as stakeholders (neighbors, representatives of condominiums, etc.) can be invited in the individual council. The role of these representatives will be both to help the gathering of information about the circumstances around the person and to ensure there is no conflict of interest or risk of violation of rights.

The facilitator observes and monitors how those involved in the council act in view of/interpret the best wishes of the person in the particular circumstances and in the specific context conforming to the following mandatory criteria:

- the interpretation is not based only on the external behavior and the condition of the person;
- all relevant circumstances are taken into account;
- all necessary efforts are made so that the person alone to make the decision;
- the circumstances related to the maintenance therapy are specifically discussed;
- past and present wishes, feelings, beliefs and values of the person are taken into consideration;
- the views of those close to the person are discussed and taken into account

The individual council makes the following decisions:

- supportive: they do not generate immediate legal consequences and are associated with providing the necessary support to the person.
- restrictive: they generate immediate legal consequences (for example – restrict a specific right of the individual to whom the measure is administered);
- administrative: only in certain cases specified by the law *where the goal is* the immediate protection from direct harm of the life, health and property of the person. .

**Example:** Krastinka is 54 years old . An only child. Both her parents are from wealthy families . She is unmarried and has no children. Suffers from a severe mental disorder that began in adolescence. She graduated from secondary and higher education with honors, speaks English well but has never worked. She used to live long with both her parents and her grandmother. Krastinka deteriorated in 2011, when the last member of her family died, and she was left alone. Her ability to care for her health and daily life, to maintain the apartment and get along with her neighbors was strongly reduced. Her apartment was in a very bad condition: filled with trash, with a broken window, no door, no electricity. There were several fires. For a while the neighbors take care of her, give her food and then prompt her to eat and dress . Meanwhile they send letters to all relevant authorities and institutions. After a few months, due to the poor state of the apartment and the risk of another fire the neighbors sealed the door, thus blocking the access of Krastinka to her home.

Meanwhile, due to the letters Sofia Municipal Court stipulated compulsory treatment (Krastinka was hospitalized in SPH "St. Ivan Rilski ") and later placed under restricted legal capacity. All her living relatives refuse to assume the role of guardian of Krastinka.

Krastinka is referred to the program by the guardianship authority (the regional mayor). When specialists come to visiting at her address they find Krastinka in front of the block of flats in a very neglected state (dirty, smelling, half-naked and with lice). Her mental health condition was also severely degraded and she was unable to make decision at this stage.

Solution: Krastinka was referred to the SDM program. She was assigned a facilitator to try to establish a relationship of trust with Krastinka. Meanwhile a council was established which included representatives of all stakeholders in the region, as well as neighbors, representatives of civil and human rights organizations. All present form a guardianship council for Krastinka and the mayor is designated as her guardian. After intensive treatment, Krastinka was invited to participate in the discussion of the guardianship council. She has the desire to keep her accommodated in a municipal housing, her social worker takes care of her under the active care in the community program.

## ANNEXES

### ANNEX 1:

#### Rules for participation in support group of equals

1. Participants: People with mental health problems in a state of remission, which we are willing to share their experience and views on various issues participate in group meetings.
2. We accept people as they are. We do not judge, are not guided by prejudice and public opinion.
3. Discretion: During group meetings we talking only about the people who are present. We do not disclose and discuss outside the group what was said during meetings.
4. We are careful not to discredit each other in the circle of our friends, colleagues and others: When we meet a member of the group outside the gathering, and he/she is not alone, we do not raise issues of mental health problems and diagnoses.
5. We hear and respect each other mutually: Everyone listens carefully the person one who is speaking without interrupting. Hearing and mutual respect is the foundation on which we build our group work.
6. Right to disagreement t: Each of us has his own opinion on questions drawn from his/her own personal experience. When expressing disagreement with the views of other participants we continue to respect each other as individuals.
7. We focus on the theme: We avoid redundancy and deviations. When an interesting side issue arises we, discuss it at the end of the meeting or dedicate any of the following meetings especially to it.
8. We speak from personal experience only: we speak only in the first person and the only about the things we have experienced. We avoid giving advice and making.
9. Receiving feedback: Everyone in the group can ask for feedback from other participants and in this case gets friendly and based on personal experience comment. We do not discuss and comment on stories, if the participant has not required feedback from us.
10. The right to ask a question and the right to refuse to answer: When what was told by someone is not clear – we ask, we do not try to read others' thoughts. Each of us is free to ask any questions. Each of us is free not to answer questions on which he/she does not want to talk.
11. Shared responsibility for the existence of the group: We are a group and it exists and works until we come to the meetings and participate in them. We respect everyone's time that is why we come and leave on time.
12. Stoplight rule: The work of the group is managed by three colors with the following meaning:
  - **GREEN: Start**
  - **RED: Stop**
  - **YELLOW: Attention**

