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Cost Benefit Analysis of Supported Decision-Making

BCNL, 2014

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INTRODUCTION

Historically, people with mental health problems (MHP) and intellectual disabilities (ID) have been placed under legal guardianship regimes, losing the right to make their own choices about life issues such as where to live and whether to work, marry, or receive health care. Supported Decision-Making (SDM), by contrast, offers an opportunity for adults with disabilities to make their own decisions, consistent with fundamental human and legal rights, and an emerging international consensus.

SDM is a process in which adults who need assistance with decision-making receive the help they need and want to understand the situations and choices they face, so they can make life decisions for themselves, without the need for undue or overbroad guardianship. Introduced as part of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), SDM can be a key element for improving experiences and opportunities for many people with mental health problems and intellectual disabilities.

Article 12 of the CRPD challenges the existing system of guardianship. It pushes us to move toward a new framework where people are supported to be their own decision-makers. Article 12 recognizes that all people have legal capacity and that governments must take appropriate action to provide people with access to the supports they need and want to make their own decisions and order their own lives to the maximum of their capabilities.

The present cost-benefit analysis is implemented within the Program “Art. 12 – Next Step in Bulgaria” (2012-2014). The pilot program started in October 2012 and is implemented by the partnering organizations Bulgarian Center for Not-to-Profit Law (BCNL), Global Initiative in Psychiatry – Sofia (GIP), the Bulgarian Association of Persons with Intellectual Disabilities (BAPID), and the National Organization of Mental Health Services Users (NOMHU). It is aiming at support of the practical application of the models for supported decision making in the country by covering of a minimum of 40 persons with intellectual disabilities and mental health problems. The main purpose of the project is to coordinate the activities of the partners within the program (testing approaches for supported decision making for persons with mental health problems and persons with intellectual disabilities), as well to support the preparation of adequate legal mechanisms and regulations, that can guarantee ability of persons with disabilities to exercise their rights.

In the course of the program evidences from the fieldwork within the pilot projects in Sofia and Vidin (BAPID) and Sofia and Blagoevgrad (GIP) came in support of the thesis that the supported decision making not only has its benefits for the people with disabilities in terms of securing their legal rights and improving their quality of life, but also represents a cost effective practice for the society.

The present analysis is the first attempt to provide evidence that SDM as alternative to guardianship system is beneficial to both the persons with ID and MHP and the society not only in terms of non-monetized effect – increased QL and consistency with UNCRPD, but also from merely economic perspective. Regardless the scarce statistical data, the short period of time and the small scale of piloting SDM in Bulgaria, the authors of the report believe that at this initial stage of introducing SDM mechanisms the presented methodology, results and the conclusions in this initial cost-benefit analysis can serve as a basis for future research based on more exhaustive data at a more advanced stage of the process of advancing SDM in Bulgaria.

Regardless the indisputable prove that SDM has also economic benefits for the society, we believe that the financial benefits should only serve as an additional secondary argument for making policy choices regarding the necessity of introducing mechanisms for SDM. The non-monetized benefits that cannot be expressed in financial terms have in the case of SDM much bigger value. Quality of life, respect for human rights, independent living and inclusion in the community for people with ID and MHP are “priceless” benefits that give the strongest argument to policy makers.

The analysis is divided into four parts. It begins with presenting the overall objective of the cost benefit analysis of SDM and the basic question it addresses. In the first part is given an overview of the analytical frame and explanation of the key concepts as well as the limitations of the analysis that need to be taken into consideration, when reading the report. In the second part the presentation and interpretation of the results for the non-monetary benefits of SDM is presented. It discusses the effects of SDM mechanisms on the quality of life of people with mental problems and intellectual disabilities, the protection of their civil rights, independent living and inclusion in the society. In the third part are explored the potential financial costs and benefits for the society of SDM vs. guardianship. It includes comparison of the financial cost of the interventions SDM and guardianship, the financial benefits of the potential changes as results of SDM in the usage of social services and some health services, as well as a rough estimation of the benefit for the society of the employment of persons with mental problems and intellectual disabilities. Finally it concludes on the answer on the basic question set at the beginning of the analysis - do the benefits of SDM exceed the costs?

CHAPTER 1. KEY CONCEPTS

Guardianship

Guardianship is defined a legal relationship established by a court process between an adult who is deemed to lack the requisite legal capacity to make personal decisions and the person appointed to make decisions on that adult's behalf¹. The legal mechanism of guardianship exists in some form in almost every country and is widely accepted as a means of protecting individuals who are deemed incapable of managing their personal affairs as a result of a mental health problem, intellectual disability, degenerative disease or profound physical or sensory disability. Guardianship is established through court proceedings, or a combination of court and administrative processes, during which adults are found to either partially or completely lack capacity to make decisions on their own behalf. The outcome of such findings is be that an adult is 'legally incapacitated'. Bulgarian legislation does not provide for any alternatives for protection of the person and his/her property, security, liberty, etc. other than guardianship.

Guardianship has a profound effect on the lives of those placed under its status. In many cases adults who are placed under guardianship lose their right to make even the most basic decisions as well as the right to exercise other fundamental human rights. The effectiveness of guardianship as an institution heavily depends on certain personal qualities of each guardian, such as their competence, diligence and conscientiousness. Abuse and neglect of an adult can result from a guardian.

Supported Decision making

Supported Decision Making as an alternative to guardianship is premised on the fact that with proper support, a person who would otherwise be deemed to lack capacity is, in fact, able to make personal decisions. Supported Decision Making is referred to in the Convention in Article 12 on Equal Recognition before the Law. Article 12(3) provides that States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. SDM as a community based skills building model of support, which empowers people with intellectual disabilities and mental health problems to make and communicate decisions about their lives. Supported Decision Making model assumes that all people have will and, which can be built into autonomous decisions when people are supported to do so. It recognizes that "people with disabilities have histories and aims"² which are expressed through the decisions they make. In supported decision-making, the individual is always the primary decision maker, but it is acknowledged that autonomy can be communicated in a number of ways, thus provision of support in different forms and intervals can assist in the expression of autonomous decisions. SDM can take various forms: support networks of family and friends, peer support, advance directive, nominated representatives, and/or personal ombudsmen, facilitated decision-making, etc.

Guardianship vs. supported decision making

In the guardianship system an adult's decision-making is substituted: it is the guardian who makes decisions on behalf of the adult with disabilities and in his or her 'best interests', and very often against his/her wishes and preferences. SDM means that the adult himself/herself makes the decision. Instead of making decisions in the name of the adult, supporters assist the person to reach and communicate his/her own decisions. While the guardianship system is based on a relationship of paternalistic subordination, where guardians 'know what is good' for the adult, the core principle of supported decision-making is a relationship of trust between the person with disabilities and supporters.

In guardianship systems, guardians are appointed by a court or other authority, and can be either a social welfare centre or the guardianship authority. Supported decision-making, on the other hand, is based on

¹ Mental Disability Advocacy Center (MDAC).

² The United Nations Handbook, Chapter Six: From Provisions to Practice: Implementing the Convention, <http://www.un.org/disabilities/default.asp?id=242>

the free agreement of the adult and supporters. In other words, supported decision-making consists of a voluntary relationship between the adult and his or her supporters.

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

Overall objective of the analysis

The overall objective of the analysis is to provide policy makers with information about policy choices aiming at achieving the overall goal - Quality of life of ID and MHP and life in community in ways consistent with Art. 12 UNCRPD. One of the main outcomes from the program Next Step was the finding that it is impossible to implement SDM for people who are not leaving in community. This is the reason that in this analysis the observations are made on the indivisible relations between article 12 and article 19. The analysis focuses on exploring the costs and the benefits of SDM as an alternative intervention to the existing system of guardianship. The research analyses and makes conclusion on the monetized and non-monetized costs and benefits of SDM in the country specific situation of Bulgaria in comparison to guardianship, but always in relation to the overall goal. Therefore the aim is not paying a “low price” as a society, but achieving improved QL for ID and MHP and life in community in ways consistent with Art. 12 and Art. 19. The analysis of the costs is the net effect on the aggregate value of the intervention SDM and is done by determining the change in the total resources of society caused by it. But as such it can be only an additional matter with secondary importance when policy choices are to be made. The desired outcome always comes first and represents the biggest benefit for the society that cannot be expressed in monetary units.

The analysis presents a broader perspective on the monetized and non-monetized benefits and the costs of the intervention SDM rather than reducing the analysis to a simple ration of costs.

The cost-benefit analysis of SDM is designed in view to this outcome to address the following Basic question:

Do the benefits of Supported Decision Making exceed the costs?

COST-BENEFIT ANALYSIS OF SDM

OUTCOME: Improved QL for PID and PSP and life in community in ways consistent with Art. 12 and Art. 19



Analytical frame

In view to provide information for policy choices the analysis explores what are the costs and the benefits of SDM for the society “as a whole” in comparison with the existing intervention – guardianship. Therefore we say that the analytical perspective of the analysis is the one of the society.

The analysis frame is elaborated on the basis of dividing the analysis variable in two big groups – A. Non-monetized benefits and B. Monetized costs and benefits. The authors of the analysis defined all the variables in relation to the overall goal – the desired outcome of the interventions: *QL and life in community in ways consistent with Art. 12 and 19*. The analysis is structured according to the table below.

In order to answer the basic question: *Do the benefits of SDM exceed the costs?* The hypothesis is that the listed variable are either a cost or a benefit for the society as assumed in the table below. For each of the variables the collected data has been analyzed in view to providing evidence that the assumptions in Table 1 are correct and the listed variable are indeed a cost or benefit for the society as follows:

Table 1. Analytical frame

Analysis variables are designed in view to the desired outcome and express the costs and benefits (monetized and non-monetized) related to SDM as alternative intervention to Guardianship.

	ANALYSIS VARIABLE	Analytical perspective Society as a whole
I.	Non-monetized Benefits of SDM	
1.	Increased quality of life	Benefit
2.	Equal recognition before the law (Art. 12)	Benefit
3.	Independent living (Art. 19)	
3.1.	- self-determination	Benefit
3.2.	- personal development	Benefit
4.	Inclusion in community (Art. 19)	
4.1.	- interpersonal relations	Benefit
4.2.	- improved education, social and cultural life	Benefit
II.	Monetized costs and benefits of SDM	
1.	Cost of intervention	Cost
2.	Usage of social services	
2.1.	- Housing and Support for living services	Benefit
2.2.	- Daycare activities and consultative services	Cost
3.	Usage of healthcare	Benefit
4.	Employment	Benefit

Analytical Frame of Costs – Benefits Analysis of SDM

Monetized costs and benefits



Non monetized benefits



Methodology

Group of respondents

In order to conclude on the extent to which SDM improves QL of ID and MHP and brings monetized benefits, in November 2013 the research team undertook a 1/measurement of Quality of life and 2/Assessment of the independency level and the perspective of a respondent group of 53 persons with mental problems and intellectual disabilities.

All the respondents are persons with mental health problems or intellectual disability who are either under guardianship or are participants in the pilot projects implemented by GIP and BAPID in Sofia, Blagoevgrad and Vidin.

The characteristics of the respondent group are as follows:

- 36 persons (16 with ID and 20 with MHP) - Participants in the pilot projects of BAPID and GIP who have been under supported decision making for a period of at least 6 months;
- 6 persons (with ID) who are under guardianship and live in the community;
- 11 persons (6 with ID and 5 with MHP) who are under guardianship and live in specialized institutions.

The overall number of interviewees is 53³

The aim is to measure the QL under guardianship and under supported decision making and to compare the outcome.

All respondents signed an informed consent which shortly described the purpose of the study. The informed consent as well guaranteed the anonymity of the respondent. The informed consents were read together and if necessary further explained.

³ Note: one of the instruments used in the research for measuring QL has been Personal Outcome Scale (see description below in this chapter) for the people with ID. This scale has self-report version (which mean that the persons with ID disabilities answer the questions asked by the interviewer themselves) as well as a direct observation version which is filled in an interview with a close relative, friend or a social worker who knows the client well and can answer questions on how she/he sees the client's life events and circumstances Therefore within the research have been interviewed another 22 direct observants (relatives, friends, social workers).

Some tools for the facilitation of communication were used during the interviews with the intellectually disabled clients. When necessary, smiley faces and pictures were used to visualize the questions and to enhance the communication in general.

Instruments

The instruments used in the analysis have been as follows:

1. for analysis of the non-monetized benefits have been used two instruments for measuring QL, namely

- Personal outcome scale (POS) for the intellectually disabled persons. /Appendix 1/
- WHOQoL questionnaire for the persons with psycho-social problems. /Appendix 2/

2. for analysis of the monetized benefits the research has undertaken a desk research on the costs of the different services as well as collecting data from the respondents thought a developed by the research team instrument – open questionnaire for assessment of the level of independency, the needs and the perspective of the clients. /Appendix 3/. The outcome of the QL questionnaires (POS and WHOQoL) has also been used in the analysis of the monetized costs and benefits as a cross reference and additional source of information extra to the open questionnaire. The researchers have also conducted interviews with social workers, family members and professionals from the practice in order to obtain the necessary data. Review of some of the personal profiles and individual plans have also been carried out, following the principles of privacy protection.

Personal outcome scale (POS)

In this research, the POS is used to evaluate the quality of life of the respondent group of ID. The Personal Outcomes Scale has been developed by researchers at Arduin Foundation and Ghent University to measure an individual's quality of life. Principally, the scale was developed to use with people with intellectual disabilities. The POS is based on a conceptual framework, which assumes the multidimensional character of the quality of life concept. The instrument has been proved to have a satisfactory reliability and validity, and is therefore considered to be a valid way to measure an individual's quality of life. Both objective and subjective aspects are measured, by using a self-report version as well as a direct observation version of the scale (van Loon, Van Hove, Schalock, & Claes, 2009). The instrument has been translated from English into Bulgarian and minor mainly linguistic modification have been made

The instrument is scored on a 4-point scale. Self-report and direct observation ratings are transferred onto the POS Summary Profile by the interviewer. The domains are according the Conceptual Framework of Quality of Life (Schalock, Bonham, & Verdugo, 2008) as follows: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being, material well-being. For each of the domains are asked 6 questions. The six item scores per domain form together the 'Domain Score'. The overall number of questions is 48.

Personal outcome scale questionnaire – Appendix 1.

WHOQoL questionnaire – Appendix 2

The questionnaire of the WHO Quality of Life (WHOQoL) is specially designed for persons with mental health problems. It was elaborated with the joint efforts of 15 national centers around the world (WHOQoL group, 1998a). These centers are in countries with different cultures and industrial development. Until now, WHO approved 35 national versions of the questionnaire, among which is the Bulgarian version, adapted by Dr. V. Petkov, Dr. G. Mihaylova and Dr. N. Butorin .

The authors use the model of satisfaction in different areas. This approach reflects the view that quality of life is a subjective evaluation, which is determined by the context, the culture and the values of the individual. So the quality of life is a broader concept of „health", „lifestyle", "living standards", "mental health" and "welfare".

WHO questionnaire aims to assess the quality of life such as the individual believes that it is. That is why the questionnaire is for self-assessment. The respondents simply fill it in themselves and return it to the professional.

Open questionnaire for assessment of the level of independency, the needs and the perspective of the clients.

This questionnaire has been developed especially for the needs of this research and has been structured to cover the life domains in relation to the needs of the clients. The analysis of the questionnaires has been made aiming at determining the “right amount of support” for the clients and also to obtain information about their perspective. For the group of clients from the pilot project the questionnaire has been filled in twice in a period of 6 months measuring the improvement/change of conditions before and after supported decision making. The procedure of interviewing the clients has taken place after the QL measurement in both cases.

Open questionnaire – Appendix 3

Comparison Method

In order to conclude for the QL and the independency level under guardianship and under SDM the following comparison method has been chosen by the research team:

- The participants in the pilots (16 with ID and 20 with MHP) have been measured the QL and independency level twice during the research – once before SDM (in the first weeks after the start of the pilots) and second time (after at least 6 months being within the program with SDM). The scores are compared in order to observe the variation.
- The scores of the participants in the pilots (the results from the second interviews - with SDM) are compared with the scores of the persons under guardianship /in the community and in institutions/.

In both comparisons also the differences between the two target groups (ID and MHP) are noted and discussed.

Limitations

The present cost-benefit analysis is the first attempt in Bulgaria to get an overview of the monetized and non-monetized costs and benefits of SDM compared to guardianship. SDM is piloted in Bulgaria within the program for a very short period of time (six months) and on a very limited scope (around 40 persons). Already this fact sets the ambition of the analysis to serve more as a source of information about the noticeable trends rather than represent a comprehensive and scientifically proven evidence. The results in the different chapters /QL measurement, cost of intervention, usage of social services, healthcare, employment/ are partly based on series of assumptions mainly due to the fact that it is hard to predict the time frame needed for establishing the benefits (especially the non-monetized ones). A lot of the data required for the analysis has been hard to obtain because of the lack of statistics and therefore the analysis doesn't claim for providing exhaustive and exact figures. The method of extrapolation has been used on several occasions and some of the calculations are based on estimations and interpretations but this according to the research team does not effect the recognized tendencies and the overall conclusions.

CHAPTER 2. NON-MONETIZED BENEFITS OF SDM



Quality of life, equal recognition before the law, independent living and inclusion in the community of ID and MHP are the benefits of SDM which cannot be measured with monetary units. They have a higher value for the society than any purely financial benefit and are in fact the main goal and outcome of SDM. This outcome is the position from which in this analysis SDM is compared with guardianship system. Therefore the non-monetized benefits of SDM are explored in this chapter from the following perspectives:

- Quality of life
- Equal recognition before the law (Art. 12)
- Independent living (Art. 19)
- Inclusion in the community (Art. 19)

In order to come to a conclusion to what extent the above 4 categories are indeed non-monetized benefits for the society resulting from the supported decision making interventions, the results from the field research are presented below.

1. Quality of life

THE BASIC QUESTION IN THIS CHAPTER IS:

Is Supported decision making indeed contributing to a greater extend /than guardianship/ to quality of life of people with mental problems and intellectual disabilities?



From QUALITY OF LIFE, supported decision making improves the overall physical and psychological well-being of persons with psycho-social problems and intellectual disabilities by creating a sense of empowerment which in turn gives positive QL outcomes. While guardianship is restricting the person's right to make his own decisions, SDM improves the QL of people with disabilities by empowering them - increasing their self-determination, giving them motivation for personal development and desire for having control over their own life. SDM influences all QL domains and contributes to the overall well-being of the persons with disabilities in many way – it gives them the possibility to execute their rights, to have quality interpersonal relations, to be included in the society, to have a sense of security and belonging to a group and to experience positive emotions and successes.

1. QUALITY OF LIFE: THE CONCEPT AND DEFINITION

Quality of life has been defined in different ways, and many of these definitions reflect the idea that the basic composition of quality of life is the same for everybody – people with and without disabilities. The definition that has been put forward by Schalock, Keith, Verdugo, and Gomez (2009), states that quality of life is “a multidimensional phenomenon composed of core domains influenced by personal characteristics and environmental factors. These core domains are the same for all people, although they may vary individually in relative value and importance». The conceptual framework of quality of life, developed by Schalock, Bonham, and Verdugo (2008) consists of 3 factors (independence, social participation, well-being), which are divided in 8 domains (personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being, material well-being) which are characterized by indicators, as in Table 1. The domains and indicators can be seen and measured in an objective and in a subjective perspective.

Table 1. Conceptual Framework of Quality of Life (Schalock, Bonham, & Verdugo, 2008)

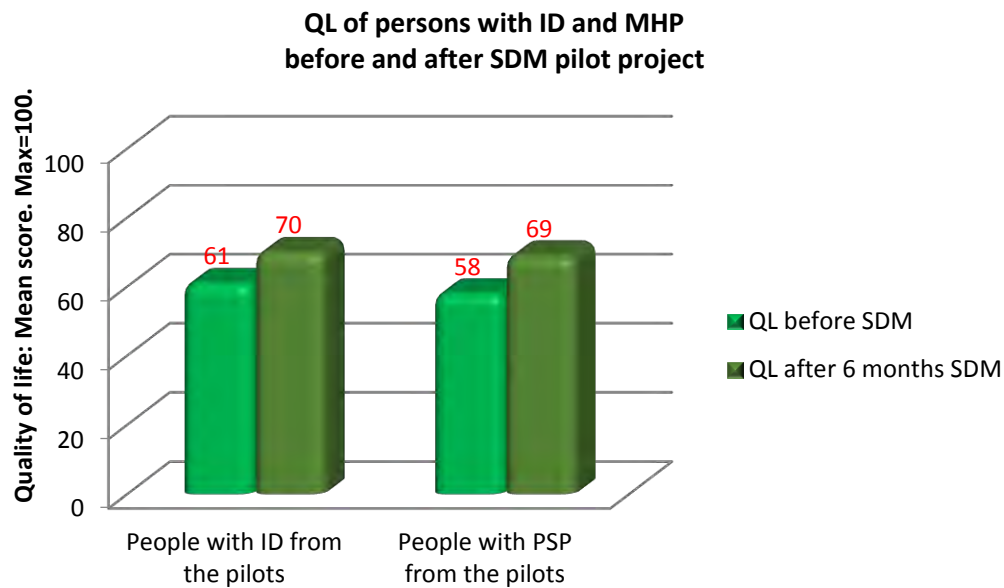
Factor	Domains	Exemplary indicators
Independence	Personal development	Educational status Personal skills Adaptive behavior
	Self-determination	Choices/decisions Autonomy Personal control Personal goals
Social participation	Interpersonal relations	Social networks Friendships Social activities Interactions Relationships
	Social inclusion	Community integration/participation Community roles Supports
	Rights	Human rights (respect, dignity, equality) Legal rights (citizenship, due process)
Well-being	Emotional well-being	Safety and security Positive experiences Contentment Self-concept Lack of stress
	Physical well-being	Health and nutrition status Recreation Leisure
	Material well-being	Financial status Employment status Housing status Possessions

Today, the Conceptual Framework of Quality of Life (Schalock, Bonham, & Verdugo, 2008) is internationally accepted to be a valid and reliable framework, therefore the instruments for quality of life measurement used in the present research are based on it.

