



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.

ACTION RESEARCH

*The pilot programs for SDM –
is it possible to learn?*

The current research is prepared by the following team: Dr. Haralan Alexandrov (anthropologist, organizational development consultant and public process development researcher) – key researcher, and assistant researchers – all the team which was involved in the development of the pilot programs: Nadia Shabani (Program Director, BCNL), Pavleta Alexieva (Program Director, BCNL), Marieta Dimitrova (Legal Consultant), Ivan Georgiev (Legal Consultant), Sabina Naidenova (NOPPZU), Iliana Malinova (BAPID pilot project coordinator), Sonya Vladimirova (BAPID Director, Lybka Aleksandrova (RALIZ Director), Ani Andonova (Autizam Association Director), Valentina Hristakieva (GIP Director), Dimitar Germanov (GIP pilot project coordinator), Kalina Stoykova and all the facilitators, supported persons, parents, supporters in the networks, etc.

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THE METHOD

The approach of *action research* may be defined as a method of structuring experiential learning. It was created for the study and promotion of *change in groups*, organizations and communities, and recognizes the key role of *participation* in the process of learning. This method requires the active involvement of the participants in the course of the research. The participants in the change in different roles become researchers of their own activity. The method of study in the course of action is informed by the *ethics of participation*. It affirms that there is no distinction between the researched and the researchers. The resulting knowledge is owned by all the participants in the process who are free to use it for a more informed and successful management of change. Thus the knowledge and understanding already achieved at the early stages of the research are integrated into the next stages of the process of change.

There are many and conflicting attempts to conceptualize the phenomena of reflection in the process of action into a single theory. The most successful are the efforts of Donald Schön and Chris Argyris who are trying to integrate ideas from the theory of reflection of Karl Polanyi and John Dewey and the theory of learning of Gregory Bateson. In his book ("The reflective practitioner", Schön, 1983) Schön distinguishes three contingent modes of practical knowledge: knowing-in-action, reflecting-in-action and reflecting-in-practice. The boom of the reflexive practice in various fields of human activity is associated with the accelerated process of technological and social change inherent in the late modernity in which subjects develop increasingly greater capacity to critical reflection on the social conditions of their existence (Beck, 1991). The societies of late modernity develop the ability of "double reflectiveness", as people are beginning to see their institutions and culture as "socially constructed" and to treat in informed and proactive way the social world through the choices they make (Giddens, 1994).

The approach of *action research* was included in this project for two reasons: Because of its suitability for the study of complex and multi-layered process of change and due to its liberating and empowering potential which is in harmony with the values and spirit of the project. Our experience shows that the method works in the Bulgarian context and can contribute to the success and understanding of the transformational initiatives such as pilot projects. Since in this method there is no distinction between the researched and the researchers it is difficult to separate the process of research and learning from the process of change. Here we present the main conclusions drawn from the research in the context of developments in which participants in different roles were involved and which became the reason for reflection and learning through action.

THE CHANGE

Considering how challenging is the supported decision making in our culture, the research team set the aim to monitor and promote the change in the attitudes of the participants in different social roles: users; parents and relatives of the users; facilitators¹; managers and services staff; professionals (doctors, lawyers, social workers and other assisting professionals); significant representatives of the community (administrators, politicians, journalists, opinion leaders).

The role of **facilitators** is key to the understanding of the new practice of supported decision making and its development during the project was a major focus of research and self-knowledge. For this purpose, the participants in this role were invited to do self-analysis and to share their self-reflections in a group reflection. It helped to understand and utilize various aspects and parameters of the role in the context of the existing legal, institutional and professional environment. The research showed that the role of the facilitator is not without problems in terms of perception and practice in Bulgarian conditions. It is perceived through the experience of other known roles, usually that of the social worker and the person in charge of the case: *"The elements of leading the case cannot be passed up. Some aspects of social work - in any event"*. Sometimes the requirements of the role lead to a conflict of identity: *"For me, facilitation cannot prevail upon my professional identity. I am a social worker with some uncharacteristic function in this case"*.

As a result the experience accumulated in the project and the reflection on it the role of the facilitator became real and distinctive in the participants' perceptions: *"Work is done towards revealing the desires of young people. Structured and in a protected environment yet more concrete social situations are discussed, giving space to the young people to look for solutions and to deal with crisis situations"*. *"We started to ask ourselves more often – do we give the right of choice to people with intellectual disabilities or simply decide for them what is best for them, but not according to them"*. An important lesson is that in order to successfully perform their role the facilitators also need a supportive and friendly environment and an adept with whom to discuss their doubts and to maintain their belief in an environment that asserts control on patients which is tighter than their rights.