The three colors stand in the center of the circle and each participant can pick up yellow if he/she is feeling unwell or threatened by what is being discussed at the moment or see a threat to another member of the group; and the red if the discussed topic makes him feel extremely ill and wants termination of the meeting. When yellow is raised the discussion on the topic is terminated, when red is raised the group leaves. Normally the leader raises the green and red color as a signal for the start and end of the meeting.

## ANNEX 2: DECLARATIONS

### CONSENT FORM FOR PARTICIPATION IN A SUPPORTED DECISION MAKING PILOT PROJECT

#### “Paradigm Shift in the Context of Art. 12 of the UNCRPD. Looking for Solutions for People with Mental Problems”

I, the undersigned....., Personal ID No....., address....., hereby agree to participate as a supported person in a pilot project for supported decision making aiming to establish a network to support me in the decision making process in my day-to-day life, by respecting my preferences and personal choices and my right to exercise my rights through personal actions. I hereby agree to take part in project stages as follows:

Identification of the circle of persons in the community whom I trust, are important to me and who could take part in my support network. In case no such persons are available, I hereby agree to be supported, with the cooperation of the facilitator, in establishing such relationships of trust.

Participation in the process of development of my personal plan, with the cooperation of the identified support persons, in order to formulate a vision on what I would like to and could achieve, (identification of realistic short-term and long-term objectives with the involvement of which support persons), formulation of difficult moments and challenges and development of coping strategies.

Maintenance of a contact and communication with the facilitator and participation in procedures and meetings organized by the facilitator.

Participation in project related research on possible approaches and measures for implementing supported decision making and the actual impact of supported decision making on the quality of my life.

Documentation of project stages and results through:

Camera recording	NO	YES
Participation in interviews	NO	YES
Presentation of results and information on my participation before councils set up under the project	NO	YES
Photographs	NO	YES

Use of my personal data in view of implementing project activities and in line with Bulgarian legislation.

Public communication of project results.

The in-principle consent for documentation granted herein may be withdrawn by me, at my own discretion, after receiving information about specific documentation related materials.

I hereby agree that the overall summarized experience in relation to my personal involvement in the project can be used for motivating future changes in Bulgarian legislation in relation to the adoption of supported decision making and amending the regimes of guardianship in order to ensure the adequate enforcement of Art.12 of the UN Convention on the Rights of Persons with Disabilities.

Date.....

Signature:

**CONSENT FORM FOR PARTICIPATION  
IN A SUPPORTED DECISION MAKING PILOT PROJECT**

**“Paradigm Shift in the Context of Art. 12 of the UNCRPD. Looking for Solutions for People with Mental Problems”**

I, the undersigned....., Personal ID No....., address....., acting with the consent of the guardian....., Personal ID No....., hereby agree to participate as a supported person in a pilot project for supported decision making aiming to establish a network to support me in the decision making process in my day-to-day life, by respecting my preferences and personal choices and my right to exercise my rights through personal actions. I hereby agree to take part in project stages as follows:

Identification of the circle of persons in the community whom I trust, are important to me and who could take part in my support network. In case no such persons are available, I hereby agree to be supported, with the cooperation of the facilitator, in establishing such relationships of trust.

Participation in the process of development of my personal plan, with the cooperation of the identified support persons, in order to formulate a vision on what I would like to and could achieve, (identification of realistic short-term and long-term objectives with the involvement of which support persons), formulation of difficult moments and challenges and development of coping strategies.

Maintenance of a contact and communication with the facilitator and participation in procedures and meetings organized by the facilitator.

Participation in project related research on possible approaches and measures for implementing supported decision making and the actual impact of supported decision making on the quality of my life.

Documentation of project stages and results through:

Camera recording	NO	YES
Participation in interviews	NO	YES
Presentation of results and information on my participation before councils set up under the project	NO	YES
Photographs	NO	YES

Use of my personal data in view of implementing project activities and in line with Bulgarian legislation.  
Public communication of project results.