2. PRESENTING THE RESULTS ON QL

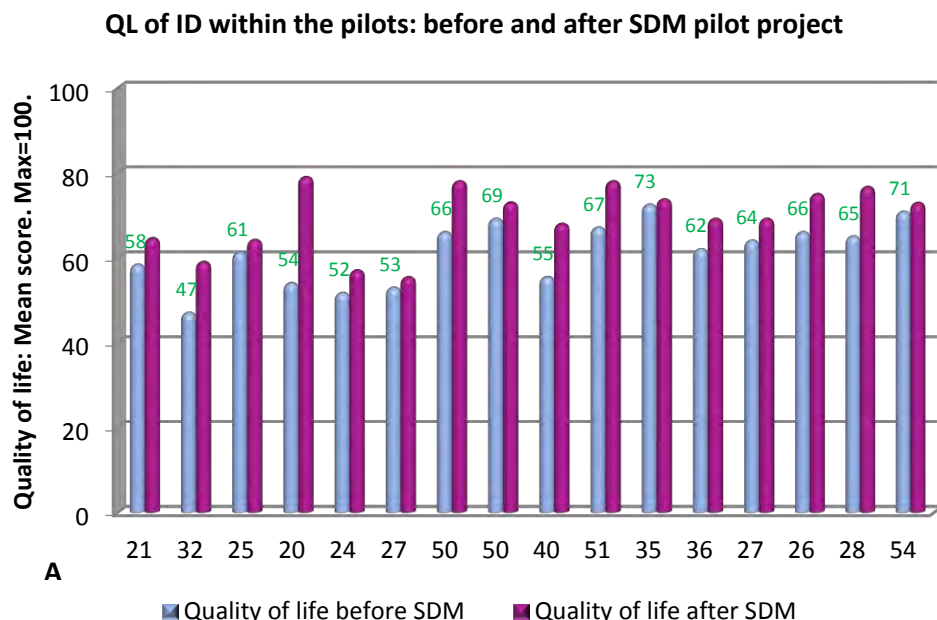
Despite the short period of implementation of the SDM pilot project (6 months), the predominant share of participants in the study demonstrates improvement of their general quality of life after entering in the program. The increase is with average 10% for the two groups.

Chart 1 illustrates the quality of life improvement of the participants in the pilot projects from both groups (ID and MHP)⁴. These are the people with whom the professionals from BAPID and GIP have been working in applying SDM mechanism for a period of only 6 months – mainly support network for the ID and peer support and anti-crises plans for the MHP.



According to the data collected, there is not a big difference in the level of improvement between clients with ID and MHP. Nevertheless clients with MHP demonstrated comparatively higher level of improvement (11%) within the project, regardless of the age factor. No specific correlation between the quality of life and gender of the clients is observed.

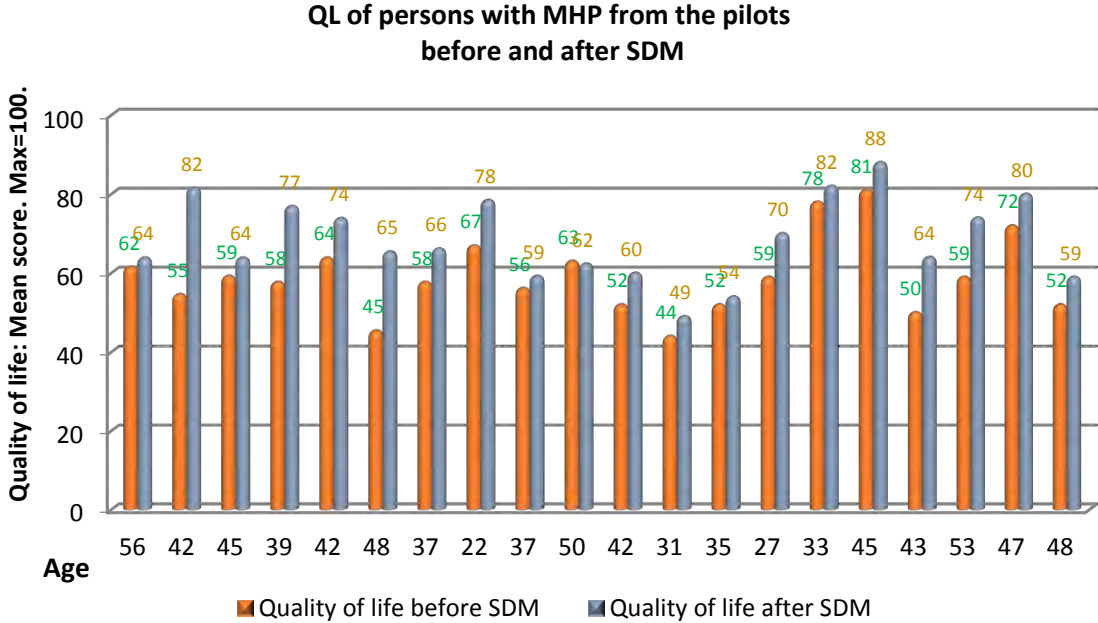
Chart 2 illustrates the increase of Quality of life (general score) of the group with ID before and after SDM in correlation with the age of the participants.



⁴ In order to make possible the comparison between the group of ID and the group of persons with MHP as for each of them is used a different scale (POS for ID and WHOQoL), the scores are calculated in percentages while answering with the highest score on all the questions equals 100% for both scales.

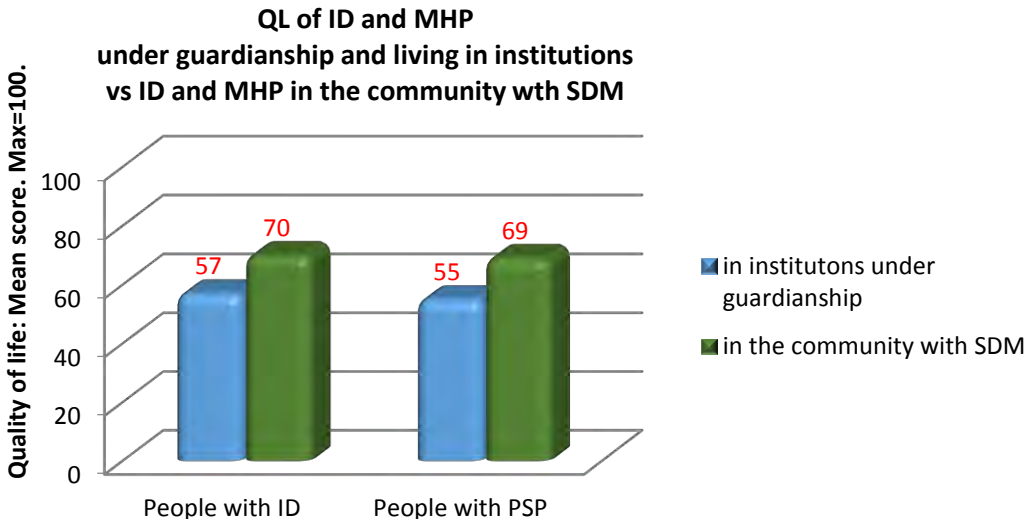
The analysis of the level of improvement shows that clients at the younger age and mild and moderate level of ID and MHP in both groups have higher results, which may lead to the hypothesis that age is also an important factor in positive influence of SDM.

Chart 3 illustrates the increase of Quality of life (general score) of the group with MHP before and after SDM in correlation with the age of the participants.



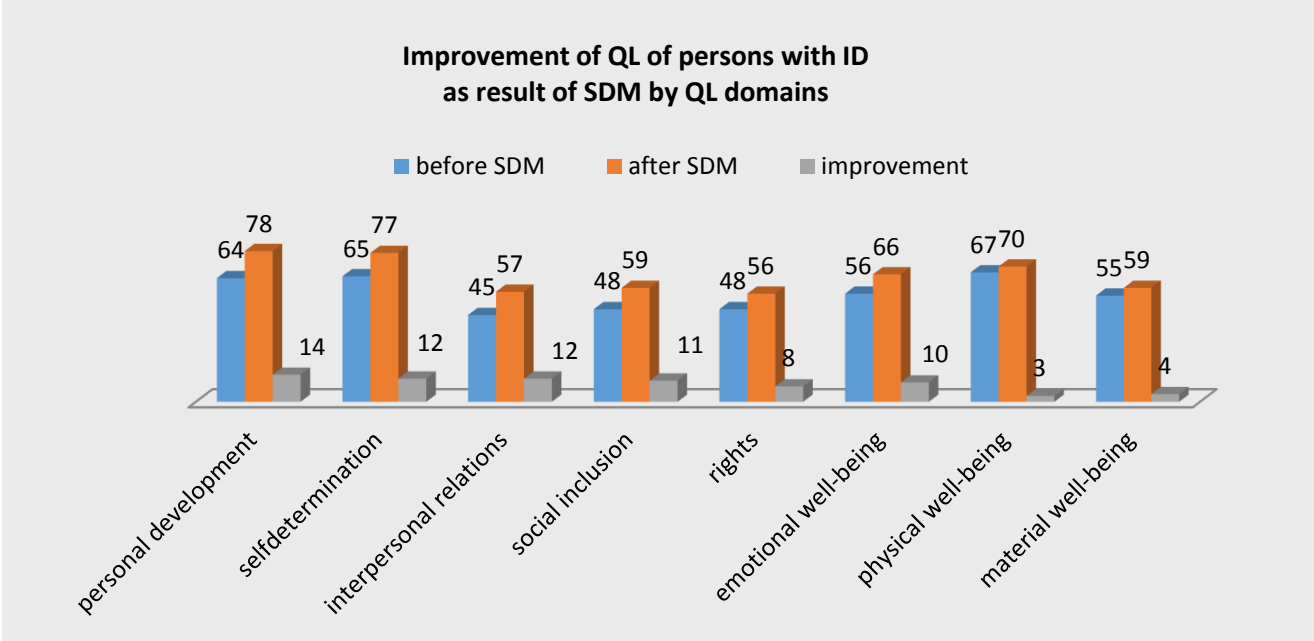
The average age of the participants from the MHP group is 41 years, while of ID group it is 34 years. Still this fact does not effect very much the scores of QL and out of the data cannot be concluded that the younger participants experiency greater QL.

Chart 4. Illustrates QL of ID and MHP under guardianship and living in institutions vs ID and MHP in the community wth SDM



The survey results vary in greatest extend depending on the type and living conditions – lowest QL demonstrate persons accommodated in institutions and living under guardianship. Their level is also sensitively lower than the score before SDM of the persons who live in the community.

Chart 5 illustrates the improvement of QL of ID as result of SDM by the different domains



The analysis of present situation based on the data collected from the research on improvement of QoL of persons with ID and MHP in direct comparison is that, persons with MHP demonstrate an average higher level of QoL in the different domains. However clients with ID achieve greater improvement of their QoL within the pilot project.

Greatest improvement is registered for both groups in domains of Personal development, Self-determination and Interpersonal relationship with an average of 12 percent for all of them. Personal development and self-determination are exactly those two main domains determining and contributing to greatest extend to improvement of quality of life. Significant is the positive change for the predominant part of the persons participated the research in terms of social inclusion (increase by average 10 percent within the implementation of the pilot project). The lowest performance for the both groups of respondents participated the research is in the field of Physical well-being and Material well-being, although these domains are with various (but not with lowest) level of performance. These are indeed the domains (together with Rights) for which it is either not possible with SDM to change some conditions (physical for instance) or it requires much longer time in order to occur improvements (material well-being and rights).

What is noticeable is that for all the participants in the survey without an exception SDM has positively affected the overall QL.

CONCLUSION

Based on the research data it can be concluded that SDM indeed contributes to improving the QL of ID and MHP. Therefore increased QL can be a non-monetized benefit of SDM intervention.

Quality of life –
a Non-monetized benefits of SDM



2. Equal recognition before the law (art. 12 UNCRPD)

THE BASIC QUESTION IN THIS CHAPTER IS:

Can “Equal recognition before the Law” be considered as a non-monetized benefit of SDM? Is SDM indeed contributing to a greater extend /than guardianship/ to “equal recognition before the Law of persons with mental problems and intellectual disabilities?”



For finding the answer of this question the research team chooses not to step on the results from the field research, rather than to briefly discuss the two interventions (SDM and guardianship) from the point of view of UNCRPD. The reasons for this decision are that 1/ the discussion for the consistency with Art. 12 of UNCRPD is on principle level and the arguments are based in the very concepts of guardianship and SDM 2/ the POS scale used in the field research in the chapter “Rights” does not provide enough content information to conclude on this issue⁵. Moreover no substantial deviations in the domain “Rights” can be expected for the short period of 6 months implementation of SDM in the pilots⁶.

Consistency with UNCRPD

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

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

Article 12 of the CRPD represents a so-called ‘paradigm shift’ in addressing legal capacity. This paradigm shift requires recognition of the principle “that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (CRPD Article 12 (2)). This

⁵ In the domain “Rights” in POS the questions are as follows Q25-30: Q25 Does the person have personal items and a place to store them - room or other private space? Q26 Does the person have control on the key from his/her home? Q27 Can the person have a pet if he/she wants? Q28 Does the person have a partner?/ Can he/she have a partner if he/she wants? Q29 Can the person meet with his/her partner as often as he/she wants? Q30 Does the person vote on elections?

⁶ For example – on Q 30 “Does the person vote on elections?” - there have been no elections within the measured period therefore variation in the score cannot be measured.

means that States must not deny legal capacity to people with intellectual or psycho-social disabilities, but instead, must, “provide access by persons with disabilities to the support they may require in exercising their legal capacity” (CRPD Article 12 (3)).

SDM is a way to implement the norm of equal legal capacity. In contrast to guardianship SDM recognizes the personhood of persons with mental health problems and intellectual disabilities and avoids stripping them of their fundamental freedoms.

The main principle of SDM is that all individuals are persons before the law and have a right to self-determination and respect for their autonomy, irrespective of disability. SDM in contrast to guardianship, avoids the use of disabling labels such as “incompetent”. On the contrary - it stands for that all individuals have a will, and this will is capable of being interpreted and forming the basis for competent decision making. SDM is consistent with Art. 12 CRPD and the call for states to provide access to the support that persons with disabilities “may require in exercising their legal capacity.”

CONCLUSION

SDM in contrast to guardianship is consistent with Art. 12 and therefore “equal recognition before the law” can be considered a non-monetized BENEFIT of SDM for the society.

Equal recognition before the Law (Art. 12)– a Non-monetized benefits of SDM



3. Independent living (Art. 19)

THE BASIC QUESTION IN THIS CHAPTER IS:

Is SDM contributing to a greater extend /than guardianship/ to independent living (Art. 19) of persons with mental problems and intellectual disabilities and can it be considered as non-monetized benefit SDM for the society?



Independence is a fundamental value in the society, it is "choosing how to live one's own life within one's inherent capabilities and means and consistent with one's personal values and preferences"⁷. Supported decision-making acknowledges the independence of persons with disabilities. In fact interdependence is a normal method of decision-making for everyone. SDM gives ID and MHP this normality. It makes possible for them "independent living» - freedom of choice, self-determination and opportunities for personal development. Independent living is the converse of being obliged to live one's life as others want that life to be lived, which is exactly what guardianship system is doing.

Self-determination and Personal development according to Schalock's QL frame⁸ determine the independent living. The results from the field research on these two domains are presented below to provide evidence that SDM interventions in the pilot project have contributed to the independent living of the clients.

3.1. Self determination

Self-determination is the degree to which an individual's behavior is self-motivated. Self-determined behavior is "acting as the primary causal agent in one's life and making choices and decisions regarding one's *life* free from undue external influence or interference"⁹. It is a combination of attitudes and abilities that lead people to set goals for themselves, and to take the initiative to reach these goals. SDM empowers people and makes them more self-determined. It is about helping ID and MHP being in charge, making their own choices, learning to effectively solve problems, and taking control and responsibility for one's life. SDM is practicing self-determination. It also means practicing that one experiences the consequences of making choices.

There is a very strong connection between self-determination and general QL. The extent to which a person is self-determined either influences or is influenced by other domains of quality of life and, in combination with these other domains, impacts the overall quality-of-life status.¹⁰

This is also proven by the research over the persons with ID and MHP in the pilot projects who are having SDM. Persons with ID and MHP who report a higher quality of life are also identified as being more self-determined.

Chart 5. Illustrates the measured self-determination level of the participants in the pilot projects before and after SDM

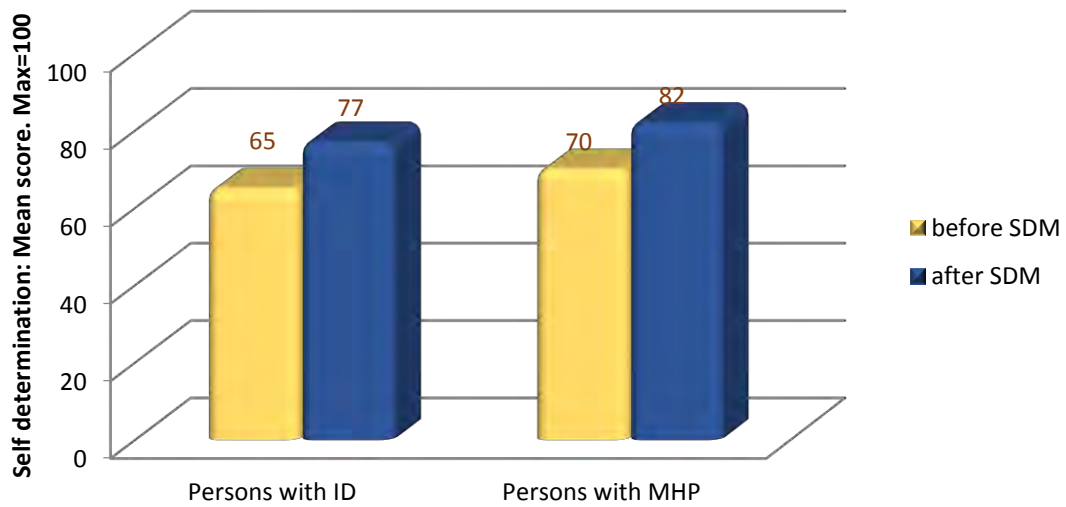
⁷ A. P. Turnbull and Turnbull (1985)

⁸ Conceptual Framework of Quality of Life (Schalock, Bonham, & Verdugo, 2008)

⁹ Wehmeyer & Schwartz, 1998; Wehmeyer & Schalock, 2001

¹⁰ http://jennyhatchjusticeproject.com/sites/default/files/self-determination_quality_of_life_implications_special_education.pdf

**Self determination of persons with ID and MHP:
before and after SDM pilot project**

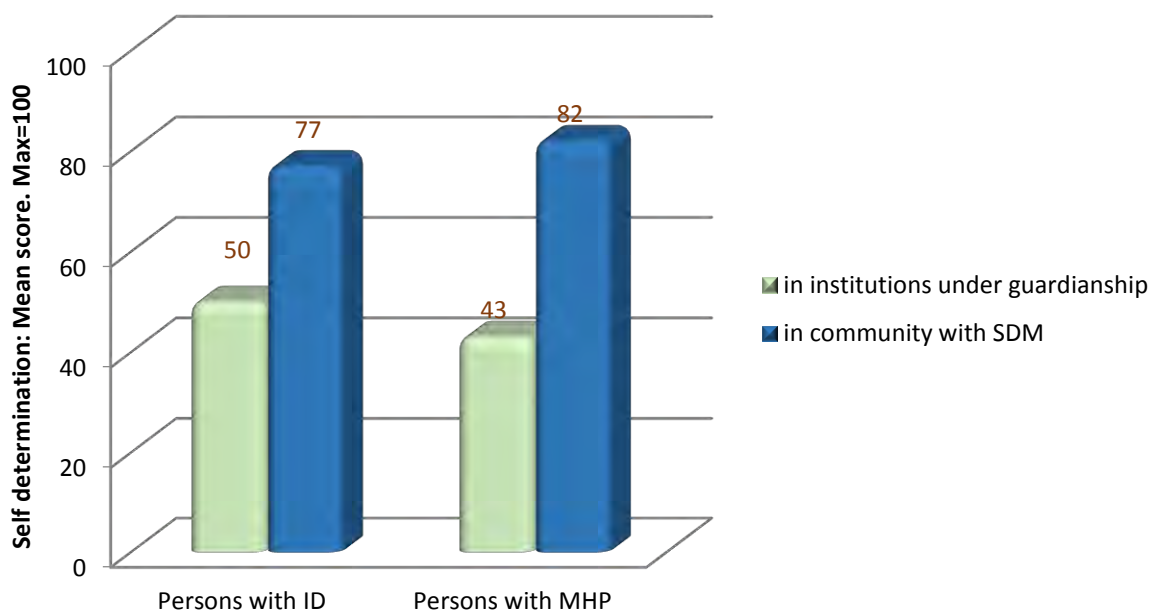


The output from the study demonstrates that there is a sensitive increase in the self-determination level as a result of SDM for both target groups. The mean score of improvement registered for the period of implementation of the pilot projects in both groups is comparatively high –12 percent.

