



SUPPORTED DECISION-MAKING

HANDBOOK FOR
SUPPORTED DECISION-MAKING
INTERPRETERS



BULGARIAN CENTER
FOR NOT-FOR-PROFIT
LAW

SUPPORTED DECISION-MAKING

Bulgarian Centre for Not-for-Profit Law

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ABBREVIATIONS USED

CCP	Code of Civil Procedure
SSA	Social Services Act
SDM	Supported decision-making
CRPD	Convention on the Rights of Persons with Disabilities
ID	Intellectual Disabilities
AAC	Augmentative and alternative communication
MHP	Mental health problems
NPSMA	Natural Persons and Support Measures Act
PFA	Persons and Family Act
ECHR	European Court of Human Rights
CRAS	Civil registration and administrative services
PDA	Persons with Disabilities Act
EW	Expert witnesses
SAA	Social Assistance Agency
SAD	Social Assistance Directorate
ICD	International Classification of Diseases
WHO	World Health Organization
IDD	Intellectual Developmental Disorders

DEFINITIONS

Persons with Disabilities Act – *Supported decision-making is a combination of social interventions whose purpose is support for making decisions which have legal consequences and produce specific results for the person with disabilities.*

Natural Persons and Support Measures Act – *Supported decision-making is a support measure whereby the supporting person approved by the court, under the conditions of a trusted relationship, assists the supported person in expressing their wishes and preferences when making decisions about specific legal actions to be performed.*

Supported decision-making measure – *Communicating the content to the individual by significant persons, which results in a behavior whereby a conclusion on the individual's will and wishes can be drawn in a categorical and indisputable way (only for the purpose of this procedure).*

Person with limited legal agency – *A person whose ability to express their will (expressing will, consent, wishes, and preferences) has been deprived/partially limited, in a court procedure, in terms of the legal validity and consequences thereof, including acceptance by the third parties (all the others) as valid.*

Placement under full guardianship – *Guardianship is instituted, and a guardian is appointed; the individual's expression of will is invalid, and instead the guardian's expression of will has legal validity.*

Placement under partial guardianship – *Custodianship is instituted, a custodian is appointed; the individuals' expression of will has legal validity only if made jointly with and in conformity with the custodian's expression of will.*

SDM Interpreter – A professional with special knowledge whose task is mediating in the court with the aim to ensure the understanding of the consent expressed by the individual in relation to questions asked. The SDM expert can be defined as an Interpreter – the term used in the now effective Civil Code of Procedure. This type of interpreter differs from the expert who performs sign translation. He/She has specific knowledge and experience with understanding the way people with ID think and communicate, which is based on the communication protocol which he/she draws up. The interpretation consists in communicating the content of what the individual wants to say. The interpreter finds the content of the information in the means of communication that the individual has, irrespective of the degree and level of expression. It is generally accepted that any individual can express themselves in their specific way which can be understood against various criteria as repetitiveness of the means of expression used in respect of the people they target, repetitiveness in different or identical situations, etc.

SDM Facilitator – A professional trained to apply SDM who assists the individual with selecting and creating their supporting network. The individual themselves chooses the persons who are significant to them, and this is their first choice; the facilitator's task is to: make sure that the SDM processes are correctly conducted in each supporting network; assist the individual with creating a supporting network; assist with building relations among the supporting persons; adapt the individual's participation in the supporting network in a specific manner (for example, how the individual will express themselves in order to be understood, what is needed for this, who will ensure it); provide assistance to the networks created until they become stable and begin operating independently as natural supporting networks.

Expert witnesses – A legal term, the short for being 'expert'. These are professionals who, due to their education, training or (professional) experience, have expertise in a certain area which goes beyond the usual knowledge and experience that most people have, and this expertise of theirs is sufficient to rely on their testimony and opinions which are of a scientific, technical or another nature in relation to evidence or a fact falling in the scope of their expertise, and are thus called 'an expert opinion' and play a facilitating role in establishing and proving the facts. Expert witnesses assist with the work of institutions, courts, the police, insurance companies, etc. through analytical actions and methods called expert evaluations/opinions in a specific field. They are appointed by the body who needs their competence in case it lacks the necessary expertise.

Algorithm – A set of knowledge, steps and measures in a specific systematic consequence which an SDM Expert can use and which guide him/her in the process of supporting an individual with intellectual disabilities in relation to the individual's access to justice and expressing consent in court proceedings for the choice of a place to live.

Classical judicial psychiatric expert opinion – The expert psychiatrist evaluates the individual's state and whether the individual is able to express their will. Unlike this expert opinion, the interpreter's expert evaluation is aimed at providing interpretation (it does not question the person's ability to express their will).