The in-principle consent for documentation granted herein may be withdrawn by me, at my own discretion, after receiving information about specific documentation related materials.

I hereby agree that the overall summarized experience in relation to my personal involvement in the project can be used for motivating future changes in Bulgarian legislation in relation to the adoption of supported decision making and amending the regimes of guardianship in order to ensure the adequate enforcement of Art.12 of the UN Convention on the Rights of Persons with Disabilities.

Regardless of the fact that the person ..... is incapacitated and in line with Art.12 of the UN Convention on the Rights of Persons with Disabilities, prior to putting my signature as a guardian as per active Bulgarian legislation, this consent form was presented to ..... (supported person) in an accessible and easy-to-read format and I hereby confirm that the participation of the person ..... in the project complies with his/her desire and choice, thereby supported by me.

Date..... Signature: 1.....(supported person)  
2.....(guardian)

**CONSENT FORM FOR PARTICIPATION  
IN A SUPPORTED DECISION MAKING PILOT PROJECT**

**“Paradigm Shift in the Context of Art. 12 of the UNCRPD. Looking for Solutions for People with Mental Problems”**

I, the undersigned....., Personal ID No....., address....., hereby agree to participate as a support person in a pilot project for supported decision making aiming to establish a network to support ..... (supported person) who is a ..... of mine in the decision making process in his/her day-to-day life, by respecting his/her preferences and personal choices, his/her right to exercise their rights through personal actions and act in their best interest.

I hereby agree to take part in project stages as follows:

Identification of other persons who could get involved in the support network of .....

Participation in the process of development of a personal plan of the supported person whose network I make part of, with the cooperation of the other identified support persons and the facilitator in order to formulate a vision on what the person would like to and could achieve, (identification of realistic short-term and long-term objectives with the involvement of which support persons), formulation of difficult moments and challenges and development of coping strategies.

Maintenance of a contact and communication with the facilitator and participation in procedures and meetings organized by the facilitator;

Participation in the work of the various councils established under the project, if necessary;

Sharing of experience;

Participation in project related research on possible approaches and measures for implementing supported decision making and the actual impact of supported decision making on the quality of disabled peoples’ lives;

Documentation of project stages and results through:

Camera recording	NO	YES
Participation in interviews	NO	YES
Presentation of results and information on my participation before councils set up under the project	NO	YES
Photographs	NO	YES

Public communication of project results.

The in-principle consent for documentation granted herein may be withdrawn by the person, at their own discretion, after receiving information about specific documentation related materials.

I hereby agree that the overall summarized experience in relation to my personal involvement in the project can be used for motivating future changes in Bulgarian legislation in relation to the adoption of supported decision making and amending the regimes of guardianship in order to ensure the adequate enforcement of Art.12 of the UN Convention on the Rights of Persons with Disabilities.

Date.....

Signature:

## ANNEX 3

### JOB DESCRIPTIONS OF GIP FOUNDATION - SOFIA

#### 3.1 Job description of a support network facilitator for persons with mental disabilities:

##### JOB DESCRIPTION

##### OF

Facilitator of Supported Decision Making for Persons with Mental Disabilities

**NATIONAL CLASSIFICATION OF PROFESSIONS AND POSITIONS CODE – 3343-3006 (in case the persons are employed under labor contracts)**

##### 1. BACKGROUND INFORMATION

Administration	GIP Sofia
Unit	Project, internal No. 0695 “Paradigm Shift in the Context of Art. 12 of the UNCRPD. Looking for Solutions for People with Mental Problems” (2012–2013)
Type of contract	Labor
Contract duration ( <i>from the date of signing</i> )	10 months

##### 2. ORGANIZATIONAL CONTEXT OF THE POSITION (SUBORDINATION)

Director of the Global Initiative on Psychiatry Sofia Foundation
Project Coordinator “Paradigm Shift in the Context of Art. 12 of the UNCRPD. Looking for Solutions for People with Mental Problems”, GIP Sofia
Facilitator of Establishment of Support Networks for Persons with Mental Disabilities

##### 3. KEY OBJECTIVE OF THE POSITION

Support the establishment of support networks for mentally ill persons to ensure their social inclusion.