The highest scores for both groups are registered on questions 8, 9 and 10: *Q8. To what extent the person makes free choice when have to be made decisions? Q9. To what extent the person has the opportunity to choose what is best for him/her – even when this choice is not considered by the others as ‘the best choice’? Q10. To what extent are the person’s decisions taken seriously by the others.*

Chart 6. Illustrates the comparison of self-determination between the persons with ID and MHP in institutions /under guardianship/ and the persons with SDM within the pilot projects

**Self determination of persons with ID and MHP:
institutions vs SDM pilot project**



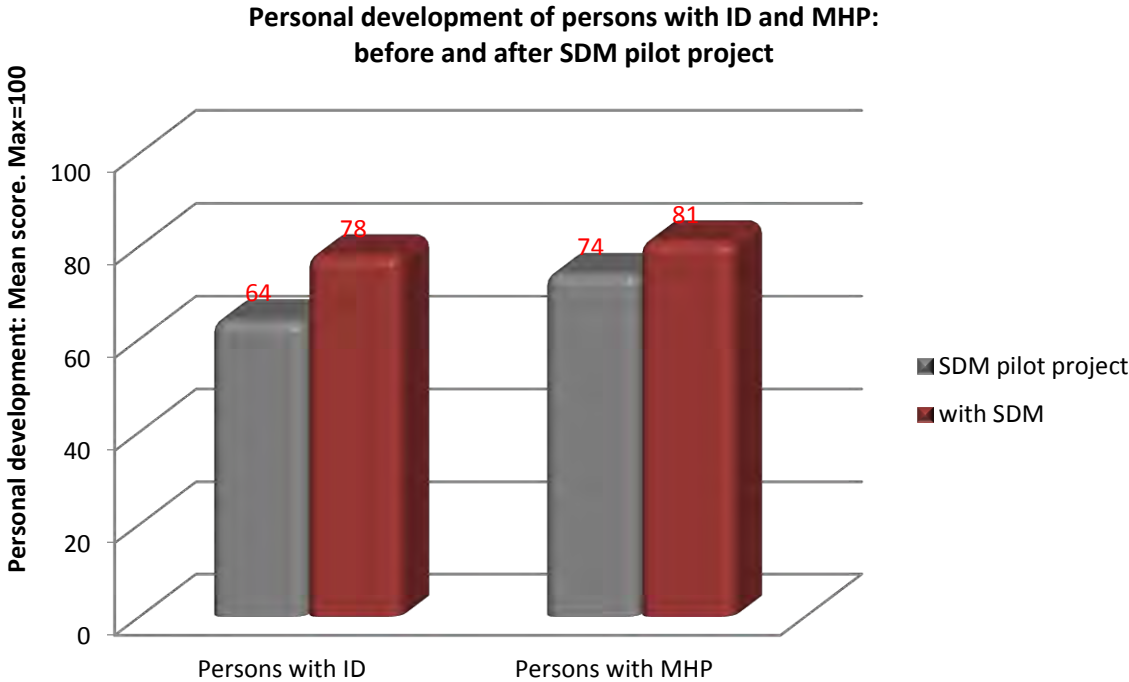
This area of development seems to be the most sensitive in terms of comparison between persons under guardianship in institutions and those included in SDM pilot project. Here are the highest scored margins for the entire research – 27 percent of difference within the groups of persons with ID and 39 percent for those with MHP.

Which comes to prove that self-determination of persons in institutions is very low. The restricted environment in the specialized institutions and the daily regime deprive people from their right to make choices even for the small things in their lives. Institutionalized people have no control over their lives and which is worse – they also suffer from lack of motivation.

3.2. Personal development

Personal development is the other domain of high importance. In this research along with the self-determination ‘personal development’ play the most significant role in determination of QOL. As it can be noted from the data collected, clients with ID traditionally have lower scores compared to those with MHP, however both researched groups demonstrated positive growth of their personal development within the SDM project and especially in applying of newly mastered skills and knowledge and proactive attitude of behavior [Q4, Q5].

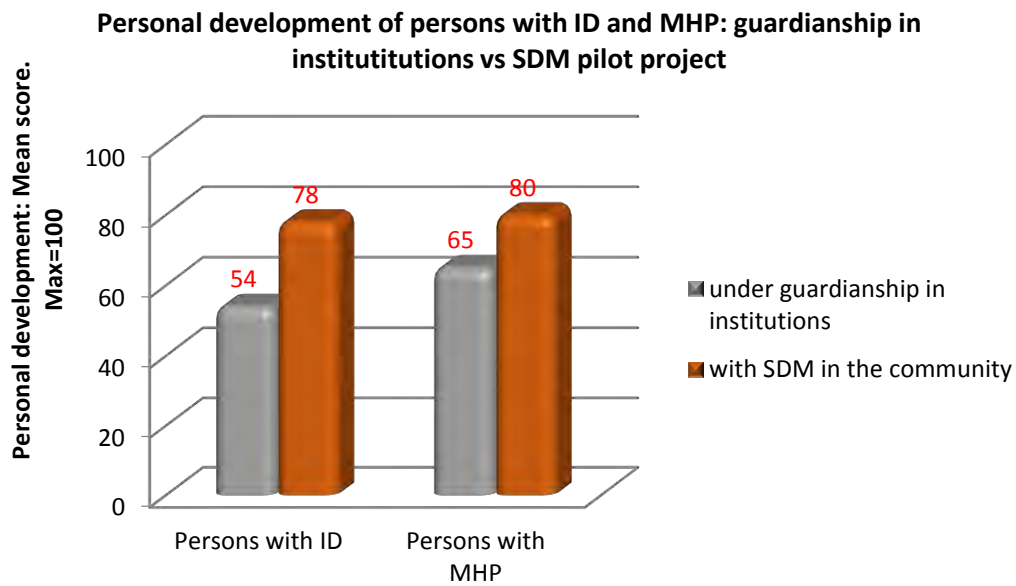
Chart 7. Illustrates the scores on personal development of ID and MHP before and after SDM



Measurements in this particular domain stands out significant change in terms of the two following questions: *Q3 To what extent the person has acquired new skills and/or knowledge for the last 6 months? Q4 to what extent the person uses the new skills and has the opportunity to demonstrate them?*

This means that SDM is giving the people the opportunity to learn new skills and also makes them realize the importance of their abilities. SDM also motivates them to exercising the new skills. The importance of being able to demonstrate abilities is also very important for the respondents and with SDM there is a noticeable change for improved opportunities as people feel more included and have more people to share their experiences with.

Chart 8.



As can be observed from the above chart people in institutions again score much lower on the domain “personal development” than people living in the community (their scores even before SDM). Which once again come to prove that guardianship system and institutionalization of ID and MHP not only restricts person’s rights but also deprives the people from the opportunity to develop and to experience joy from his/her personal growth and the realization of his/her potential.

CONCLUSION

SDM contributes to Independent living (Art. 19) of persons with mental problems and intellectual disabilities through positive influencing the self-determination and the personal development. Independent living can be considered as non-monetized benefit of SDM for the society.

**Independent living (Art. 19)–
a Non-monetized benefits of SDM**



4. Inclusion in community (Art. 19)

THE BASIC QUESTION IN THIS CHAPTER IS:

Is SDM contributing to a greater extend /than guardianship/ to Inclusion of persons with mental problems and intellectual disabilities in the community (Art. 19) and can it be considered as non-monetized benefit SDM for the society?



Supported decision making is a necessary and logical step in creating an inclusive society that guarantees equal human rights and participation of people with disabilities in all aspects of social life.

Although ID and persons with MHP are two distinct groups, stigma is the common reaction to both. This leads to social exclusion and discrimination. Therefore both groups are also likely to face similar barriers to full and equal participation in society. Social exclusion refers to the extent to which individuals are unable to participate in key areas of economic, social and cultural life. The emphasis here is on non-participation arising from constraint, rather than choice. SDM is consistent with the social model of disability says that the problem is not within the individual, but in the society which does not meet this person in such a way that he can function.

The different forms of SDM improve the interpersonal relations and also gives people with disabilities the opportunity to participate actively in the society as full citizens. With SDM they are part of the social life in the community – education, employment, social and cultural life. Moreover only learning how to make decisions is also a reflection of being socially included.

In order to conclude on the effects of SDM on social inclusion we are going to observe the following 2 domains – “interpersonal relations” and “social participation – in terms of improved education, social and cultural life”

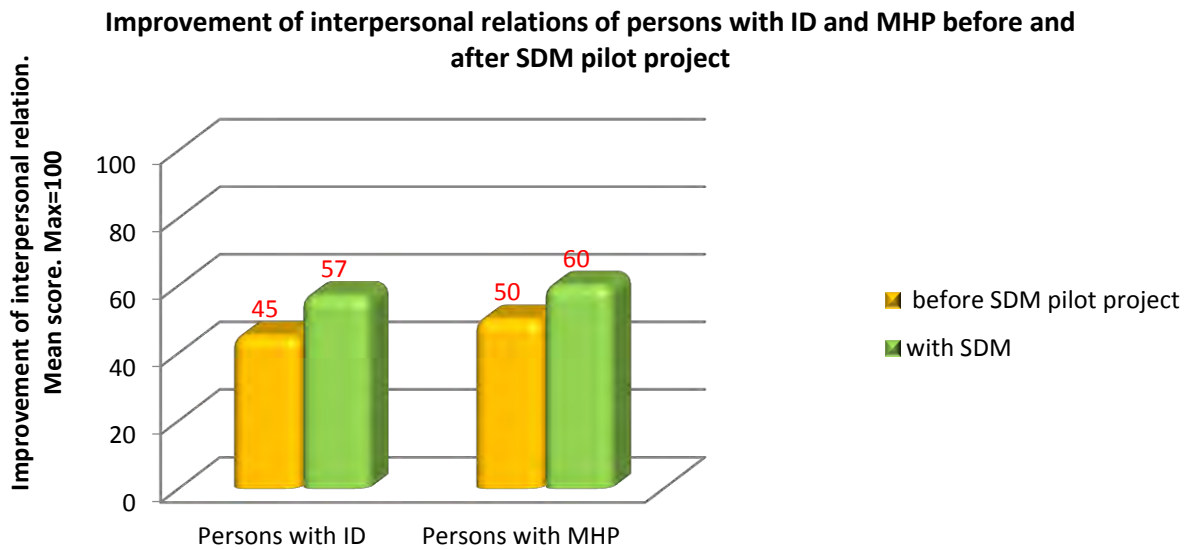
4.1. Personal development

Persons with ID and mental health problems have a great need for social interaction, just like other people. In practice, however it is difficult for them to build and maintain relationships. The social network of these people is mostly limited to family, professional staff members and fellow clients. They also have a strong need for a long-lasting relationship. In most cases, however, this is not always possible and has consequences for their QOL.

Persons with ID and mental health problems deal with a low self-image, as a result of, for example, experiences of failing. By empowering them SDM helps people with ID and MHP raise their self-esteem and also to improve their interpersonal relations. They build stronger connections with their family members, close relatives and friends and feel more emotionally secure. As a result they enter easier and with less fear into new social contacts and widen their personal network /natural supports/. The emotional pressure of the families is also reduced as a result of SDM.

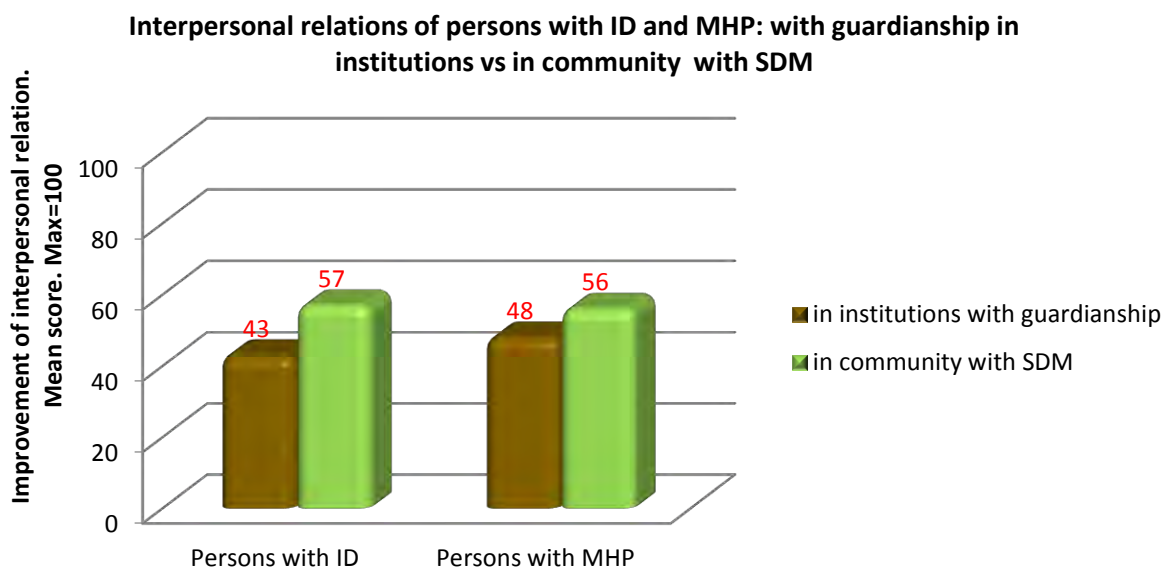
The predominant part of the participants in the study demonstrates significant improvement in the domain of interpersonal relations. Best results are shown in mutual participation with friends and relatives in social activities and support from others [Q14, Q18]. Compared to the other domains, here the interviewed demonstrate a bit lower, but yet positive level of development [Chart 9].

Chart 9 illustrates the improvement of interpersonal relations of ID and persons with mental problems as a result of SDM



The improvement of interpersonal relations is more noticeable by ID (with 10%) although the persons with mental health problems score in general higher in this domain. Possible explanation is their higher IQ and better developed skills for maintaining social contacts.

Chart 10. Illustrates the difference in the domain “interpersonal relations” between persons under guardianship in institutions and with SDM in the community.

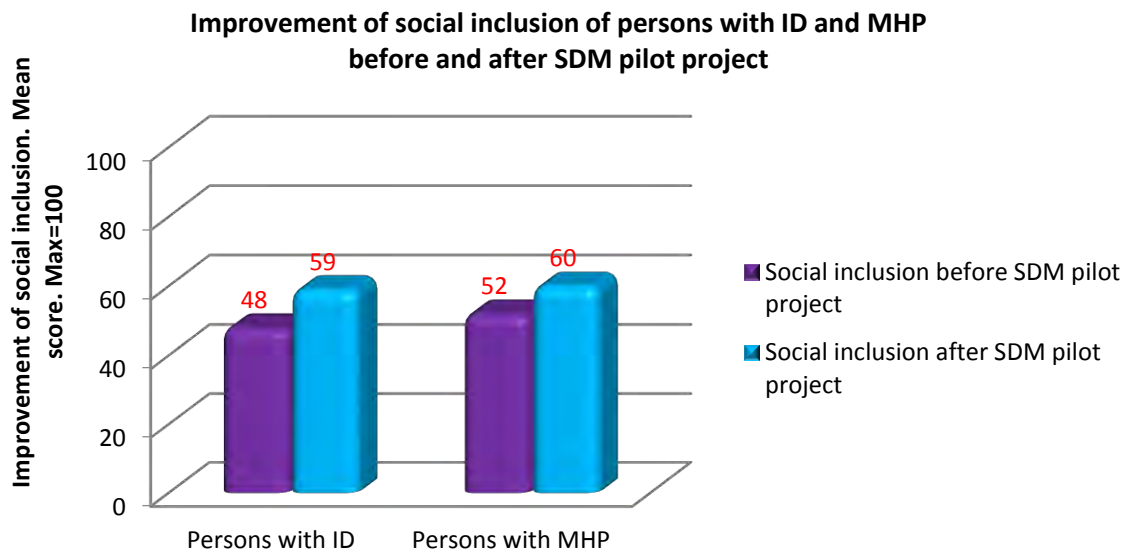


For interpersonal relations persons under guardianship in institutions have lower score (43% for ID and 48% for MHP) than the persons in the community even before SDM.

4.1. Inclusion in the community /improved education, social and cultural life

In terms of consistency with Art 19 – Living independently and being included in community, the conducted study gives inarguable evidence for the quality of social inclusion persons achieve under SDM process. Those who live in community and have been under guardianship and now with SDM indicate that now they participate in activities in the community more often and more freely.

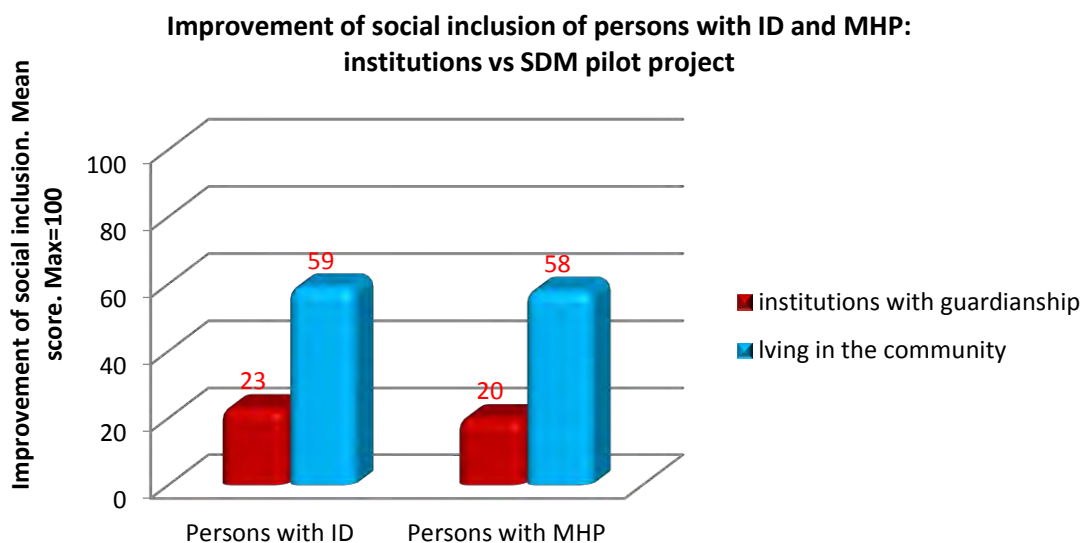
Chart 11.



In general, supported decision making influences positively the social inclusion on both of persons with ID and MHP. The improvement level of ID is higher – 11%. They go to cafes, visit cultural and sport events, use public transport (Q24).

Respondents living in community-based services or in their families have significantly higher level of social inclusion (mean ID = 48, mean MHP=52), compared to those in institution (mean ID= 23, mean MHP=20). This brings the major difference evolving from the strongly limited opportunities people in institutions (and consequently) under guardianship suffer – two and a half (for ID patients) and almost three times (for persons with MHP) lower scores compared to persons participated the SDM pilot project. [Chart 12]. Most visibly this becomes from the following questions in this domain: *Q21: How often is the person involved in activities nearby (Cafe - shops - barber-cinema - religious activities - bus - concert - sport)?* and *Q24: How often does the person participate in social activities (gym, sports, rehabilitation procedures)?*

Chart 12. Illustrates persons with ID and MHP: with guardianship in institutions vs. in community with SDM



The research team doubts for the validity even of these low score. The reason for this is that some of the questions were “do you know your neighbors by name and do you sometimes receive/give help from/to them?” To which the persons in the institutions might have answered having in mind their fellow-clients as their neighbors while in the POS scale by “neighbors” is meant people from the community.

In any case it is indisputable that persons in institutions under guardianship in practice are excluded from the society and their exclusion is not a result of their lower level of functioning (on the contrary some of them clients from the institutions had very mild level of disability) but as a result of the institutionalization as such.

CONCLUSION

SDM contributes to Inclusion in the community (Art. 19) of persons with mental problems and intellectual disabilities through influencing the personal relations and the participation in the community life – education, culture, social life. Inclusion in the community can be considered as non-monetized benefit of SDM for the society.