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INTRODUCTION

To the Reader

Dear Reader,

If you are unfolding this Handbook, you probably have an educational background and/or experience in the area of social work, and are challenged by the idea of applying new techniques and knowledge in working with people with intellectual disabilities. You might be a lawyer in search of new and efficient methods to ensure access to justice for the group of people with intellectual development disorders.

Whatever the professional profile or interest urging you to read through the pages to follow, let us start by pointing out that this Handbook will be of benefit to:

- Professionals who work with people with intellectual disabilities (ID) and seek opportunities to present and improve the communication with this group, and the communication of third parties with this group;
- People who are concerned with ensuring equal recognition before the law for a group that is so difficult (from the perspective of the others) to communicate with;
- Organizations that wish to implement innovative methods of training and working with people with ID in order to protect their rights.

Two years ago, it happened to have the chance (due to the judiciary) to assist a group of people with intellectual disabilities (to various degrees) with communicating their will and preferences in court proceedings. We were convinced that the legal and social expertise we had, the longstanding therapeutic experience with this group of people, our wish to create and develop tools whereby we could also enable these individuals to communicate with the court, were a guarantee for a good beginning. Being led by the sole concern for the human being.

The following chapters tell almost everything we know, have tested, and are able to do in terms of training expert supported decision-making Interpreters. Such materials are still few in Bulgaria, and we believe that the more trainers and trainees in Bulgaria and worldwide “tell” this story, the better the chances will be for the change to occur:

- 1.** changing the law and the practice in a way that will allow people with intellectual disabilities to live in dignity and
- 2.** have a better quality of their life in which they are supported, and not deprived of rights,
- 3.** being able to defend their choice, without being at risk of abuse and manipulation

What we will not be able to relate on these pages are the countless stories of success, solidarity, the joy of life when we applied the values and methods of supported decision-making, and the numerous sad stories of human destinies that have been made even sadder, as the law, instead of providing a fair solution, introduced restrictions, isolation, and irreparable abuse.

We believe that everyone is able to express themselves, communicate and make decisions about their own lives. They only need to get the necessary help and support.

We have the best of hope that at some point in time we will have the opportunity to share our experience live if you take part in the future trainings for SDM Interpreters.

By the authors,
Nadya Shabani, Rossitsa Savova, Maria Stancheva

Special gratitude

Our special gratitude to the person who was our greatest inspiration – Dr. Michael Bach who has always firmly believed in the supported decision-making version which was developed within the framework of the Next Step Program, and was incorporated, for the most part, in the draft of the Natural Persons and Support Measures Act¹, and who taught us how to confirm in practice the new legal agency formula and manage the process of changes at various levels. Furthermore, our special gratitude to the Bulgarian Association for People with intellectual Disabilities, and to all the judges and panels from Sofia regional Court who opened the doors of the judiciary to hearing people with intellectual disabilities, and declared their support for the future development of this initiative and similar ones.

¹ Bill on Natural Persons and Support Measures, approved by the Council of Ministers and submitted to the 43rd National Assembly of the Republic of Bulgaria, August 4, 2016.

Next Step Pilot Program implemented by the Bulgarian Centre for Not-for-Profit Law, the Bulgarian Association for People with Intellectual Disabilities, the Global Initiative on Psychiatry-Sofia (GIP)

The Next Step Program started as a pilot initiative in 2012 with the aim to approve in a systematic manner the support measures for people with intellectual disabilities (ID) or mental health problems (MHP), monitor the outcomes and document specific conclusions based on which legal solutions are proposed by taking into consideration the contextual features in various areas across Bulgaria, and the specifics of the individual groups of persons covered by the Program.

The Program covered over 150 persons with disabilities (ID and MHP) and over 1,500 family members and friends; it was implemented in Sofia (Autism Association and Global Initiative on Psychiatry-Sofia), Vidin (Regional Society for the Support of People with Intellectual Disabilities), Plovdiv (Parallel World Association), Dobrich (St. Nikolay the Wonderworker Foundation), Lovech (Protection Association), and Bobov dol (Innovation Association). The pilot SDM projects were incorporated within the framework of social services for people with intellectual disabilities which are operational and have accumulated experience over time. The confirmation of the new approach – person-centered planning – in the provision of social support to the persons involved in the project and the targeted work to improve the individual's functioning in terms not only of everyday self-care but also of identifying and prioritizing personal wishes and needs, and analyzing alternative ways to meet them by making specific decisions serves as the background against which the outcomes and evidence relevant to building the new legal tools are registered.