##### 4. POSITION DESCRIPTION

The facilitator assists clients participating in the program in creating a network of support persons to facilitate their active and independent participation in public life.

In his/her work, the facilitator is led by the principle of individual approach based on client’s will, needs and abilities in order to support the process of emancipation from guardianship and dependence.

The facilitator works directly with program clients, persons nominated by them, support professionals, etc. He/she also plans and takes part in family conferences and meetings when needed.

To achieve good professional competence, the facilitator participates in training, team meetings, supervisions, interventions, etc.

Professional duties may include travel outside Sofia.

## 5. PLACE OF WORK

The facilitators' place of work will be determined based on program clients' needs. Places may be different from the project office, for example:

- clients' places of residence
- support network members' workplaces or places of residence
- government offices and other institutions
- education institutions, employment services, other services, including recreation
- medical doctors' offices – all specialties
- mental institutions
- GIP Sofia services.

## 6. AREAS OF ACTIVITY AND DIRECT OBLIGATIONS

### 6.1 *Direct work with clients*

As part of his/her obligations, the facilitator keeps direct contact with clients referred to the program by performing duties as follows:

- acts like a liaison person for a definite number of users in the process of support network coordination;
- participates in the selection of program clients;
- makes initial contact with potential clients to present the project and, upon their consent for participation, informs clients about program details and program related processes;
- initial interview and defines areas of work;
- ensures users' effective involvement in relation to the implementation of the agree plan and supports their regular participation in the respective planned tasks;
- assists clients in the process of support network identification and maintenance;
- develops a work plan with each client in line with program methodology;
- supports individuals in the process of social inclusion by actively involving and encouraging them in implementing daily activities, recreation, work/volunteering, training and education opportunities;
- promotes in a positive manner the independent living in the community to clients and their circles;
- promotes users' rights, obligations and recovery;
- ensures respect for individuals' ethnicity, religious beliefs and culture in all situations;
- establishes regulated relationships of trust with program clients and their support network members, but with adequate and transparent boundaries;
- provides regular practical support to users and their families/friends to maintain and develop their independent and dignified existence;
- assists individuals and their families in identifying early crisis symptoms by tracking the client's development, their level of functioning and mental status and involving the respective staff;
- ensures the prevention of discriminative practices and signals such activities and stigmatizing attitudes.

### 6.2 *Interventions to establish program clients' support networks*

To assist the creation of a support network, the facilitator:

- establishes contacts with program clients' families/friends to present program objectives and implementation procedures;
- facilitates the process of involvement of persons identified by clients in a support network by establishing contacts, participating in meetings, etc.;
- provides logistic support for organizing support network meetings;
- conducts training of the support network;
- provides need based support and conflict mediation;
- sees to the conduct of support network meetings and implements activities for intensifying meetings, if necessary;

- communicates with different institutions and organizations based on concrete requests and needs;
- sees to the respect of program clients' dignity and authority by support persons.

### *6.3 Information and publicity*

The facilitator contributes to publicizing and distribution of program objectives/results by:

- presenting the program to potential clients, families, friends and other stakeholders and providing information related to work processes and principles;
- presenting the program and program results to other support professionals by taking part in training, discussions and public debates;
- training program users, professionals and families in the rights stipulated in the UN Convention on the Rights of Persons with Disabilities and subsequent needs of changing practices and attitudes;
- participating in media events to present program values and principles.

### *6.4 Feedback, supervision, continuing and advanced training*

To ensure a higher quality of supported decision making services, regular feedback on implemented activities needs to be provided. This happens through:

- participation in team meetings and interventions;
- exchange of information about program advancement;
- committed involvement in supervisions;
- keeping regular documentation on supported decision making;
- specific job related training.

Continuing and advanced training is an additional method for maintaining a high standard of supported decision making activities. Training is a mandatory part of requirements for facilitators. Facilitators also participate in on the job self-training programs.