Conclusion on the chapter non-Monetary benefits of SDM

As set in the beginning the outcome of the two interventions – SDM and guardianship should be “Improved quality of life, Equal recognition before the Law (Art 12) and independent living and inclusion in the community (Art 19)” of people with intellectual disabilities and persons with mental problems. Based on the presented results of the analysis we can conclude that all the aspects of the defined outcome are a fact regardless the short period of piloting SDM in Bulgaria. As result of SDM the society will indeed gain non-monetary BENEFITS in terms of “Improved quality of life, Equal recognition before the Law (Art 12) and independent living and inclusion in the society (Art 19)”.

CHAPTER 3. MONETARY COSTS AND BENEFITS OF SDM



In this chapter are presented the results of the research regarding the monetized costs and benefits of SDM compared with the existing intervention – Guardianship. The research comprises the fields in which the new intervention – SDM would have a cost or benefit that could be expressed in monetary value for the person with ID/MHP or the society as a whole. The research fields defined in view to the desired outcome are as follows:

- Cost of intervention
- Usage of social services
- Reduced usage of Healthcare directly related to the disability¹¹
- Employment

Based on analysis of the available data from the official statistics and the field research out of the pilot projects the research team concludes for each of the four fields what would be the economic effect in BGN of introducing mechanisms of SDM in Bulgaria.

The results are summarized at the end of this chapter – Key findings for Monetized costs and benefits, where the difference (+ or -) in money value (BGN) between the existing intervention (Guardianship) and the alternative (SDM) is presented for each of the four fields and summed up to conclude on the overall result.

1. Cost of the intervention

THE BASIC QUESTION IN THIS CHAPTER IS:

Is SDM less expensive in terms of costs for the intervention compared to guardianship



In order to answer this question the research team has examined the related costs for both interventions for 10 years period to come to a conclusion for the price of each intervention per person per year. The choice for taking 10 years period as the basis of the calculation is due to the fact that both interventions have long term effects and the related costs differ in value in the course of the years from the start of the intervention. The set goal is to find the relative

¹¹ The analysis does not explore the overall usage of general healthcare but provides only an overview of the reduction of psychiatric (hospitals and regular consultations);

difference between the costs, rather than an exhaustive financial picture in exact figures, therefore the calculations are based on the fees and prices of services/goods at the present moment and no possible influences (inflation and other long-term financial factors) are taken into account.

A. Guardianship – cost of the intervention¹²

Brief process description

Bulgarian law employs a two-stage process for establishing guardianship. The first stage is the incapacity process through which an individual may be deprived of his/her legal capacity either partially or fully. This is done through a court procedure. The second is the point at which a guardian is appointed for a person who has been either partially or fully deprived of legal capacity. Courts do not appoint the guardian rather the guardianship authority, an office consisting of local governmental authorities (municipality office), make the appointment. Once appointed, a guardian exercises the person's rights and accepts legal responsibilities on behalf of the person under guardianship. Guardianship in Bulgaria is honorary activity and is not remunerated.

Therefore the costs of guardianship are formed by the following main categories:

Procedure/activity	Cost in BGN per person
I. Incapacitation Procedure	
1. Costs related to the court proceeding¹³	250
2. Attorney's fee¹⁴	150
3. Expert's fee	200
4. Travel, accommodation and daily allowance for the attorney¹⁵	38
5. Travel, accommodation and daily allowance for the expert (if necessary)¹⁶	57
Total I:	695
II. Procedure for Appointment of a Guardian	
Costs related to the guardianship authority for appointing guardian and guardianship board¹⁷	96
Total II:	96

¹² Due to the fact that in Bulgaria there is a lack of statistical information about the costs related to the intervention guardianship some of the data presented in the following calculations is based on information out of the practice and estimations.

¹³ The costs related to the court proceeding are related to the resources spent by the court incl. time of judges, prosecutors and administrative staff. The value is taken from court decisions in cases when after court proceeding the person is not found incapable and the claimant has to pay the court cost which is calculated to amount at 250 BGN.

¹⁴ Art. 7, par. 1, item 4 of the Regulation No 1 for the minimum rate of attorney fees.

¹⁵ The full costs of travel, accommodation and daily allowance is as follows: Travel– 70 BGN, accommodation – 80 BGN, daily allowance – 40 BGN according to the Regulation for the business trips in the country; it is estimated that by 20% of the cases this expenses are necessary as the attorney has to visit another city. Therefore the calculation is based on 20% out of 190 BGN.

¹⁶ It is estimated that the experts need to travel in 30% of the cases. Therefore the calculation is 30% of 190 BGN.

¹⁷ The costs are related to the resources and time spent by the officials for appointing guardian and guardianship board. It is based on the average municipal staff wages of 6 BGN per hour – approx. 16 hours.

III. Operational costs for the 1 st year	
Administrative costs and communication (guardianship authority, guardianship board) ¹⁸	50
Follow-up and monitoring (annual reports) ¹⁹	48
Total III:	98
IV. Operational costs for the period 2 nd - 5 th year ²⁰	
Administrative costs and communication (guardianship authority, guardianship board)	200
Follow-up and monitoring (annual reports)	192
Total IV:	382
V. Operational costs for the period 5 th – 10 th year ²¹	
Administrative costs and communication (guardianship authority, guardianship board)	250
Follow-up and monitoring (annual reports)	290
Total V:	540
VI. Costs of the Bulgarian state for lost cases for violation of human rights before the European Court of Human Rights ²²	25
Total VI:	25
VII. Proceeding for modification and/or termination of the guardianship ²³	250
Total VII:	250
Total cost per person under guardianship for 10 years period:	2 086
Total cost per person under guardianship for 1 year:	208 BGN

Due to the lack of official information on the exact amount of costs for some of the activities in the above calculation are made estimations based on interviews with persons involved in the practice. Without claiming to be exhaustive we can state that the costs of the society related to guardianship for one person per year are an average of **208 BGN**.

¹⁸ Estimation on the annual resources spent by the guardianship authority (municipality) for administration (hours of administrative staff) and communication costs.

¹⁹ Cost related to time and capacity spent on reviewing the annual reports and monitoring the activities of the guardian calculated on approx. 8 hours on annual base x 6 BGN/hour (municipality costs): According to the law they should have more meetings but in the practice they do not have more than 1-2 meeting a year.

²⁰ The costs are calculated on the basis for the 1st year multiplied by 4.

²¹ The costs are calculated on the basis for the 1st year multiplied by 5.

²² The costs of lost cases in Strasbourg is calculated as part of the costs of the intervention guardianship because the guardianship system is in fact the cause for it. It is estimated that in 10 years period there would be a minimum of 5 lost cases as the case *Stanev v. Bulgaria* 2012 which costed to the Bulgarian state 36 000 BGN. Therefore this amount (36000 BGN) is multiplied by 5 and divided by the number of people at the present moment under guardianship (7 102).

²³ This cost occurs every time there is a request/claim for modification and/or termination of the Guardianship. Adults under partial guardianship have the right to request termination of guardianship. Adults under plenary guardianship may only request someone else to file the request on their behalf but have no right to file the application themselves. The procedure and the related costs are the same as the Incapacitation Procedure. Out of the statistics for people under guardianship in the last years requests for termination of guardianship (mainly partial) occurs in 30% of the cases for 10 years period (regardless the result of the proceeding which is often negative the costs are spent). The calculated cost per person is therefore 30% of the full cost (837 BGN).

A. supported decision making – cost of the intervention

For calculating the related costs for the alternative intervention – SDM the following steps have been carried out:

1. Defining the SDM mechanisms that are applicable to the country specific situation of Bulgaria
2. Estimation of the number of people who are potential users of SDM mechanisms
3. Estimation of the costs related to SDM (including initial costs and costs for implementation for 10 years period)
4. Conclusion for costs in BGN per client per year

1. Defining the SDM mechanisms that are applicable to the country specific situation of Bulgaria

The partner organizations under the program “Advancing Art. 12 – Next Step in Bulgaria” (2012-2014) – BCNL, BAPID, GIP and NOMHU with the support of the Canadian experts from IRIS have explored the international experience in SDM in order to design the pilot projects intervention in the best possible way for Bulgaria. They have held numerous meeting discussing the forms and mechanisms of SDM that could be implemented in the Bulgarian practice taking into account the local Bulgarian situation and the specifics of the two target groups (ID and MHP). As a result of the discussions several forms of SDM have been chosen to best suit to the local conditions and have been piloted by GIP and BAPID in the period June-December 2013. Those forms of SDM are as follows:

Peer support

Peer support is a form of SDM which provides the opportunity to people with MHP (mainly) and ID to informally share in small or larger group their experiences, successes and challenges. People with disabilities provide this kind of valuable support to one another, by sharing information and experiences, and providing encouragement. People with MHP find it more useful than people with ID but still it is for both groups a valuable tool to support people to take their own decisions. Peer support requires little recourses as it is on voluntary basis and in most of the cases no paid facilitator is required. In an informal environment users build up skills and knowledge which helps them build self-determination. Recommended frequency of meetings – once a week.

Access to professional specialized support

In a lot of cases people with MHP and ID seek advice and input when making an important decision. This advice should be provided by trained professionals who are aware of the SDM principles and are experienced in supporting people to take their own decisions. This form of SDM is crucial and requires resources for training and motivating professionals (lawyers, psychiatrists, psychologists etc.) and securing easy access to their services for the people with ID and MHP.

Professional mentor

Professional mentor as form of SDM is mainly used by people with MHP. The mentor is holding meetings with the person on regular base (once a month) to help him/her make decisions and resolve difficult situations. It requires resources for training professional mentors and the ongoing support.

Anti-crisis plan – advanced directive

The person with MHP assisted by a trained facilitator and members of his personal network elaborates an anti-crisis plan which outlines his/hers wishes and desires regarding important for the person matters – personal care, health, financial etc. The anti-crisis plan ensures that in

times of crisis when the person is not capable of making decisions those who does will act in accordance to the person's will. This measure is very much used by people with MHP anticipating on crisis. In terms of resources it requires time and the efforts of trained facilitator and often consultations with trained professional (lawyers, social workers, bank experts, etc.). The anti-crisis plan is elaborated once and then on a regular base reviewed and changed if necessary.

Support network

It is a process in which support networks (composed usually of two to four-five persons) help adult people with intellectual, psychological or cognitive difficulties in planning their future lives in the community and decision making on their personal lives, health and funds/property. Supported persons choose independently the people who will help them and include in their networks family members, friends, advocates who they trust.

These unpaid supporters form a personal support network and help the person with disability to gather, understand and consider relevant information about the decision in question, assist the person to weigh pros and cons, predict likely outcomes and consequences or evaluate the available options, communicate the decision and interpret the best will and preferences of the person to third parties.

Establishing comprehensive support networks requires effort and financial commitment for the start-up period. A paid facilitator together with the person and his trusted people elaborates personal profile. The facilitator is present at only the first few meetings of the network after that the support network functions on voluntary base and the facilitator is only called if necessary.

Facilitation

Facilitation (assisting) – (this is the “heaviest” measure): the purpose of the measure is to appoint a facilitator and create individual council to take decisions about the particular person in regard to his will and preferences. Pre-conditions: (1) There is an obvious risk of serious loss of property or immediate risk of serious and irreversible damage for the person or someone from his close circle, (2) the person expressing a preference at a particular time, but they are very much differ from previous will/preliminary injunctions or SDM. Facilitation is limited to facilitating decision-making about (1) where the person lives, (2) disposition of property above a certain value, and (3) the choice of emergency treatment. In terms of resources

Estimation of the number of people who are potential users of SDM mechanisms

In contrast to the mechanism of guardianship, whose idea is to protect a person with deficits by creating restrictions on him, the mechanism of SDM contributes to the person's development (and also improves the context). The person function better thanks to the created new opportunities by which he is helped to overcome his/hers limitations. In this sense, mechanisms of SDM are applicable to a much wider group of people than the scope of guardianship. Many people who would not be under guardianship, as it is not necessary for them, could benefit from SDM, and through the support it provides, they may increase their quality of life and reduce the negative effects of their disability/illness on society.

According to the official statistics the people under guardianship at the present moment are 7102. In the long run forms of supported decision making will be applied not only to people formally under guardianship but also to a large group of ID and people with MHP who are in risk of guardianship or who by whatever reason (family relations, communication problems etc.) have low self-determination and experience difficulties in making own choices for their

lives. Having the official statistics²⁴ that in Bulgaria people with ID are 45 877²⁵ and people with psycho-social problems 103 987²⁶ (SDM) in the table below is calculated the estimate number of people for whom in the future forms of SDM would be needed.

Estimation on the number of people potential users of SDM in Bulgaria

	Number of people in Bulgaria	% of people who are in need of mechanisms for SDM	Number of people - potential users of SDM
Intellectual disability²⁷			
- mild	22 939	60%	13 763
- moderate	16 056	90%	14 450
- severe and profound	6 882	100%	6 882
Total ID:			35 095
Psycho-social problems			
- Severe mental disorders	103 987	80%	83 190
- Common psychiatric disorders ²⁸	1 456 408	0,3%	4 369
Total MHP:			87 559
TOTAL:			122 654²⁹

Potential users by the different forms of SDM

Peer support	70% of the MHP	61 291
Access to professional specialized support	30% of ID + 40 % MHP	45 552
Professional mentor	70% of the MHP + 20% ID	68 310
Anti-crisis plan	80% MHP + 10% ID	45 587
Support network	90% of ID + 20% MHP	85 822
Facilitation	5% of MHP + ID	6 132

²⁴ The calculation are based on data by the National statistical institute – 31.12.2012. Population of Bulgaria - 7 282 041;

²⁵ Statistical tool for ID, De Pasarel Foundation – people with ID 0,63% of the population;

²⁶ Statistical data 2013 National center for community health and analysis – psychiatric and behavioral disorders 1428 to 100 000 population (1,428%);

²⁷ Intellectual disability is not in itself a mental health problem. People with intellectual disabilities do, however, have increased rates of mental illness, behavior disorders and pervasive developmental disorders. In these circumstances they are doubly disadvantaged in terms of stigma, exclusion and discrimination, as a result of both their intellectual disability and their other problems.

²⁸ WHO – common psychiatric disorders 20% of the population;

²⁹ This is not including the group of people with heavy sensory and physical disabilities who experience communication problems who in future research should also be taken into account.

The data for the above distribution by forms of SDM and type of disability is based on research of the international practice and the results of the pilot projects in Bulgaria. Note: Big part of the users especially with MHP use more than one form of SDM.

Estimation of the costs related to SDM

(including initial costs and costs for implementation for 10 years period)

The initial costs are calculated for activities that need to set the pre-conditions for start applying SDM mechanisms, such as trainings and awareness raising campaigns. The costs are calculated per client as follows:

Initial costs

Initial costs	Cost per client
1. Trainings	
1.1. Trainings of facilitators ³⁰	100
1.2. Training of professional mentors ³¹	100
1.3 Training of professionals (legal advisers, psychiatrists and others) ³²	6
2. Awareness raising campaigns³³	8
Total initial costs:	214

³⁰ Trainings of facilitators - 10 days x 150 BGN = 1500 BGN; 1 facilitator works with 15 clients therefore the amount of 1500 is an investment in training that will serve 15 clients. The calculation per client is 1500 BGN/15 = 100 BGN\

³¹ Training of professional mentors - 10 days x 150 BGN = 1500 BGN; 1 mentor works with 15 clients therefore the amount of 1500 is an investment in training that would serve 15 persons. The calculation per client is 1500 BGN/15 = 100 BGN

³² Training of professionals (legal advisers, psychiatrists and others); the calculation is based on 500 professionals on national level x 10 days training x 150 BGN = 750 000 BGN. This amount is an investment that would serve the whole group of ID and MHP therefore the calculation per client is 750 000/122654 (number of potential users of SDM in Bulgaria).

³³ For nationwide awareness raising campaigns is calculated the amount of 1 000 000 BGN which is divided by the number potential users of SDM 122 654;

Cost estimation of the different SDM mechanisms for 1 year per client

An average estimation of the costs for each mechanism is presented as follows:

SDM mechanism	Cost per client for 1 year
1. Peer support³⁴	
1.1. Rent of hall for meetings ³⁵	87
1.2. Communication, administrative ³⁶	20
Total costs per year Peer support per client:	107
2. Access to professional support	
2.1. Professional's fee ³⁷	120
Total costs per year Access to professional support:	120
3. Professional mentor	
3.1. Mentor's fee ³⁸	288
3.2. Administrative	120
Total costs per year Professional mentor:	408
4. Support network	
4.1. Elaboration of Personal profile ³⁹	180
4.2. Building-up the personal network ⁴⁰	60
4.3. Meetings of the support network ⁴¹	36

³⁴ Peer support is free and it doesn't require any involvement of social worker. Therefore the expenses are calculated only for provision of suitable premise for the meetings and some administrative costs. Usually the premise is provided by a social service.

³⁵ The peer support groups meet on weekly basis. The size of the group is 10-12 persons. Therefore the calculation is as follows: 52 weeks x 1 meeting x 2 hours x 10 BGN (rent) = 1 040 BGN/12=87 BGN per person yearly

³⁶ Peer support administration and communication costs: 20 BGN per month x 12 months = 240 BGN/12 clients = 20 BGN per client yearly

³⁷ The calculation for consultations with trained in SDM legal adviser, psychiatrist, psychologist and other specialist is based on average of twice a year consultation per person. Average fee: 60 BGN x 2 hours = 120 BGN;

³⁸ The sessions with the professional mentor (case manager) are on 2 weeks basis. The fee is calculated on the basis of the average wage of social worker in Bulgarian social services equals the fee of the facilitator – 6 BGN/hour. 24 times x 2 hours x 6 BGN = 288 BGN per client yearly;

³⁹ For elaboration of the personal profile a facilitator needs to intensively work with the client and his family/close circle. The calculation is based on facilitator's fee for meetings and elaboration of PP: 30 hours x 6 BGN = 180 BGN
(the fee per hour is calculated on the basis of average monthly salary of social worker)

⁴⁰ Building up the support network: facilitator's fee for meetings and communication with the members of the network: 10 hours x 6 BGN = 60 BGN;

⁴¹ The facilitator is only present at the first 3-4 meetings of the support network and occasionally when needed: 3 meetings x 2 hours x 6 BGN = 36 BGN.

4.4. Administrative and communication⁴²	120
4.5. Court procedure⁴³ 250	75
4.6. Publication in special registry⁴⁴	24
Total costs Support network	495
5. Anti-crisis plan	
5.1. Elaboration of anti-crisis plan⁴⁵	192
5.2. Regular reviews of the plan (for 1 year)⁴⁶	96
5.3. Publication in special registry	24
Total costs Anti-crisis plan	312
6. Facilitation	
6.1. Facilitator's fee⁴⁷	600
6.2. Coordination and communication⁴⁸	100
6.3. Follow-up and monitoring⁴⁹	541
6.4. Court procedure⁵⁰	250
6.5. Legal capacity office expenses for establishing the Facilitation and administrative⁵¹	98
Total costs Facilitation:	1 589

⁴² Support network administration and communication costs: 10 BGN per month x 12 months = 120 BGN

⁴³ Court procedure is necessary with formal SDM. For support network mechanism this cost would occur in 30% of the cases. The court procedure is calculated on the basis of guardianship court procedure – 250 BGN.

⁴⁴ This expense is done by the legal capacity office (alternative body to guardianship authority). It requires 4 hours x 6 BGN.

⁴⁵ Elaboration of the anti-crisis plan requires facilitator's work - fee for meetings and elaboration of the plan; 24 hours x 6 BGN = 192 BGN;

⁴⁶ The anti-crisis plan is reviewed on regular base throughout the year by the facilitator/support network: 16 hours x 6 BGN = 96 BGN

⁴⁷ In the cases of facilitation is required urgent and intensive efforts on behalf of well-trained facilitator. Therefore the hourly fee in this case is 15 BGN. Estimated time is 40 hours: 40 hours x 15 BGN = 600 BGN;

⁴⁸ Coordination and communication costs (preparation of necessary documents, telephone calls etc.) are estimated 100 BGN per case;

⁴⁹ Facilitation requires follow-up monitoring on regular base: 12 months x 3 hours x 15 BGN = 540 BGN;

⁵⁰ In case of Facilitation court procedure is required in 100% of the cases.

⁵¹ Equals the cost for appointing guardian and follow-up by the guardianship authority.

Estimation of the average cost per year for applying SDM mechanisms on national level

Form of SDM	% potential users of SDM by the different groups	Number of people	Cost per client/yearly	Total cost per Intervention in BGN
Peer support	70% of the MHP	61 291	107	6558137
Access to professional specialized support	30% of ID and 40 % MHP	45 552	120	5 466 240
Professional mentor	70% of the MHP + 20% ID	68 310	408	27 870 480
Support network	80% of ID and 20% MHP	45 587	495	22 565565
Anti-crisis plan	90% MHP + 20% ID	85 822	312	26 776 464
Facilitation	5% of MHP + ID	6 132	1 589	9 743 748

Average estimation of the costs per client for the 1st year: **807 BGN**

Estimation of the costs per client for 10-year period (including initial costs and costs for implementation for 10-year period)

In contrast to Guardianship in SDM the costs for the intervention decrease over time as its mechanisms are directed towards development of the person and making him/her less dependent. After the first year the costs are reduced with average 15%, and after the 5th year with 20%.