It turned out that for the **users** themselves the adoption of the new practice is not seamless either. Initially they perceive facilitation as something incomprehensible and abstract. For users who are victims of custody and have developed a learned helplessness it is difficult to see the process of decision making separated from the specific problematic situations in which they are immersed. Attitudes change with gaining experience of supported decision making. Some clients are able

¹ More for the role of the facilitator as social intervention can be found in *Guidelines to the exercise of rights*, Sofia 2014.

to use the support to achieve specific life goals. In others the change occurred in the relationship between them and an important person in their environment: *"The way people think about themselves and their capabilities is changing - they use the group for support to become more active and independent"*. The people with intellectual disabilities participating in the project become active participants in the preparation of profiles and in the planning of their lives: *"Their opinion is important and it counts."*

Initially, **the families** of users have difficulty understanding the meaning of supported decision making and perceive the new practice as an opportunity to unburden of the care for the mentally ill: *"The relatives want to replace them ... to do away with this commitment, someone else to take it on... Someone else to take care for them"*. *"The parents cannot trust their children. They think that children do not know what they want, they have difficulty formulating their desires"*. For understandable reasons relatives often have fears and resistance to outsiders becoming involved in a support network. As the project evolves, users' parents will see a possibility for their children to have a future after they will no longer be able to care for them: *"The parents started naming their fears. They ask questions regarding their future: where they will live and will they be protected, who will support them in their daily lives, what occupation would be appropriate for them, will they have any friends and how to be supported in their social- emotional relationships, can my child make a choice - where to live , where to work , and others "*.

Piloting the new practice allows to identify deficits of **care and services** in the community. *"One of the general findings of facilitators was that supported decision making cannot happen in a vacuum of social services. If people do not use other social services which allow them to work on their other problems they either do not use facilitating effectively or they push the facilitator to take the role of the person in charge of the case or of a social worker. In other words, in the absence of the necessary social services clients begin to recognize the facilitator as a service provider and to require from him/her support and assistance"*. By the end of the project the staff from different services who participated in the preparation of personal profiles for persons with intellectual disabilities changed the method of work and placed the person in the centre and respect his/her wishes. The main change in the method of work is that seminars and activities are organized largely "through" the young person, his/her wish and personality. Encouraging the activity of clients requires more effort by the facilitators and managers, but they perceive this as a success: *"It's an inconvenience worth suffering. It makes sense."*

Social transformation related to empowerment of disenfranchised individuals and groups is perceived with more difficulty by the representatives of **professions** and the social roles which exert the greatest institutional power - in this case these are psychiatry and law. Professionals are sceptical, for them interventions with "trusted" close people who matter to the person, and especially to "respect" the results of this remain highly risky, difficult and seemingly less effective.

Somewhat surprisingly, practising judges were more open to the change than the educational establishment in law schools which emerged as the proponents of conservative values and attitudes. Lawyers directly involved in the project have evolved in their views and understandings

about the nature and the role of law as a regulator of social relations : *"The pilot projects helped us see the practical unsoundness of the now existing regime of partial and full guardianship and to realize that this regime does not protect the rights of people with intellectual disabilities or mental health problems - rather it creates conditions for abuse and puts them in an even more vulnerable position".* The experience from the project helped the lawyers involved in it to abandon the arrogant view of law as a social knowledge of the highest order and to develop a more humble idea of its role and meaning: *"Legal education creates the wrong idea that you have an answer to everything when the answer is dressed in law". "Law should intervene only when there is a need to establish a certain position (public relations) in a certain way so that it is true (obligatory) for all other persons. This indicates that efforts are needed to interrelate the social and legal part in the care for man".*

Regarding the **attitudes in the community** the starting point is unfavourable: the environment demonstrates ignorance, scepticism, conservative and suspicious attitude towards the idea of supported decision making. Initially both the social services and the family and the users themselves looked upon the support network more as a new service than as an empowering and inclusive social structure. The project changed the way of thinking about the issues of restriction of legal capacity: *"Attitudes to restriction of legal capacity have changed ... The people in the team have begun to think more about whether it's OK – restriction of legal capacity". "In promoting the project and also due to the involvement of outsiders in the Advisory Board and in the support networks the attitudes of the local community to persons with intellectual disabilities and their capabilities are changing".*

CONCLUSIONS AND LESSONS

Supported decision making can change the way people with severe mental disorder perceive themselves, their capabilities and resources and the extent to which they can influence their life in the present or in the future. The way people around them - involved in their lives in formal or informal ways - think of them may also be changed. In turn, the change in the mentality can lead to concrete changes in people's lives.

At this stage the resources available in the environment are insufficient to build a successful and sustainable support networks - the relationship between users and their relatives are often tense and conflicting, marked by alienation or painful dependency. This suggests the need for some modification of the approach. The users need a "launcher" - someone who can create an initial structure and give them an initial push and thus allow them to "gather momentum" and gradually become autonomous of this support as well.

Pilot projects have shown that people, whether they are "normal" or suffer from mental disorder or have a learning disability have similar values, aspirations and expectations (for example for all of us it is important to have control over our lives and to make our own decisions) . In this regard, it was important to recognize that the measures relating to the implementation of the Convention² should be neutral towards disabilities and be aimed at all (the so-called mainstream approach).

The project introduced in the Bulgarian environment a different type of ethical thinking – *the ethics of concern*. The ethics of concern arises in response to unsatisfactory solutions to dilemmas related to natural and emotional relationships which the ethics of justice (the law) and the utilitarian ethics (politics) offer. The ethics of concern is particularly relevant to the practice of the helping professions - healthcare, social work, special purposes education, etc. - that require the establishment of relations of trust, care and support between the practitioner and his/her patient or client.

² UN Convention on the rights of people with disabilities, 2006; ratified and in force for Bulgaria from 2012.