### *6.5 Crisis interventions*

Facilitators can provide crisis intervention following training. This may include:

- extra working hours
- involvement and close cooperation with other offices/services
- respect and support for the personal circle (roommates, family members, neighbors)

### *6.6 Reporting and administration*

As part of his/her obligations, the facilitator also performs duties as follows:

- takes part in project team meetings to present the activities he/she is responsible for;
- prepares work schedules and plans;
- prepares monthly reports on his/her activities as per preliminary developed report forms;
- participates in the evaluation of project activities' effectiveness by providing feedback, collecting and processing project beneficiaries' feedback;
- participates in the development of methodological guidelines, analyses and other documents regulating project activities;
- takes part in the elaboration of internal reports, reports to the funding organization and in the development of opinions and recommendations as a result of his/her direct work on the project;
- keeps clients' files on a regular basis by complying with confidentiality procedures in relation to project beneficiaries' personal data in line with the provisions of the project, the organization and the Obligations and Contracts Act;
- collects and processes information related to his/her work with clients as per work methodology;
- takes part in activities and meetings to assess the effectiveness of interventions.

### *6.7 General obligations*

Obligations and responsibilities above must be performed in line with the following:

As per personal data protection legislation, each team member shall ensure protection of all personal data, whether on hard copy or electronic media. This includes data related to clients and other team members. The data may not be provided to unauthorized persons and must be considered strictly confidential at all times. The facilitator will handle clients' personal data and other confidential information. It may not be shared or revealed to unauthorized persons. The work with users is based on respect and fair treatment in compliance with clear professional boundaries. The work must comply with office policies, procedures and guidelines, including creation of any conditions and responsibility for promotion of healthy and non-discriminatory work environment. Facilitators will participate in certification, training and development of individual professional plans, as well as in supervision. They may be active members of a network of specialists working with mentally ill people or a supported decision making network. This also includes participation in job related training. The facilitator can also undertake other assignments within the scope of the position to ensure effective service management.

## 7. WORK ASSIGNMENT AND PLANNING

### 7.1 Assignment:

Receives tasks for implementation from the Coordinator of the project "Paradigm Shift in the Context of Art. 12 of the UNCRPD. Looking for Solutions for People with Mental Problems" in line with the functional obligations of the Coordinator of the activity "Peer Support and Network Building".

### 7.2 Planning:

Plans the organization of the implementation of assigned tasks in line with the general and specific terms and conditions of the contract with FOSI.

## 8. RESPONSIBILITIES RELATED TO THE ORGANIZATION OF WORK, STAFF AND RESOURCE MANAGEMENT

8.1 Responsible for the implementation of tasks assigned by the Project Coordinator in line with the facilitator's functional obligations.

### 8.2. Responsible for:

- Provided equipment (office – equipment, furniture, etc.)
- The lawful implementation of assigned tasks within the statutory (specified) deadlines.
- Provision of opinions in the area of the implemented activity in line with the job competency as specified in the job description.
- Keeping in secret confidential data and data for office use revealed in relation to activity implementation and non-usage of this data for own or someone else's interest.

8.3. Being familiar with and complying with the internal regulatory framework of GIP Sofia.

8.4. The distribution of tasks related to the implementation of project activities.

### 8.5. Workplace safety:

Compliance with safety, labor hygiene and fire precaution rules.

As per Regulation No. 3 of the Ministry of Labor and Social Policy, on the job, periodical and emergency instructions are delivered to workers and employees.

8.6. Protection of others' health and working capacity: as per the Internal Rules and Regulations of GIP Sofia and fire and emergency safety rules.

8.7. Protection of confidential information: ensure the confidentiality of the information about program clients in order to protect their rights and dignity by signing a confidentiality form as per the Personal Data Protection Act, the Internal Rules and Regulations and the Ethical Code of program staff.

### 8.8. Interchangeability

May replace another project facilitator provided job transfer procedures are complied with.

May be replaced by another project facilitator provided job transfer procedures are complied with.

## 9. CONTACTS AND REPRESENTATIVE FUNCTIONS

9.1. Internal – Within the work process, maintains relations with other project team members. Interacts directly with the Project Coordinator.

9.2 External – Maintains coordinated relations with BCNL and BAPID representatives, different institutions and services at the local and regional level in relation to supporting the people with mental diseases and building networks in Sofia, as well as with representatives of initiative bodies and committees established under the project.

## 10. PROFESSIONAL ETHICS

Obligated to comply with the Ethical Code of the organization. Respects each user's personal dignity and rights. When pursuing his/her duties, does not distribute personal or job related information that could be detrimental to users' and staff's interests. The employee must be loyal to their employer by not misusing their trust or distributing confidential information and by keeping the organization's good name. He/she may not use the professional knowledge and skills gained in the process of work for the organization for their own financial favor. In events of possible ethical conflicts, he/she must inform their direct supervisor.