	Cost in BGN
Initial costs per client	214
Average per client for the 1 st year	807
Average per client for period 2 nd -5 th year ⁵²	2 743
Average per client for period 5 th – 10 th year ⁵³	3 228
Total costs per client for 10 years period	6 992
Total costs per client per year:	699

CONCLUSION

The answer of the basic question of this chapter: “Is SDM less expensive in terms of costs for the intervention compared to Guardianship?” is NO. In terms of costs per intervention guardianship system is less expensive with 491 BGN per client per year.

⁵² The calculation is based on the costs for the first year with a reduction of 15% yearly as the intensity of the support of SDM decreases with the increased self-determination of the client;

⁵³ The calculation is based on the costs for the first year with a reduction of 20% yearly as the intensity of the support of SDM decreases with the increased self-determination of the client;

Guardianship

208 BGN

Supported Decision Making

699 BGN

Difference: 491 BGN



2. Usage of social services

THE BASIC QUESTION IN THIS CHAPTER IS:

As SDM results in increased self-determination, personal development and independency of ID and persons with mental problems, does this lead to reduced intensity of the support and consequently reduced price of social services (monetized benefit) for the society?



This chapter explores the effects of SDM on the usage of social services by people with intellectual disabilities and Psycho-social problems. It aims at providing objective information on the economic effects of SDM on the social services system and giving an overview of the changing needs and their economic value for the Bulgarian tax-payer.

Data

The research is based on the data out of the pilot projects which demonstrates the clients' needs, level of self-determination, personal development and independency before and after the SDM intervention under the project. It concludes on the clients' needs in terms of types and intensity of the support from social services at the present moment compared to the situation (before SDM) when they (bigger part of them) were under guardianship or without SDM.

SDM mechanisms have not been piloted in specialized institutions therefore the research for the group in institutions (ID and MHP) has been focused on assessment of the clients' independency level and their quality of life. The data in this chapter /for the people in institutions/ presents the assessed need for lighter form of support if they were also using SDM mechanisms.

Limitation

The calculations in this chapter are based on the assumption that the clients receive from the social services the support they need (no more no less) based on their level of independency. The Bulgarian system of social services is not yet matured enough to provide to the clients the right type and amount of support. The lack of diversity in terms of intensity of the support is due to: 1/ lack of developed system of needs assessment based on the level of functioning of the client rather than on the diagnosis; 2/ financial system which is based on financial standards for the different types of social services (institution, sheltered living, daycare center, center for social rehabilitation and integration etc.) rather than on individual packages of “support needs” based on the objective level of independency of the client; 3/ capacity of the social services is disproportionately distributed over the territory of the country – at some regions there is no access to social services while at others there is an overcapacity; 4/ on the level of the single social service - insufficient level of management and professional competences and skills to make the diversification of the provided support within the service (grouping and diversification of the activities according the level of disability/independency).

Therefore the provision in this chapter is that the current analysis presents the economic result to which SDM could lead if the Bulgarian social services system makes a step in diversification of the support and deinstitutionalization.

In order to “capitalize” in reality the increased level of independency of the clients achieved through SDM in monetized benefit for the society (reduced costs of social services), the process of implementing SDM mechanism should go parallel with measures for optimization of the social services system.

Determining the support domains and the levels of diversification in terms of intensity of the support /in the frame of the existing Bulgarian system for each of the domains/

For the purpose of the analysis the social services provided to ID and MHP are divided into 2 domains:

2.1. Housing and support for living

This domain comprises the services that provide support for living and place of residence. The home care services are also included in this group as the lightest form for those who can live independently with some help /less or more intensive/ from personal/social assistant. In the Bulgarian context these services are as follows:

Housing and support for living	Intensity of the support
- Specialized institution	24 hours/ 7 days a week
- Sheltered living	24 hours/7 days a week
- Supervised home	8 hours/7 days a week
- Home care/hourly based	Hourly based

2.2. Daycare and consultative services

This domain comprises the services for daycare activities and consultations with specialists – rehabilitator, speech-therapist, psychologist etc. In the Bulgarian context these services are as follows:

Daycare and consultative services	Intensity of the support
- Daycare center	8 hours/ 5 days a week
- Center for social rehabilitation and integration	Hourly based

Presentation of the results of the analysis

The results of the field research (questionnaires and interviews) were analyzed in view to evaluation of the independency skills of the participants. The presented data below illustrates the distribution of the people from the two groups (ID and MHP) from their present situation (the social service they use now) to services that best fit their level of independency (which is at this moment partly achieved through the SDM).

Provision: The level of independency of the participants in the field research which is assessed by the questionnaires and interviews and on the basis of which the match with the most suitable form of social service for the person is made is partly a result of the Supported Decision making intervention. Of course a big part of the people have had the independency skills for using a lighter form of support even before the SDM intervention but this is hard to be assessed and given value to. The discrepancy between the present and desired /right amount of/ and support is in most of the cases due to the lack of objective needs assessment and diversification of the social services system that meets the different level of needs.

A. Housing and support for living

Based on assessment of the independency level of the participants in the field research the following charts illustrate the objective necessity of the living support services (as a percentage out of the total number of people):

1. Assessed need of type of living support for ID and MHP who at present live in institutions

The research demonstrates that the predominant part of the people in institutions have sufficient independency skills to cope with lighter form of support in the community with SDM mechanisms. Their potential level of independency is much higher and SDM increases it even more in terms of need for less intensive and less expensive services for support for living.

1.1. ID - People with intellectual disabilities who at the present moment live in institutions are assessed to have the level of independency skills to live in the following community based social services:

- 42% of them need 24 hours support in their daily activities and therefore can live in Sheltered livings.
- 53% need lighter support in their everyday life - more supervision than full time intensive care. Therefore they can live in Supervised homes.
- 5% of the ID at present in institutions can easily live independently with some hourly based ambulatory support.

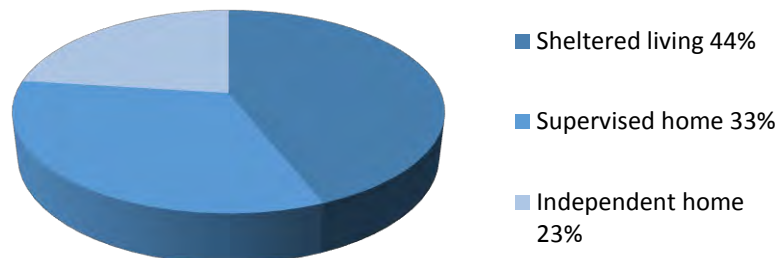
**Persons with ID
who at present live in institutions but have the necessary
independency skills to use a lighter form of support for living**



1.2. MHP - People with psycho-social problems who at the present moment live in institutions are assessed to have the level of independency skills to live in the following community based social services:

- 44% of MHP in institutions need 24 hours intensive living support and their level of independency require support in Sheltered living
- 33% of MHP need more supervision and availability of staff rather than 24 hours support. For these group is recommended Supervised home service in order to encourage them develop the independency they have lost to a major extent as a result of the institutionalization.
- 23% of this group can live independently with ambulatory support, supervision and only occasionally intensive care

**Persons with MHP
who at present live in institutions but have the necessary
independency skills to use a lighter form of support for
living**



Observation: People with MHP compared to ID out of institutions are more prepared for less intensive living support (33% supervised homes, 23% independent home) because their intellectual level and everyday life independency skills are higher. At the same time due to their unstable condition as a result of the psychiatric disorder they would need more intensive and adjusted to their needs SDM mechanisms. This goes especially for the group of MHP who have been institutionalized for a long time.

Conclusion: More than half of the people from both groups (57% of ID and 56% of MHP) who at the present moment live in institutions in fact do not need 24 hours support. People are placed in specialized institutions not because of objective need for intensive support but due to lack of enough and adequate alternatives (Sheltered livings and Supervised homes) which leads to two main negative effects: 1/ decrease of the people's independency and self-determination skills and in general worsening instead of improvement of their condition and 2/ higher costs

for the society for 24 hours support in specialized institution which is not only unnecessary but also damaging for the people.

For the major part of both groups (53% ID and 33% MHP) the most suitable form of support for living is Supervised home with 8 hours support 7 days a week instead of 24 hours intensive care. The analysis of the available data shows that this type of service provides the “right amount” of support for 43% of all the persons who are at present in specialized institutions in Bulgaria.

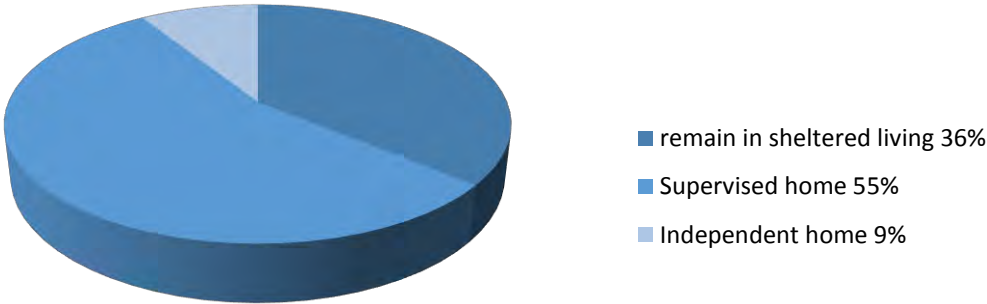
2. Assessed need for type of living support for ID and MHP who at present live in Sheltered living (with SDM)

The research focused on exploring the increase of independency level as a result of SDM of the people living at present in Sheltered livings. It proves once again that the lack of diversification of the social services system leads to provision of more intensive care than necessary also in the community based social services. This has consequences both from economic point of view (the society is paying the same price for care for the most severe and the lighter cases) and from the point of view of quality of life of the people.

The results presented below demonstrate the assessed by the questionnaires and interviews “right amount” of care in terms of type of support for the ID and MHP who at present use Sheltered livings and use SDM mechanisms.

2.1. ID who at present live in Sheltered living but with SDM have the necessary independency skills to use a lighter form of support for living

Persons with intellectual disabilities who at present live in Sheltered living but with SDM would have the necessary independency skills to use a lighter form of support for living



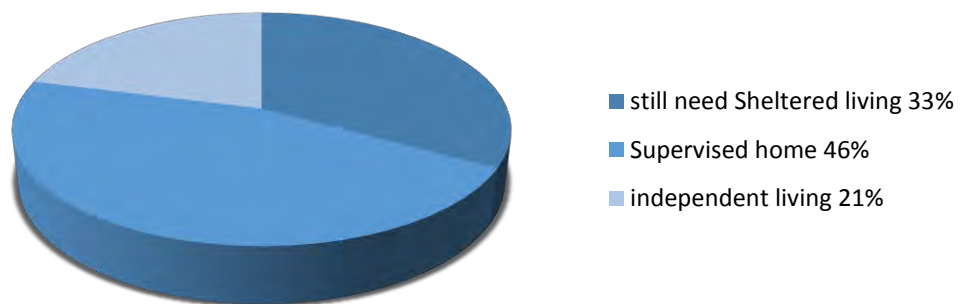
Only 36 percent of the present clients in sheltered livings indeed need 24 hours support and permanent presence of staff. These are usually the profound and severe cases with multiple disabilities

For 55% with SDM mechanisms it would be better to be moved to Supervised homes with less intensive care where they will have the opportunity to develop in less controlled environment their independency and self-determination skills. These are the ID with mild and around 30% of the moderate ID.

9% of the people from this group (ID) can live independently with SDM and ambulatory support.

2.2. Persons with MHP who at present live in Sheltered living but with SDM have the necessary self-determination and independency skills to use a lighter form of support for living

Persons with MHP who at present live in Sheltered living but with SDM have the necessary independency skills to use a lighter form of support for living



Only 33% of the people with MHP who at present live in SL also with SDM would need 24 hours support. These are the clients with heavy psychiatric disorders and serious behavioral problems.

46% have enough independency skills to live semi-independent in Supervised homes with SDM where the staff supports them in everyday activities but gives them the space for independency.

According to the research 21% need only adequate SDM and some ambulatory support.

Observations regarding the difference between the two target groups:

The MHP living in sheltered livings are more prepared for less intensive living support than the ID. This is explained by the fact that a big part of ID in sheltered livings have also multiple disabilities and need support by the staff also in the physical activities (which cannot be effected by SDM mechanisms). 21% of MHP in sheltered livings can live independently with SDM while only 9% of the ID.

Conclusion: More than 60% of the people from both groups (64 % of ID and 67% of MHP) who at the present moment live in Sheltered livings when using long-term adequate SDM can in the future cope with lighter living support or live independently. Again, less intensive living support such as Supervised home turns out to be the “right amount” of support for 50% of the whole group (ID and MHP).

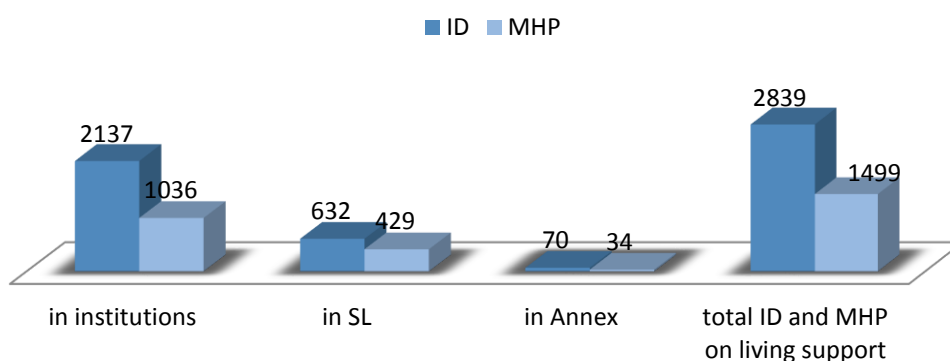
3. Overview of the present situation and the desired situation in which ID and MHP are provided the “right amount” of Living support

The results from the previous chapter are based on the research (questionnaires and interviews) which is done over a limited number of participants from the different groups. Nevertheless there are clear trends based on which it can be concluded that the diversification of the living support for ID and MHP should follow the principles of deinstitutionalization and SDM which lead to independency of the person and possibilities for personal development in the maximum possible extend. In this chapter the results will be extrapolated on a national level to give an overview of the desired change possible with Supported decision making mechanisms.

The chart below illustrates the present situation in terms of provision of living support to ID and MHP according to the official data for 2013 from Agency of Social Assistance⁵⁴

⁵⁴ Latest available data as to September 2013 - Official data from Agency of Social Assistance published in the National Strategy for Long-term Care;

Present situation – living support to ID and MHP in specialized institutions, sheltered livings and annexes (in number of people)



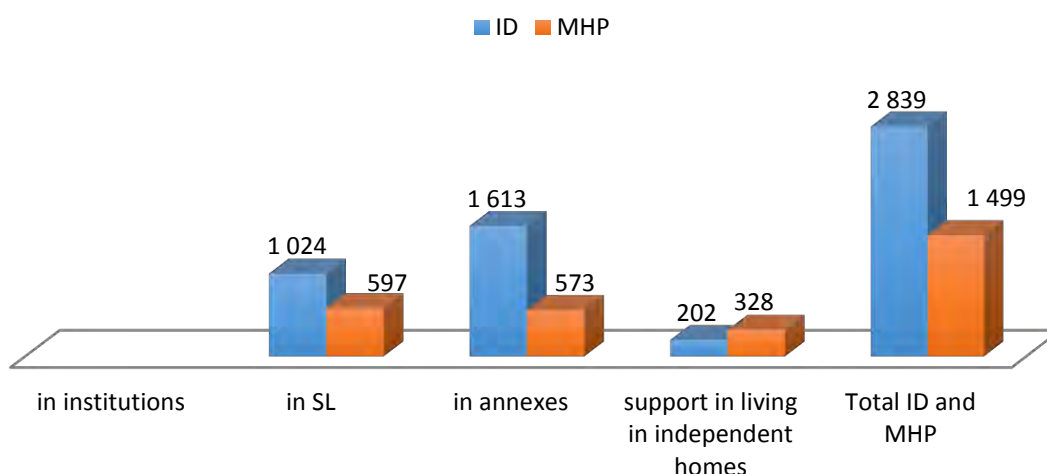
The total number of people (ID and MHP) who are provided with residential type of support in specialized institutions or community based social services is 4338 – including specialized institutions, sheltered livings and supervised homes.

The total number of people living in specialized institutions (from the two groups – ID and MHP) is 3 173⁵⁵ (2137 ID living in 27 institutions and 1036 MHP living in 13 institutions). The number of people living in community based sheltered livings is 1061 (ID 632 and MHP 429). People living in Supervised homes – 104 (ID 70 and MHP 34).

In chart N.... below is presented an extrapolation⁵⁶ of the data from the field research to the number of people with ID and MHP using residential support on national level. It is called “the desired situation with SDM” as SDM mechanisms would make the change possible.

Desired situation with SDM - Extrapolation of the data from the field research regarding the level of independency and the “needed” type of living support on national level:

Desired situation with SDM – when ID and MHP are provided the “right amount” of living support (in number of people)



⁵⁵ This is excluding the people living in specialized institutions with physical disabilities, dementia, sensory disabilities and elderly. Together with them the overall number of adults in institutions in Bulgaria is 11 039 persons.

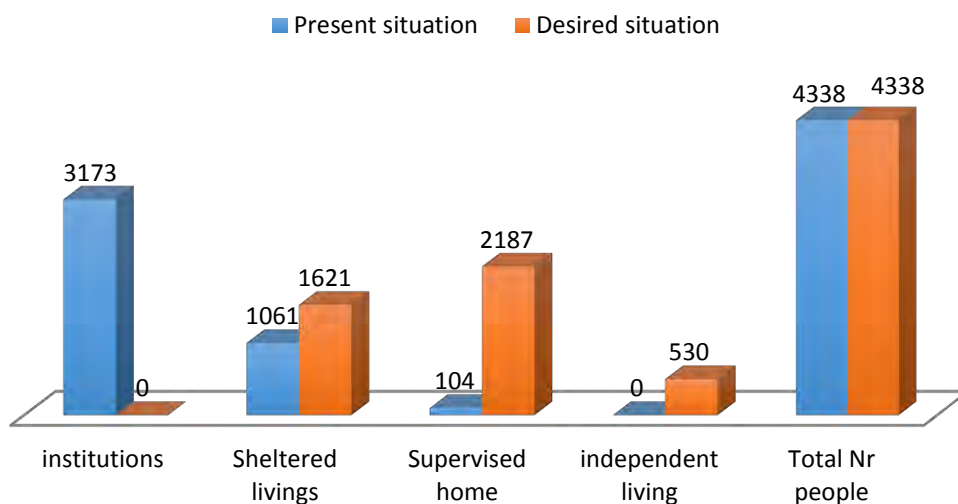
⁵⁶ Extrapolation is the process of estimating, beyond the original observation range, the value of a variable on the basis of its relationship with another variable.

In the desired situation with SDM there are no people in specialized institutions. The necessary capacity for the residential type community-based services is assessed based on the research data and shows a need for increasing the capacity of Sheltered livings and supervised homes as well as provision of ambulatory support for those who can live in independent homes. As can be seen from the chart in the desired situation with SDM the highest number of capacity places is required for Supervised homes – 2 186 places (1613 for ID and 573 for MHP), sheltered livings 1621 places (ID 1024 and MHP 597) and ambulatory support for 520 persons (ID 202 and MHP 328).

The extrapolation is made only on the basis of the number of people at the present moment who are using some kind of residential service (4338 persons). It is not including all the persons who are on the waiting lists for community based services and specialized institutions and are in need for some kind of support for living. The column “support for living in independent homes” illustrates the necessary extra need for this service as a result of deinstitutionalization along with SDM.⁵⁷

Confrontation between the present and the desired situation in terms of people and type of support:

Difference in number of people served by the different types of living support in the present and the desired situation



As can be seen from the chart above for serving the same group of people (the present users of residential services) in consistency with Art 12 and Art 19 of UNCRPD the processes of deinstitutionalization and applying SDM mechanisms would effect the necessary capacity in the following way:

- closing down specialized institutions
- increasing the capacity of Sheltered livings with 560 places
- increasing the capacity of Supervised homes with 2083 places
- opening extra capacity for homecare /ambulatory/ services – 530 places.

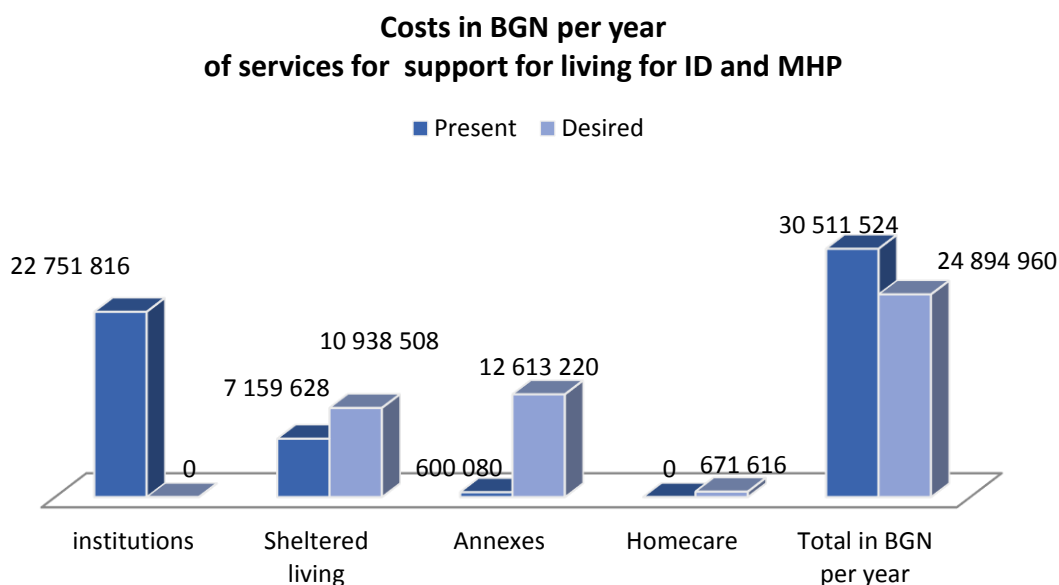
⁵⁷ The calculations in the analysis do not take into account the present number of clients and the related costs for the already existing homecare services in the Bulgarian system - personal assistant, social assistant, home assistant and assistant for independent life. The present chapter “support for living” only illustrates the changes that will occur as result of SDM and DI for the persons at present using some kind of residential service (4338 persons).

Supervised home is the service with the least capacity at the moment 104 places for the whole country. The results from the analysis demonstrate that both ID and MHP need most living support of the type “Supervised home”. Therefore the necessary increase of the capacity of this service is huge – 2083 places extra. It needs to be invested in the development of this service not only in terms of infrastructure but also the specifics of the Supervised home requires high professional level of the staff. The clients are relatively independent but still they need timely, adequate and the “right amount of support”. Supported decision making mechanisms are especially needed for this group.

Comparison of the present and the desired situations in terms of financial value

The next chart illustrates the comparison of the necessary financial resources⁵⁸ for the provision of support for living services for ID and MHP⁵⁹ in the present and the desired situation with SDM. The calculations are in BGN per year and are based on the latest approved by the Council of Ministers⁶⁰ capacity-based financial standards for the state delegated social services as follows:

- Specialized institution for ID – 7 096 BGN yearly per person
- Specialized institution for MHP – 7 324 BGN yearly per person
- Sheltered living – 6 748 yearly per person
- Supervised home – 5 770 yearly per person
- For homecare /ambulatory support/ - the calculation is based on 2.64 BGN per hour.⁶¹



⁵⁸ By necessary financial resources is meant only the costs for the provision of the services without investments for building the infrastructure.

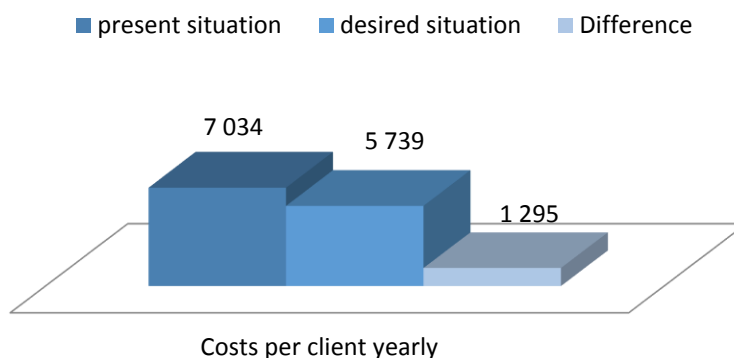
⁵⁹ Persons with ID and MHP who are on the waiting lists for specialized institutions and community-based residential services are not taken into account. The calculations are based on re-shifting the present target group (4338 persons) presently in residential services.

⁶⁰ Decision 658 of the Council of Ministers from 31 October 2013 for amendment of the financial standards of the state delegated activities for year 2014.

⁶¹ Decision 265 of the Council of Ministers from 29 April 2011. The decision states a financial standard of 5600 BGN per year, which is calculated in 2.64 BGN per hour. Since 2012 the financial standard for social assistant is not any more included in the decisions for determining the annual financial standards as the Social assistant service is administrated under a special program but the value of 2,64 has not been changed. It is including administration, training and remuneration for the social assistant.

The total amount for providing support for living services to ID and MHP will be reduced with 5 616 564 BGN per year. This is possible as a result of parallel implementation of SDM, deinstitutionalization and diversification of the social services so that clients receive the amount of support they need. The capacity of the specialized institutions and the financial recourse is shifted to Supervised homes (mainly – over 12 million BGN) and Sheltered livings (11 millions BGN).

**Difference in BGN
between the present and desired situation with SDM per served
client yearly (living support)**



The above chart illustrates that the desired situation with effective mechanisms of SDM would realize savings for the society for support for living services for ID and MHP amounting at **1 295 BGN** per person yearly compared with the present situation /institutionalized support with 85% of clients under guardianship/.

The calculation is based on the following: - number of people in Bulgaria with ID – 35 095; number of persons with MHP 87 559. Support for living is required for 90% of persons with severe and profound ID, 40% of the moderate ID and 15% for the mild ID. For the group of persons with MHP: around 25% of the whole group. In total the persons with ID and MHP to whom should be provided living support services is 37 947 persons. For each person out of the 37 947 in the desired situation with SDM would be realized saving of 1 295 BGN yearly which amounts at over 49 million in total.

Another interesting conclusion is that at this moment the governmental social services system provides support to only 10% of the needy from the groups of ID and MHP.

CONCLUSION

The analysis gives evidence that the SDM interventions which go along with deinstitutionalization process are cost effective for the society in term of running costs for the provision of the living support for ID and MHP. It will realize saving of 1 295 BGN per year per client served.

Extrapolating this figure on the number of persons (ID and MHP) who are in need for residential support/support for living services (including persons on waiting lists) the savings for the society would be 49 million BGN per year.

Daycare and consultative services

Supported decision making leads to increased independency and to change in the needs for living support services as can be seen in the previous chapter. In this chapter we are going to explore how this effects the needs of ID and MHP for daycare and consultative services. For this purpose there are two parallel processes that have to be taken into consideration:

1. For the clients who at present are in institutions but in the future will be provided community based living support: increased usage of daycare and consultative services as result of SDM and deinstitutionalization.

At the present moment only 2% of the clients in the specialized institutions are using any kind of daycare or consultative service in the community. Their complete isolation and institutionalization deprives them of any activities out of the institution including the usage of community-based daycare and consultative social services. As a result of SDM and the change of their living support services (from institutions to sheltered livings and supervised homes) the clients would start needing also daycare in the community which requires increase of the existing capacity and consequently the costs.

2. For the clients in the community:

Change⁶² in the usage of daycare and consultative services as result of SDM and the increased independency of the clients who live in the community.

SDM increases the independency level of the clients and this leads to changes in the necessity of daycare and consultative services. The tendency is that clients with SDM from the community need less daycare /in terms of hours or intensity/, need only consultative services instead of daycare or even do not need any daycare or consultative as a result of increased independency, strengthened personal network and finding a job opportunity.

In order to explore the processes of change of necessity of daycare and consultative services, the results from the field research are extrapolated on national level and the following formula has been applied:

A) Present capacity of Daycare and consultative services
+
B) Increase of capacity of DC and CS as effect of SDM for people at present in institutions who will be deinstitutionalized and use community-based living support
+
C) Change of capacity of DC and CS as result of SDM for clients in the community

⁶² For the clients in the community the need for full time daycare is reduced with SDM while the need for hourly based consultative services increases therefor it is referred as "change".

A) Present capacity of Daycare and consultative services

The present capacity of Daycare centers and consultative services for ID and MHP is as follows:

Capacity in daycare centers (both for ID and MHP)⁶³ is 1 740 places in 65 daycare centers all over the country.⁶⁴ This capacity is used only by people living in the community (private homes) or community based residential services – ID and MHP from institutions hardly never used daycare centers in the community (less than 1%).

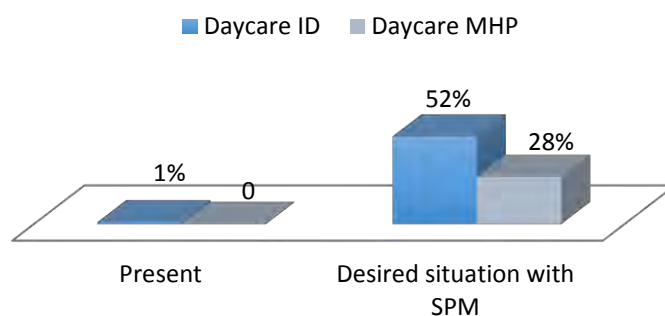
The consultative services within the social services system are provided by Centers for social rehabilitation and integration (CSRI). The present capacity of CSRI's in Bulgaria is 2 277 in 71 centers.

B) Necessary increase of capacity of Daycare and Consultative services as effect of SDM for ID and MHP at present in institutions but who will be deinstitutionalized and use community-based living support

i/ Daycare centers increase of capacity

According to the data from the field research in the specialized institutions it can be concluded that the processes of DI and SDM would lead to increased usage of daycare services for both groups -people with ID and MHP. For the people out of the institutions it is essential to be provided all possible community based support (to the level it is needed). Almost regardless the level of the disability this group is damaged by the long institutionalization and needs to be provided along with SDM both living support and daycare/ consultative services.

Necessity of Daycare services for the people out of institutions - Confrontation present and desired situation



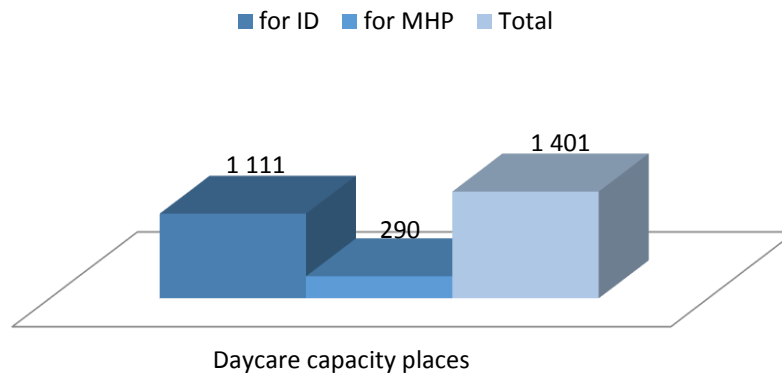
The figures in the chart illustrate the estimated need of Daycare services out of the limited number of interviewed/assessed institutionalized clients included in the research. Nevertheless it demonstrates a clear trend that more than 52% of ID and 28% of MHP would need daycare service in the community after they start using community-based living support. The low percentage of MHP is explained by the fact that MHP are in general more independent and here by daycare service is meant full-time daycare – 8 hours a day which is not necessary for the bigger part of MHP. For this group (accept for those with serious behavioral problems) it is more appropriate part-time daycare or consultative service plus part time/ employment.

⁶³ There is not enough available data for how many of the capacity places are used by ID and how many by people with MHP. Based on an overview of the existing data it can be considered that around 30% are for MHP and 70% for ID.

⁶⁴ Latest available data as to September 2013 - Official data from Agency of Social Assistance published in the National Strategy for Long-term Care

The above estimation is calculated in number of people/capacity places needed in daycare centers for the ID and MHP out of the institutions.

**Increasing the capacity of daycare centers
(necessary extra capacity for ID and MHP from institutions)**

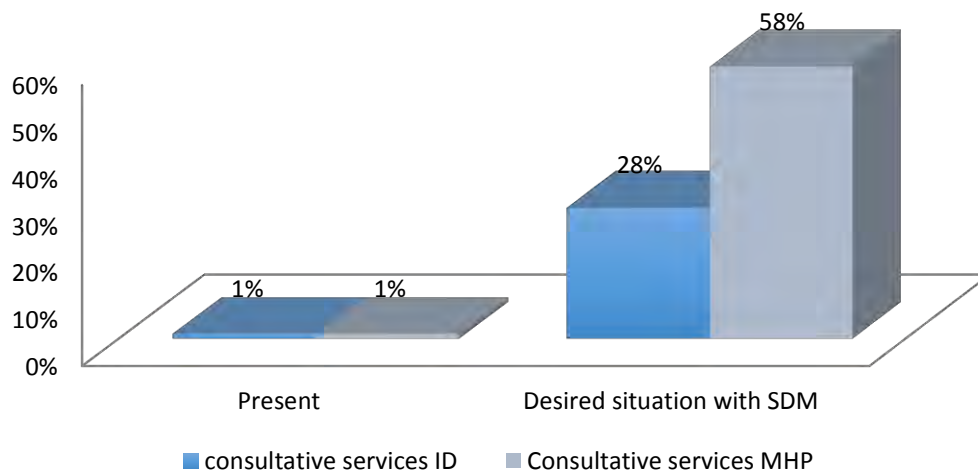


Compared with the existing capacity of daycare centers (1740 places) the necessary extra capacity for the clients from the institutions (1401 places) is an increase of 80%.

Having the current financial standard for daycare center capacity place – 5 855 BGN yearly, the increase of 1401 places would mean a financial costs **8 202 855 BGN** per year.

ii/ Consultative services increase of capacity for ID and MHP out of institutions

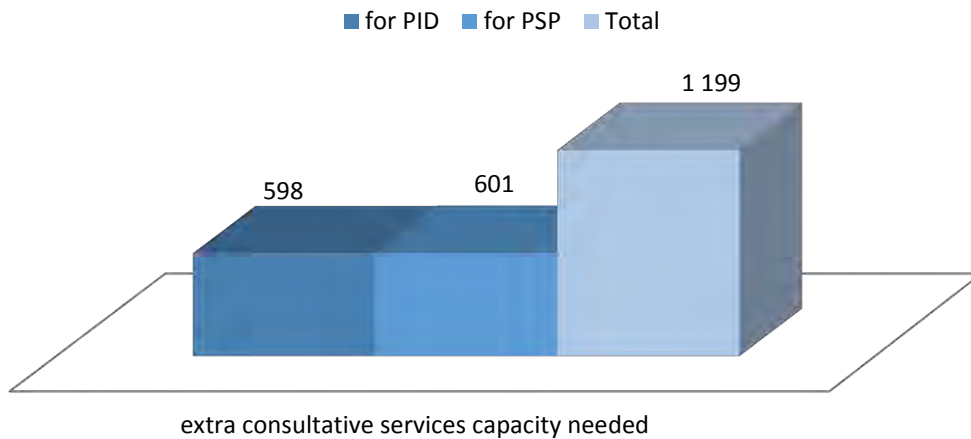
Similarly for the clients out of the institutions would need to be secured access to consultative services in the community. The estimated need is shown in the chart below:



It can be noticed that the need for consultative services is greater for the MHP while for ID is more necessary full-time daycare. This fact is related to the greater independency level of people with MHP. When included in the community they would need effective SDM mechanisms and adequate consultative services to restore their full-right citizenship.

Based on the number of people at the present moment in institutions the chart below illustrates the increase of number of people for whom should be provided consultative services in the desired situation with SDM:

Increased usage of consultative services (extra for ID and MHP from institutions)

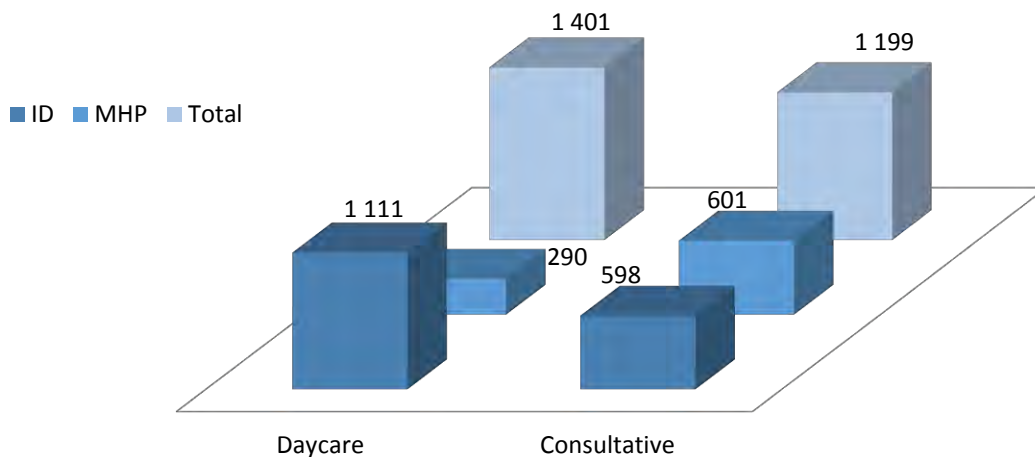


In the desired situation additional 1199 people would need access to community-based consultative services (598 ID and 601 MHP).

In financial terms the increase of the usage of consultative services would mean an increase of **3 116 201 BGN** yearly⁶⁵.

B i) + ii) Total increase of Daycare and consultative services for ID and MHP out of institutions

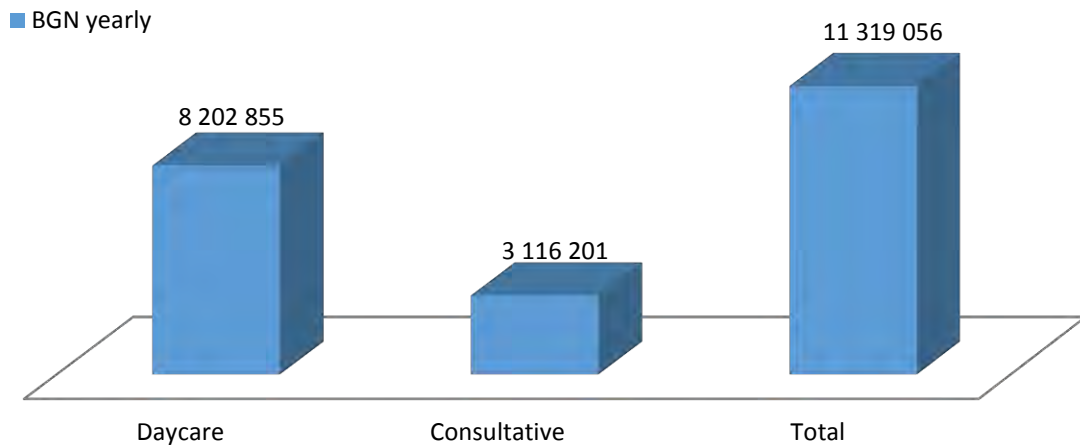
Increasing capacity of daycare and consultative services (necessary extra capacity for ID and MHP from institutions)



SDM and DI would lead to increase of the capacity of Daycare centers with 1401 places (1111 for ID and 290 for MHP) and of CSRIs with 1199 places (598 for ID and 601 for MHP) which would have the following financial effect:

⁶⁵ Based on the financial standard for CSRI for 2014 – 2 599 BGN.

**Financial effect of the increased capacity
of Daycare and consultative services
(for ID and MHP from institutions)**



The total yearly costs for increasing the capacity of the supportive community based social services for the ID and MHP from the institutions is **11 319 056 BGN**.

CONCLUSION

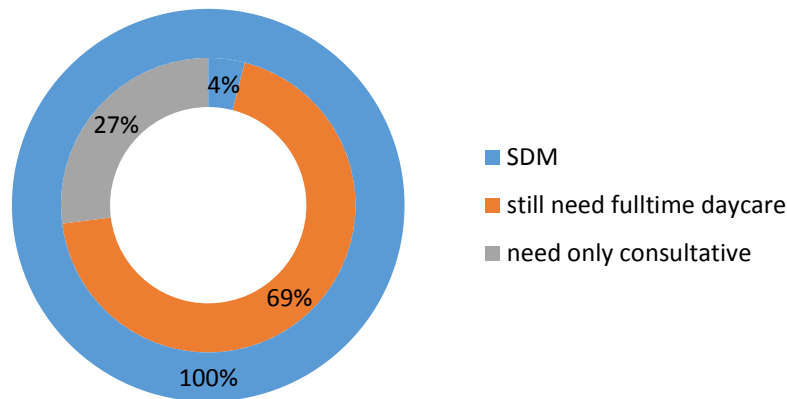
While for the residential services as a result of DI and SDM there will be realized an yearly saving of 5 616 564 BGN for the daycare and consultative services the costs will increase with 11 319 056 BGN. Especially for the group out of the institutions the inclusion in the community is mainly happening through the services that support the people in their everyday activities – daycare and consultative. Therefore the investment in good quality supportive services along with SDM would highly increase the speed of the clients’ integration in the society, which makes it a worthy long-term investment

C) Change of capacity of Daycare and Consultative services as result of SDM for clients in the community

Parallel to the process of increasing the need for Daycare and consultative services for the clients in the institutions, for the ID and MHP from the community who are provided with SDM there is also a tendency of changing the needs for those services. This tendency has been observed in the pilot projects with the clients with whom has been experimented with SDM for 6 month period. The changing need for Daycare and consultative services of the clients with SDM have been assessed through questionnaires and summarized in the following charts.