## 11. KNOWLEDGE AND EXPERIENCE, SKILLS AND COMPETENCIES

To achieve their objectives, the facilitator must observe the values and use the gained skills in their daily activities by constantly complying with program clients' individual needs. This includes the opportunity to demonstrate knowledge and competencies as follows:

- establishing contacts and community development
- effective time management
- in-depth understanding of the reasons for social exclusion and the consequences for mental health

In addition, the facilitator must:

- like working with people
- be flexible and available
- not allow themselves to give estimation statements in relation to users or their network members that can undermine their dignity
- not act hastily
- be ready to assist with the implementation of daily practical tasks
- comply with ethical principles and ensure respectful attitude toward users
- have a strong sense of personal inviolability
- take care of their own mental health.

### 12.1 Education and/or experience

While no specialized education background is needed for the position of a support network facilitator, the specifics of the job require:

- completed secondary education
- education, life and professional experience in conformity with the supported decision making facilitator's role and responsibilities.

### 12.2 Skills

- Be familiar with the social exclusion experience of other people and be able to channel his/her own and their experience in the direction of problem resolution
- Have good communicative and active listening skills
- Have empathy skills and ability to involve their clients, including clients from ethnic minorities
- Be able to put adequate professional boundaries
- Have hands-on skills in providing day-to-day support
- Be able to provide support for empowering clients and work for ensuring their well-being
- Be able to assist clients in community life involvement

- Be able to commit to long-term teamwork and be open to receiving regular supervision and training
- Be able to participate in the development and practical implementation of quality service provision systems
- Be capable of managing strongly emotional or conflict situations without becoming the center of the process
- Be flexible in their work with families functioning differently from their own family
- Be able to express their position and defend it without going into conflicts
- Be able to communicate in a sincere, clear and concise manner
- Be able to work in various conditions (subject of risk assessment)
- Be familiar with the challenges facing people with mental problems
- Be familiar with the consequences of mental diseases.

Prepared by: Valentina Hristakieva, Director of GIP Sofia

Presented to the employee:

I am familiar with (have a copy of) the job description.

Date:

Signature:.....

## ANNEX 4: QUESTIONNAIRE FOR WARNING SIGNALS

Select the correct answer for each of the following statements:

	Seldom	Just before my condition worsens	Often
1. I don't want to do anything.	_____	_____	_____
2. I am not interested how I look and how I am dressed.	_____	_____	_____
3. I am discouraged by the future.	_____	_____	_____
4. It's hard to concentrate and think properly	_____	_____	_____
5. My thoughts are so quick that I cannot follow them	_____	_____	_____
6. I am estranged from my friends and family.	_____	_____	_____
7. Religion is very important for me.	_____	_____	_____
8. I have difficulty making simple decisions.	_____	_____	_____
9. I am bothered by thoughts which I can't escape.	_____	_____	_____
10. I have trouble with my sleep.	_____	_____	_____
11. I seldom see my friends	_____	_____	_____
12. I feel bad without reason	_____	_____	_____
13. I feel nervous and tense	_____	_____	_____
14. I feel depressed and worthless	_____	_____	_____
15. I remember things with difficulty	_____	_____	_____
16. I eat very little	_____	_____	_____
17. I have difficulty in understanding with my family and friends	_____	_____	_____
18. I have the feeling that people mock at me, laugh and talk about me.	_____	_____	_____
19. I can enjoy the small things	_____	_____	_____
20. I feel extremely tense	_____	_____	_____
21. I speak in a way others don't understand	_____	_____	_____
22. I have nightmares	_____	_____	_____
23. I am too aggressive and pushy	_____	_____	_____
24. I get angry about unimportant things.	_____	_____	_____
25. I have thoughts of self-harm and suicide	_____	_____	_____
26. I often have pains	_____	_____	_____
27. I am afraid of going mad.	_____	_____	_____
28. I have thoughts of hurting or killing someone else.	_____	_____	_____