The charts illustrate the necessity of daycare and consultative services for the clients in the community before and after the SDM interventions.

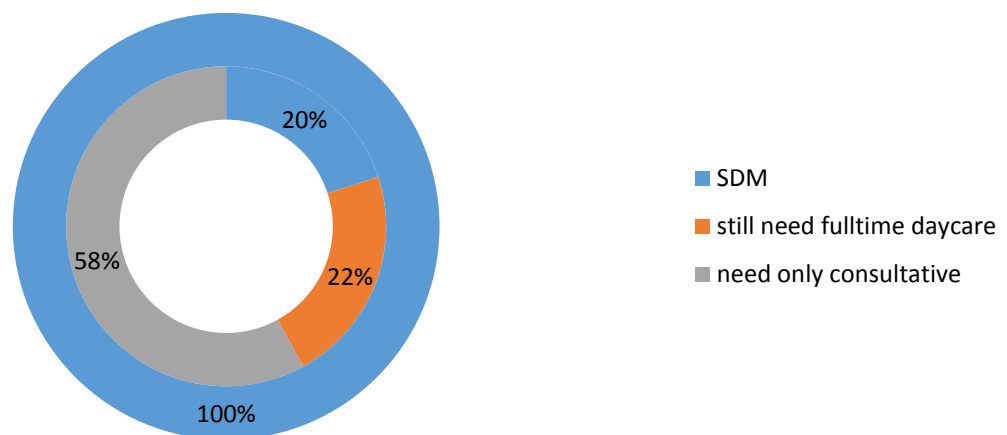
Reduced need for Daycare as result of SDM for ID in the community



From the whole group of clients with ID who use SDM and full-time daycare only 69% would continue to have the necessity of full-time daycare. These are the clients with severe and profound disabilities and those with additional physical problems for whom although SDM has increased their self-determination, their skills for everyday independent living have not radically improved. For 27% of the ID SDM has given them confidence, the necessary support from the network and independency to be able to cope with less intensive support from the social services⁶⁶. These clients can use an equivalent of CSRI service (for specialists consultations and also group activities) with less intensity of the support than Daycare center (if available in the region). For 4% of the group the support they receive from the SDM mechanisms is sufficient.

For the group of persons with MHP the change of the necessity of the required support is as follows:

Reduced need for Daycare as result of SDM for MHP in the community



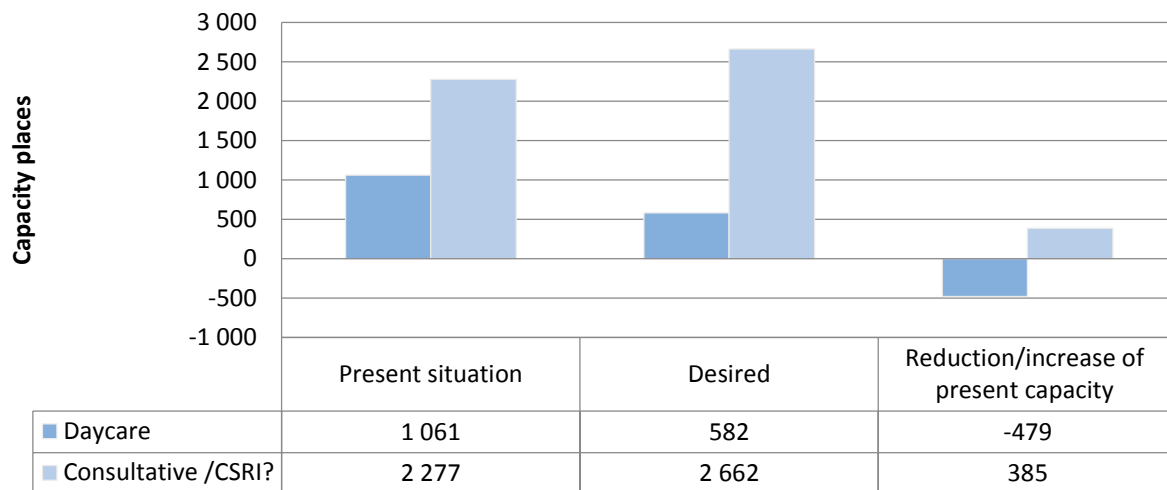
⁶⁶ For the purpose of the analysis this “less intensive support from the social services” is leveled to consultative service CSRI which is with almost half the financial standard of a Daycare center (2 599 BGN).

The bigger part of this group (58%) would need only consultative services in addition to SDM. Only 22% of the MHP who use daycare would continue to use it with the same intensity along with SDM. 20% of the clients are assessed to only need supported decision making and no daycare and even consultative services. These are the clients with high independency skills whose self-determination and confidence has increased raIDly with SDM and for whom SDM can totally substitute the need for other supportive service.

C Total - Overview of the changed need of Daycare and consultative services for the clients in the community

The extrapolation of the above trends on national level gives the following overviews in terms of number of people /necessary capacity places/ and financial resources:

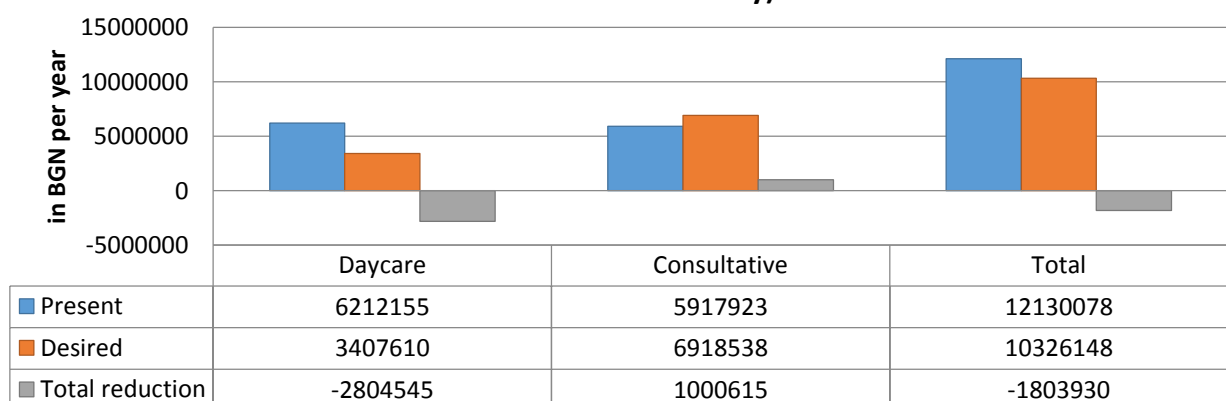
As result of SDM for clients in the community changed needs for Daycare and consultative services on national level



The estimated reduced need of daycare services as result of SDM (for ID and MHP in the community) and consequent increase of consultative services in necessary number of places is 479 daycare places less on 385 places CSRI places more than the present situation.

Financial effect of the reduced usage of daycare as result of SDM for ID and MHP in the community

Financial effect of the reduced usage of daycare as result of SDM (for ID and MHP in the community)



The total costs for Daycare will be reduced with 2 804 544 BGN while the costs for consultative services will increase with 1 000 615 BGN which in total gives a saving of 1 803 930 BGN.

Conclusion: As result of SDM for the persons with ID and MHP in the community the costs for Daycare and consultative services on national level will be reduced with **1 803 930 BGN** yearly.

A+B+C - Conclusions on the total effect of SDM and DI on the usage of Daycare and consultative services

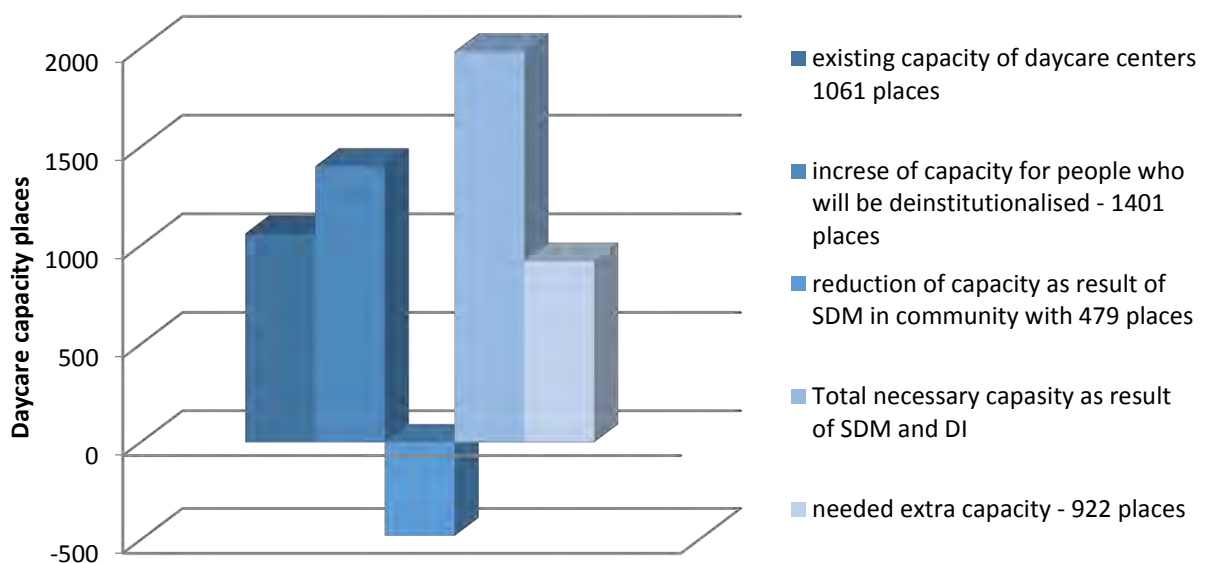
- A) Present capacity of Daycare and consultative services
- +
- B) Increase of capacity of DC and CS as effect of SDM for people at present in institutions who will be deinstitutionalized and use community-based living support
- +
- C) Change of capacity of DC and CS as result of SDM for clients in the community

In order to find out the overall effect of SDM on the usage of Daycare and consultative services we go back to the formula we set at the beginning of this chapter and calculate separately for Daycare and consultative services:

Daycare centers' capacity

Necessary capacity of Daycare as result of SDM

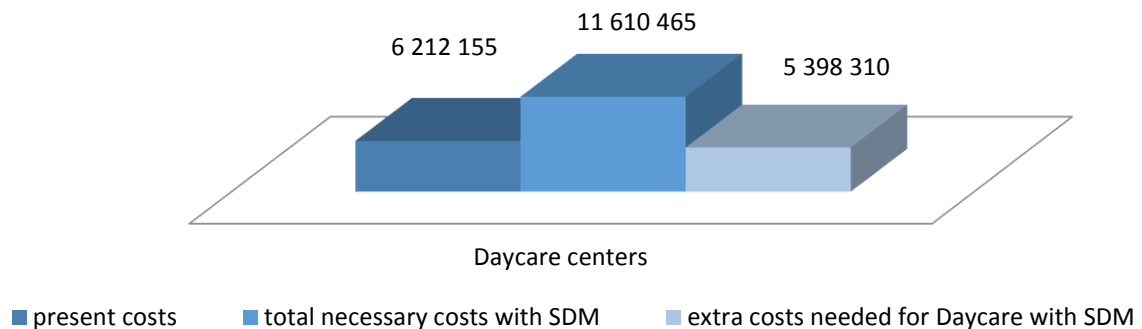
1061 (present capacity) + 1401 (necessary extra capacity for people at present in institutions who will use community based living support) - 479 (reduction of capacity as result of SDM for clients in the community) = 1 983 daycare capacity places necessary



Conclusion: the overall effect of SDM and DI on Daycare services is an increase of 922 capacity places.

Financial effect on SDM and DI regarding Daycare centers' costs (in BGN yearly):

Extra necessary costs for Daycare as result of SDM and DI /in BGN yearly/



CONCLUSION

The overall effect of SDM and DI on Daycare services is an increase of 922 capacity places. The financial effect on national level would be 5 398 310 BGN increase of the costs for Daycare centers yearly.

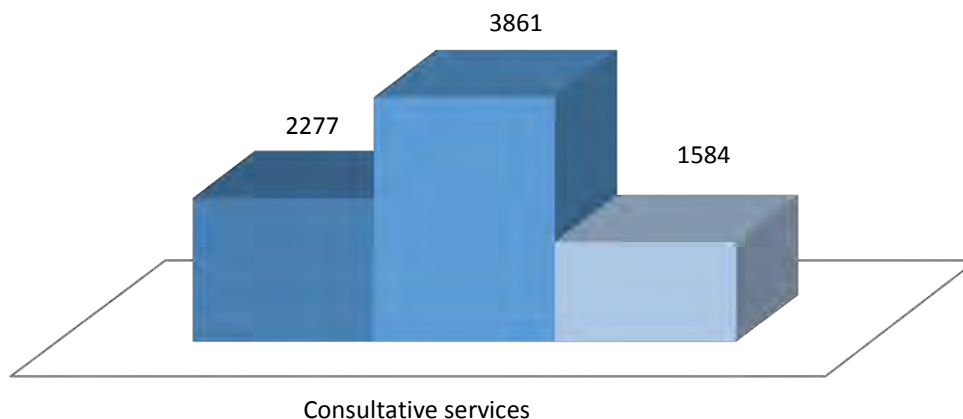
Consultative services' capacity

Necessary capacity of Consultative services as result of SDM

2 277 (existing capacity) + 1 199 (necessary extra capacity for people in institutions) + 385 (increase of capacity as result of SDM for clients in the community) = 3 861 consultative services capacity places

Capacity of Consultative services as result of SDM and DI

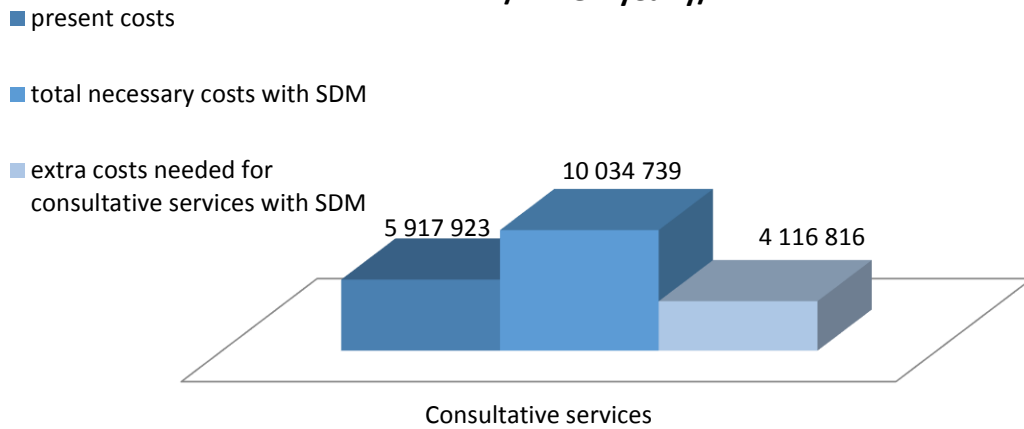
■ existing capacity of CSRI ■ necessary capacity of CSRI as result of SDM ■ needed extra capacity for CSRI



As result of SDM the existing capacity of the consultative services should be increased with **1584** places.

Financial effect on SDM and DI regarding the costs of consultative services (in BGN yearly):

**Extra necessary costs for Consultative services as result of SDM and DI
/in BGN yearly/**

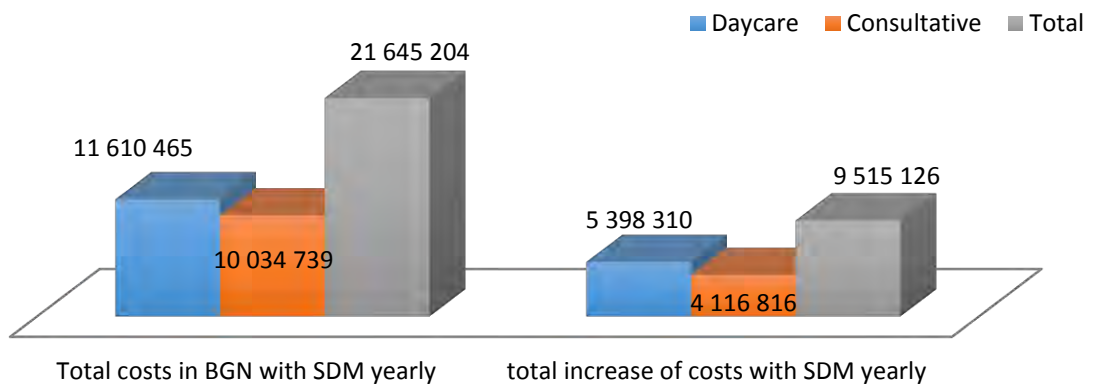


CONCLUSION

As result of SDM the existing capacity of the consultative services should be increased with 1 584 place: the financial effect of SDM and DI on consultative services is 4 116 816 BGN increase of the costs yearly.

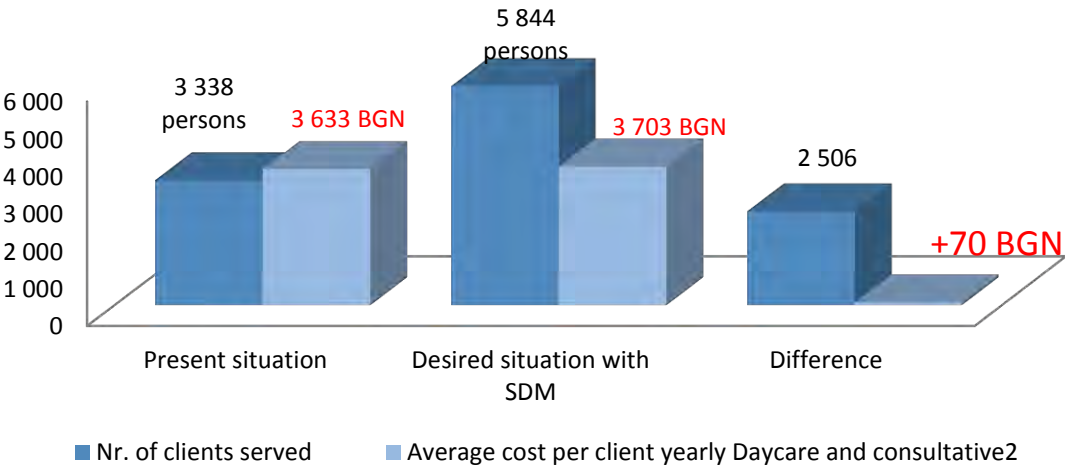
**Total conclusion on the financial effect of SDM and DI
on Daycare and Consultative services**

**Increase of costs of Daycare and Consultative services as result of SDM
in BGN yearly**



SDM and DI would **increase** the overall costs for Daycare and consultative services with **9 151 126 BGN** yearly.

Comparison of cost per client for Daycare and consultative services between the present situation and the desired situation with SDM



In the desired situation with SDM the costs for Daycare and consultative services will be more expensive than the present situation with **70 BGN yearly**.

CONCLUSION

SDM and DI would increase the overall costs for Daycare and consultative services with 9 151 126 BGN yearly. In the desired situation with SDM the costs for Daycare and consultative services will be more expensive than the present situation with 70 BGN yearly.

Conclusion on the monetized costs/benefits of SDM on Social services

Question: As SDM results in increased self-determination, personal development and independency of ID and MHP, does this lead to reduced intensity of the support and consequently reduced price of social services (monetized benefit) for the society?

The analysis provides evidence that the monetized/financial effects of SDM regarding the usage of social services by ID and MHP are as follows:

- Housing and Support for living services..... + 1295 BGN yearly per client**
- Daycare and consultative services..... - 70 BGN yearly per client**

CONCLUSION

The housing and support for living services will provide financial BENEFIT for the society of 1 295 BGN per client/yearly while the increased capacity of Daycare and consultative services will generate financial COST for the society of 70 BGN per client/yearly.

Regarding usage of social services SDM mechanisms will bring financial BENEFIT for the society of 1 225 BGN per served client yearly.

Monetized and non monetized Costs and benefits of SDM



3. Usage of healthcare services /directly related to the mental health problem/

THE BASIC QUESTION IN THIS CHAPTER IS:

As SDM results in personal development, self-determination, improvement in the level of independency and the emotional well-being of persons with mental problems and intellectual disabilities, does this lead to reduced intensity of usage of healthcare services, more specifically psychiatric consultations and treatment in psychiatric hospitals?



The goal of this chapter is to give an overview of the most obvious effects of SDM on the usage of healthcare by persons with mental problems⁶⁷. The analysis aims at coming to an average value in financial terms that illustrate the effect of SDM in:

- reduced compulsory and voluntary treatment in psychiatric hospitals for persons with mental problems.
- reduced usage of specialized support by psychiatrists for personal with mental problems

Limitation

This chapter explores in headlines only the effects of SDM on the usage of specialized psychiatric consultations and treatment in psychiatric hospitals. The improvement in the general health condition of the clients and consequently the reduced usage of general health services (GPs etc.) has not been a subject of the current analysis. The data for the frequency of usage of specialized psychiatric services and treatment in psychiatric hospitals is collected through the *Open questionnaire*. The research is based on the data out of the pilot projects,

⁶⁷ Persons with intellectual disabilities are not excluded from this research but it is mainly focused on the group with mental problems as by them can be registered the use of psychiatric help.

which is very limited (42 respondents) – these are clients living in the community. The data out of the research is collected for a very short period of time when clients were having SDM. Therefore the percentages based on which are made the calculations in this chapter are not validated, but still they outline a clear trend in reduction of usage of psychiatric hospital treatment and visits/consultations with psychiatrists.

For comparison reason the research team has interviewed also clients from the specialised institution in Podgumer (social institution for persons with intellectual disabilities and mental problems). In Podgumer the clients have received specialised psychiatric support only within the institution⁶⁸ and for the last one year none of the clients have been placed for compulsory or voluntary treatment in psychiatric hospital. These data is typical for the institutional type of care and adding it in to the overall picture would twist the conclusions on this chapter, and therefore the research team has made the choice to base the analysis only on the group of clients living in the community (pilot projects).

The effects of SDM

Social exclusion and loss of self-worth lead many people with mental problems to believe that they are useless, and so they live with a sense of hopelessness and low self-esteem. When anyone, with mental problem or not, does not have enough social contact, it affects them mentally and also even physically. Loneliness creates stress, taking a toll on health. Other things affected by social exclusion are the ability to learn, to put efforts in personal development and the motivation to make one's own decisions.

The lack of supportive environment outside the psychiatric hospital is in most cases the reason persons with mental problems have long stays⁶⁹ in psychiatric hospitals and centers for mental health. Living in the community without adequate and accessible support is a big challenge in the lives of people with mental problems. In addition very often the absence of affordable and secure accommodation is also a strong factor which leads to usage of the psychiatric hospital as a shelter. The lack of sufficient and person-centered support in the community based social services leads on other hand to turning the role of the psychiatrist into a social worker, case-manager or mentor as the clients approach him/her in a lot of the cases seeking support for their mainly social problems, rather than issues related directly to their psychiatric treatment. Very often the psychiatrist becomes or is at least seen as the «decision maker» of the person with mental problem.

The role of SDM in reducing the use of costly medical services /treatment in psychiatric facilities and consultations with psychiatrists/ is observed within the pilot projects. The data out of the research measures the usage of specialty psychiatric services before and after SDM. For the respondent group it indicates a clear tendency that SDM contributes (together with quality individualized support by the community-based social services) to less use of expensive psychiatric help. The effects of SDM in terms of increased self-determination, increased social network (contact with more people and greater support from friends and relatives), the established relations of mutual trust and the factors that make people with mental problems more secure and with less necessity of psychiatric services. Therefore the SDM mechanisms like peer support, professional mentor, support network, specialized professional support, anti-crisis plan and facilitation can be associated not only to increased quality of life of persons with mental problems but have also cost-saving implications regarding the usage of specialty psychiatric services.

⁶⁸ In the specialized institution of Podgumer there is a part-time psychiatrist appointed and paid by the social care system.

⁶⁹ For the compulsory treatment in a psychiatric hospital the maximum duration of an initial placement is three months and the court is obliged to extend that period if necessary with a new decision after taking into account a medical examination report. In many cases the doctors persuade patients to sign a consent form for voluntary treatment after the expiry of the prescribed term. This is done for purely social reasons.

1. Length of treatment in psychiatric hospitals

The data out of the pilot projects shows that before SDM for one year period 20% of the clients have been on treatment in psychiatric facility with an average length of stay 120 days (two times for a period of 60 days). Since SDM pilot projects started, only one of the clients has been on treatment in psychiatric hospital for a period of 30 days. Based on this data the reduction in usage of treatment in psychiatric hospitals is reduced with:

- In number of patients with 75%
- In length of hospital stay 75%

However the research team considers that the period of time for measurement is too short to make validated conclusion but still it is assumed that the effect of SDM interventions can be estimated to reduce the necessity of treatment in psychiatric hospitals with at least:

In number of patients with 15%

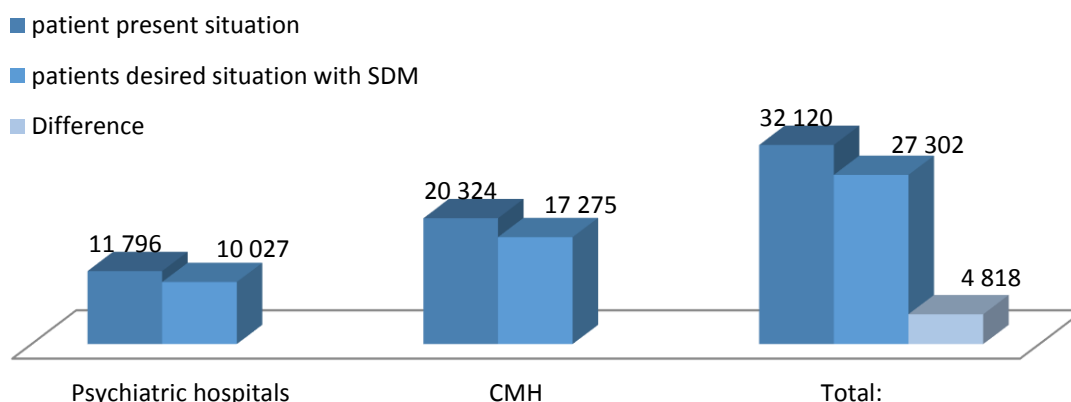
In length of hospital treatment 30 %.

Economic indicators for psychiatric inpatient services for 2012⁷⁰

	Bed/day BGN	Medicines per day BGN	Food per day BGN	Total BGN	Number of patients per year	Average stay of one patient /yearly/	Total costs yearly /for 2012/ in BGN
Psychiatric hospital	29.47	2.15	2.13	33,75	11796	58,5	23 289 727
Center for mental health	38,04	2,97	2,65	43,66	20324	19,9	17 658 182
TOTAL:					32 120	39,2	40 947 909

Based on the official statistics for 2012⁷¹ presented in the above table is made an estimation of the effect of SDM on national level in regard to number of patients:

Estimated reduction of the number of patients in psychiatric facilities as result of SDM

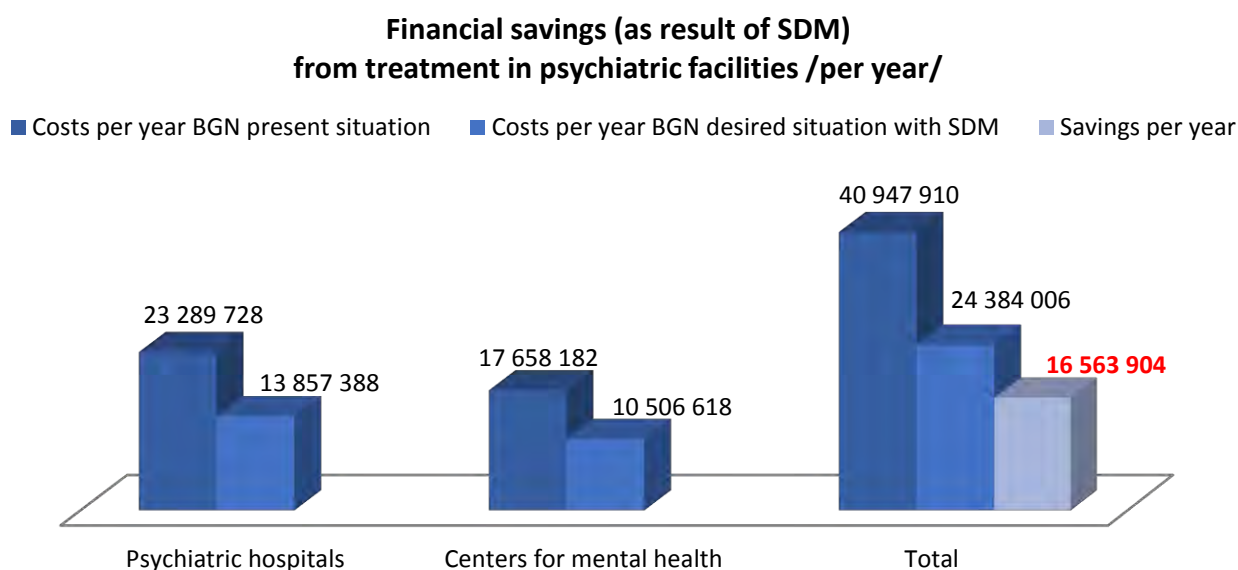


⁷⁰ Official data for 2012 of National Center for Community Health and Analysis;

⁷¹ the latest available;

As result of SDM the number of patients per year in psychiatric facilities will be reduced with 4 818 clients (from 32 120 to 27 302).

Together with a reduction of length of hospital stay (with 30% - from 120 to average 84 days yearly) for these patients the financial savings would be the following:



With supported decision making and adequate community-based support the usage of expensive stay and treatment in psychiatric hospitals will be reduces so that on national level on annual base a total saving of **16 mil.** can be realized.

In terms of costs per client compared with the present situation, the costs with SDM would be 872 while at present it is 1275 BGN. The reduction amounts at 382 BGN per client.

Visits and consultations with psychiatrists

Out of the pilot projects the data indicates an average reduction of number of consultations with psychiatrist by one patient with 40% (from average 11 consultations yearly to 7). Again considering the small scale of the study and the limited timeframe, we base the calculations on reduction of 20% (from average 11 visits to average 9).

Having the average hourly fee⁷² of psychiatrists is 30 BGN the savings per person yearly amount at 60 BGN.

CONCLUSION

The answer on the basic question of this chapter is YES.

The effect of SDM in enhanced personal development, self-determination, improvement in the level of independency and the social inclusion lead to reduced intensity of usage of healthcare services, more specifically psychiatric consultations and treatment in psychiatric hospitals.

With supported decision making and adequate community-based support the usage of expensive stay and treatment in psychiatric hospitals will be reduces so that on national level on annual base a total saving of 16 mil. can be realized. In terms of costs per client compared with the present situation, the costs with SDM would be 872 while at present it is 1275 BGN. The reduction amounts at 382 BGN per client. The consultations with psychiatrist will be reduced with 20% which will result in saving of 60 BGN per client/yearly. The total savings in the field of psychiatric aid would be 442 BGN per client yearly.

⁷² National health insurance fund

Monetized and non monetized Costs and benefits of SDM



4. Employment of persons with mental problems and intellectual disabilities

THE BASIC QUESTION IN THIS CHAPTER IS:

As SDM results in personal development, self-determination and social inclusion of persons with mental problems and intellectual disabilities, does this lead to increased employment and consequently a monetized benefit for the society?



Data and Limitations

Due to the short period of implementation of the pilot projects for SDM and the limited number of respondents in them, in this chapter are not presented direct evidence regarding the percentage of people who in result of SDM have started a job. Although there are few cases of employment of members of the target group it is hard to judge whether it is a direct effect of SDM.

For measuring employment as result of SDM in terms of «signed labour contracts» would be needed at least a 3-5 years of implementation of the mechanisms and thorough research. The data out of the present research provides information more on the level of «readiness» of the persons with mental problems and intellectual disabilities and their capability of having a job (in some cases part-time job or with supported employment). The results are that over 85% of the participants in the pilot projects are able to have labour. Being employed though depends also on the employer rather than only on the person's capability. And here comes the biggest challenge for the persons with mental problems and intellectual disabilities who in Bulgaria face stigma, prejudice and discrimination. In due course SDM practice will also slowly have effect on the attitude of the society as a whole and the employers to secure reasonable accommodations for

persons with disabilities, but this should be observed in a long-term perspective and it is not the focus of the present research to explore this issue.

Therefore this chapter discusses in general the effects of SDM on employment and provides an overview of the estimated potential benefits for the society of increased employment of persons with mental health problems and intellectual disabilities.

The effects of SDM

Work plays a central role in all people's lives. As American novelist William Faulkner observes *“Work is just about the only thing that you can do for eight hours a day”*. Work is also essentially something you ‘do’ for other people. (By contrast, in most leisure activities you “do” things for yourself.) Therefore high employment of people with disabilities in one society is the best evidence that it is an “inclusive society”. In Bulgaria we are witness of underestimation of the potential of people to contribute to society and add economic value to society. People with disabilities who have had their legal capacity denied are prohibited from signing an employment contract. They are thereby excluded from the labor market completely or forced to work outside it, meaning that they are likely to be exploited and under-paid. This practice is a manifestation of social exclusion which is not only unjust, it is also extremely costly – both to the health and well-being of individuals and their families and to society as a whole.

Employment provides a monetary reward and is inseparable from economic productivity, with its profits for the employer and its material benefits for society. In addition, employment provides latent benefits – non-financial gains – to the worker. These additional benefits include social identity and status; social contacts and support; a means of structuring and occupying time; activity and involvement; and a sense of personal achievement. Work tells us who we are and enables us to tell others who we are.

Work is crucial for people with mental health problems and intellectual disabilities, as they are especially sensitive to the negative effects of unemployment and the associated loss of structure, purpose and identity. Already socially excluded as a result of their disability, their exclusion is aggravated by unemployment. Their social networks and social functioning decrease, as do motivation and interest, leading to apathy.

SDM is reducing the exclusion by giving confidence to the people, increasing their self-determination and widening their social network. It encourages them, motivates them and provides continuous support for their personal development and independence. These effects improve persons with disabilities' employment opportunities and could yield substantial economic benefits. In part, these benefits are for the individuals themselves in the form of higher incomes, but there are also gains for the wider community. For example, government revenues increase, because of income tax and national insurance contributions payable on the extra earnings, and there would also be savings in social security spending as people move from benefits into work. In addition, there would be savings in the costs of care for those whose condition (especially by persons with mental problems) improves as a result of gaining employment.

A comparison between the financial costs and benefits for a person with disability when unemployed and employed and the society is presented in the table below. The example is based on a case study of a person with intellectual disability age 35 years with 90% disability (according to Medical commission decision – TELK) who lives in private home and uses daytime community-based social services.

Important note: The presented calculation for the employment situation is based on minimum wage of 370 BGN, while a big part especially of the people with mental problems are able and

qualified to work on position with salaries much higher than the minimum wage. Therefore the calculation shows the minimum possible benefit from employment of people with disabilities for the society.

WHEN UNEMPLOYED						WHEN EMPLOYED					
		Annual Income for the person	Annual Costs for the society	Annual Income in the state budget/society	Total annual cost for the society			Annual Income for the person	Annual Costs for the society	Annual Income in the state budget/society	Total annual cost for the society
1	Income from employment	0	0	0	0	1	Income from employment ⁷³	3 480	0	1 728	-1 728
2	Pension for disability ⁷⁴	1 584	1 584	0	1 584	2	Pension for disability	1 584	1 584	0	1 584
3	Social allowance for transport ⁷⁵	117	117	0	117	4	Social allowance for transport	117	117	0	117
4	Social allowance for telephone ⁷⁶	156	156	0	156	5	Social allowance for telephone	156	156	0	156
5	Social allowance for medicines ⁷⁷	117	117	0	117	6	Social allowance for medicines	117	117	0	117
6	Heating allowance ⁷⁸	250	250	0	250	7	Heating allowance ⁷⁹	0	0	0	0
7	Usage of Daycare ⁸⁰	0	5 855	475	5 380	8	Usage of CSRI ⁸¹	0	2 599	253	2 346
		2 224	8 079	475	7 604			5 454	4 573	1 981	2 592

The calculation shows that when a person with disability is employed this is highly reducing the costs of the society – with 66% (in the case with minimum wage) per person yearly.

⁷³ The calculation is based on employment on minimum wage – 370 BGN a month for 2014. The net amount the person is getting on monthly base is approx. 290 BGN while an amount of 144 BGN monthly are paid to the state in the form of taxes and social security payments by employer and employee.

⁷⁴ Pension for disability according Art. 90a Social Security Code

⁷⁵ Art 25 of Regulation for implementation of Integration of Persons with Disabilities Act – 9,75 BGN monthly;

⁷⁶ Art 26 of Regulation for implementation of Integration of Persons with Disabilities Act – 13 BGN monthly;

⁷⁷ Art 29 of Regulation for implementation of Integration of Persons with Disabilities Act – 9,75 BGN monthly;

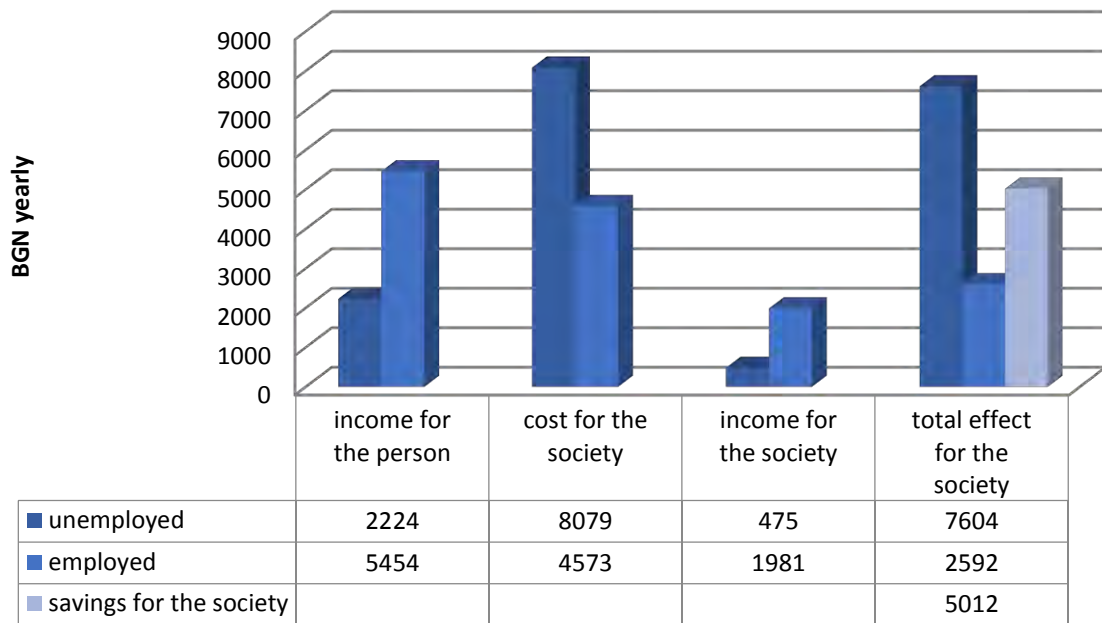
⁷⁸ The amount of heating allowance is 5 months x 350 kWh = 1750 kWh and depending on the price for kWh of the provider the yearly amount is average 250 BGN. (average price per kWh – 0.18 BGN day; 0.10 BGN night)

⁷⁹ The heating allowance is income related. When a person with disability is getting a job his/her income increases and he/she is not any more having the right for heating allowance.

⁸⁰ The cost for the state/society is the financial standard of a Daycare center, while the income is calculated on the basis of the monthly fee the person with disability pays for using the social service. In the case of Daycare this amount is 30% of the person's income.

⁸¹ When employed the person doesn't use any more the Daycare service but continue to need some support by the consultative service CSRI. The cost of the society in this case is calculated on the basis of the financial standard of CSRI. The income for the state/society is either 5% of the person's income or the full tax of the particular CSRI (in most cases around 60 BGN). According to the regulations the person pays the lower price of the two. In this case 21 BGN monthly which is 5% of the income, rather than 60 BGN full tax.

Effects of employment of persons with disabilities



The financial benefit for the society is savings amounting at 5012 yearly per person with disability who starts employment. When unemployed the person has an annual income of average 2 224 BGN which is below the poverty line while with employment the income from the salary (minimum wage), the disablement pension and social allowances amount at average 5454 BGN.

This calculation is made to roughly present the incomes and costs for the person with disability and the society, but it is not at all representing the complicity of a lot of micro and micro economic factors. What is fundamental and is not taken into consideration in the results is the “net effect of the labor of the employed” – what do persons indeed earn for the society with their labor. This is the real benefit for the society from the employment of persons with mental problems and intellectual disabilities, but at the present moment it is not possible to be calculated and given value to.

CONCLUSION

The answer on the basic question of this chapter is YES.

SDM contributes to persons with mental problems and intellectual disabilities’ inclusion in the society and improvement of their employment opportunities. The benefits for both the individual and the society in terms of financial value per year are: increase of annual person’s income with 3 230 BGN (59%); annual saving for the society of 5 012 BGN per person (66%).

Monetized and Non monetized Costs and Benefits of SDM



Regardless the indisputable prove that SDM has also economic benefits for the society, we believe that the financial benefits should only serve as an additional secondary argument for making policy choices regarding the necessity of introducing mechanisms for SDM. The non-monetized benefits that cannot be expressed in financial terms have in the case of SDM much bigger value. Quality of life, respect for human rights, independent living and inclusion in the community for people with ID and MHP are “priceless” benefits that give the strongest argument to policy makers.