<b>29.</b> I drink a lot of alcohol and take drugs.	_____	_____	_____
<b>30.</b> I think that parts of my body are changing or are somewhat different.	_____	_____	_____
<b>31.</b> I have the feeling that my surrounding is strange and unreal.	_____	_____	_____
<b>32.</b> I sleep a lot.	_____	_____	_____
<b>33.</b> People tell me that I act and look differently.	_____	_____	_____
<b>34.</b> I think too much about sex.	_____	_____	_____
<b>35.</b> I get in a lot of arguments.	_____	_____	_____
<b>36.</b> I am afraid of situations in which I felt calm before.	_____	_____	_____
<b>37.</b> I lost a lot of weight.	_____	_____	_____
<b>38.</b> I gained a lot of weight.	_____	_____	_____
<b>39.</b> I have the feeling that other don't care about me/ are not interested in me.	_____	_____	_____
<b>40.</b> I have the feeling that other people try to hurt me or make me ill.	_____	_____	_____
<b>41.</b> I have feeling and sensations different from the mentioned above.	_____	_____	_____

If you have other feelings and sensations, please describe them:

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**ANNEX 5**

**ACUTENESS OF WARNING SIGNALS**

Write down your warning signals on the left side of this sheet of paper. Then define the level of acuteness of your warning signals and write a definition on the right side of the sheet of paper.

Warning signal		<i>Acuteness</i>	
1.		Acute	
		Moderate	
		Mild	

2.		Acute	
		Moderate	
		Mild	

3.		Acute	
		Moderate	
		Mild	

4.		Acute	
		Moderate	
		Mild	

**ANNEX 6  
AGREEMENT**

<b>A.</b>	My personal warning signals of deterioration are:

**B.** Since some of the warning signals of deterioration are observed more easily by other people, I ask the people listed below to help me recognize my warning signals, to focus on them and, if necessary, to contact my doctor and / or other health specialist who treats me..

\_\_\_\_\_  
SIGNATURE OF THE CLIENT

\_\_\_\_\_  
DATE

**B.** I agree to help

\_\_\_\_\_  
NAME OF THE CLIENT

To recognize his/her warning signals of deterioration. If you notice his / her warning signals I will discuss them with him / her and will advise him / her to contact their physician or other health specialists. If he / she refuses to get help, I'll wait for a reasonable period of time. Then, if he / she still refuses help, I'll call a doctor or other health professional.

\_\_\_\_\_  
SIGNATURE OF THE SUPPORTER

\_\_\_\_\_  
Date

Relation to the client \_\_\_\_\_



3.																																	
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Acute																																	
Moderate																																	
Mild																																	
Absent																																	

4.																																	
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Acute																																	
Moderate																																	
Mild																																	
Absent																																	

## ANNEX 8

### SAMPLE ANTI-CRISIS PLAN

#### I. When I feel well and OK I

- Feel ...
- Am doing ...
- People say about me...

The things I need to do daily or on a regular basis to continue to feel well are ... (for example - have breakfast in the morning, talk with a friend, etc.)

- ...

What else I like to do:

- ...

People that love to meet often because they help me and make me feel good ...

- ...

#### II. Things that may cause worsening of my symptoms (for example, when \*\*\*\*\*is abroad and I cannot visit him / her, as I like to do, I can ...)

- ...

What can I do when bad things happen (for example – I visit \*\*\*\* when \*\*\*\*\* is on a business trip, I plan to do something else to distract myself during the difficult period)

- ...

What experiences warned me that my condition worsens (e.g. I start making excuses not to see with people whom it is usually nice to see):

- ...

What can I do when I feel that I have warning signals (e.g., talk with my mentor, spend more time for myself and the things I love to do, describing how I feel):

- ...

What shows that things are getting worse seriously? (But I still have a chance to do something!)

- ...

#### III. Crisis plan

Signs that signal to others that they have to do something to take care of me (when you need someone to take care of you it does not mean you cannot have control over the situation)

- ...

Which of these people would you like to do something for you?

- ...

What medications do you take now? ...

Are there drugs that can help in times of crisis? ...

Are there any that you should avoid?

Treatment: acceptable and unacceptable choices ...

- Outpatient
- Hospital

Actions that other people can take that may be helpful

- ...

Actions that should be avoided

- ...

What should the people who support do when I become dangerous for myself and the others

- ...

How long is the action of this plan?

- ...

#### **IV. After the crisis**

I know I'm out of the crisis, when ...

- ...

How I would like to feel when the crisis is over ...

- ...

What is advisable for me to avoid while I recover..

- ...

What should I do to avoid a new crisis during recovery..

- ...

I have a plan for discharge from hospital ...

- ...

Signs that I may be recovering as I wished ...

- ...