Within the framework of the pilot projects, we managed to develop and apply in respect of the individuals involved therein a new formula for their legal agency. The pilot projects proved that whether people are “normal” or with mental health problems or intellectual disabilities, they all have similar values, dreams and expectations – they want to have a job, create a family, be able to do things their way, be self-sufficient. The support was provided within the framework of the specific social interventions for the relevant individuals, and was based on the new approach: person-centered approach. The latter helped us assist the individual by allowing him/her to keep control over decision-making. This tool can help us draw the broad picture of a person’s life and how he/she chooses to live his/her life, i.e. the person’s overall ability to make decisions independently, and, accordingly, determine the scope of the support needed. As for reasonable accommodation, it consisted in the provision of adequate information by trained experts, and the provision and clarification of information in an easy-to-read format. While the new formula for legal agency had a limited manifestation in reality due to the existing restrictions imposed by the effective legislation, it had a substantial impact on the individuals’ life and the decisions made by them.

You can read more about the Program and the conclusions made in:

[„Ensuring opportunities and an environment in which people with intellectual disabilities and mental health problems exercise their rights. What, where, and how. Guidance on changing policies“](#) (BCNL, 2014), which presents key prerequisites and challenges for the reform in various policy areas and systems;

[„13 case studies. What may happen to me if I am a beneficiary of protection under the Persons and Family Act \(PFA\) or if I am a beneficiary of the support measures under the Natural Persons and Support Measures Act \(NPSMA\).“](#), which makes a comparative presentation of the expected development of 13 case types (identified and developed based on the experience with the Next Step Program under two assumptions: the Persons and Family Act and the draft law on Natural Persons and Support Measures (BCNL, 2016);

[„Research in action. The pilot programs for supported decision-making – is learning possible?“](#) (BCNL, 2014); [„Intro-version. From guardianship to freedom“](#) (BCNL, 2015);

[„Study on the effects and the economic benefits from supported decision-making“](#)(BCNL, 2014), which shows the economic and non-financial benefits from supported decision-making for the individual and the society..

What are the benefits from this handbook?

This handbook will assist you with acquiring special knowledge about:

- 1.**The applicable standards set out in the Convention on the Rights of Persons with Disabilities (CRPD) in relation to the communication of people with ID;
- 2.**Some important theoretical and practical issues relevant to the communication of people with ID;
- 3.**What is a SDM Interpreter and how he/she assists people with ID in communicating their rights;
- 4.**What practical tools can be used by the SDM Interpreter;
- 5.**Relevant tips in terms of participation in court proceedings in case you act as an SDM Interpreter.

We hope that what you will read in this paper will give you food for thought. This knowledge may not be fully realized by the user, but rather discursive, meaning our discussion and / or our action within a given point of view or paradigm.

We continue developing this special knowledge and experience, and we stand ready to interact with you, dear reader, to raise issues and seek answers in the context of discussions and partnership.

CHAPTER ONE



THE LAW SETTING THE FRAME



Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD) was ratified by Bulgaria and came into force in 2012². Pursuant to the Bulgarian Constitution, the Convention is a legal instrument which has primacy over the domestic legislation. CRPD introduces an entirely new legal and social paradigm which is to be applied to understand and assess disability. The following key elements need to be highlighted for the purpose of SDM:

2 Ratified by virtue of a law passed by the 41st National Assembly on 26 January 2012 – SG No 12 of 2012. Effective for the Republic of Bulgaria as from 21 April 2012.

Definition of communication under CRPD:

- **Communication** includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.

- **Language** includes spoken and sign languages and other forms of non-spoken languages.

- **Reasonable accommodation** means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or

exercise on an equal basis with others of all human rights and fundamental freedoms.

- **Universal design** means the design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.



Art. 9 Accessibility

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

(a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;

(b) Information, communications and other services, including electronic services and emergency services.

2. States Parties shall also take appropriate measures to:

(a) Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;

(b) Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects

of accessibility for persons with disabilities;

(c) Provide training for stakeholders on accessibility issues facing persons with disabilities;

(d) Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;

(e) Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;

(f) Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;

(g) Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;

(h) Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

Art. 12 Equal recognition before the law:

1. States Parties reaffirm that persons with disabilities have the right to recognition **everywhere** as persons before the law.

2. States Parties shall recognize that persons with disabilities enjoy **legal capacity** on an **equal basis** with others in **all aspects** of life.

3. States Parties shall take appropriate measures to **provide access** by persons with disabilities to the **support they may require** in exercising their legal capacity.

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

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities **to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.**

Art. 13 Access to justice

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

2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

Conclusions:

– The human rights enshrined in the Convention on the Rights of Persons with Disabilities have also been laid down in other international legal instruments adopted earlier³. While CRPD **does not regulate new rights, it addresses the issues relating to the autonomous exercise of rights by people with disabilities in a new perspective.**

³ Thus, for instance, pursuant to Articles 1 and 2 of the Universal Declaration of Human Rights adopted by the UN on 10 Dec. 1948: "All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood. Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status." The provision of Art. 14 of the European Convention on the Protection of Human Rights and Fundamental Freedoms (signed on 4 Nov. 1950 and entering into force on 3 Sept. 1953, effective for the Republic of Bulgaria as from 7 Sept. 1991) stipulates that the enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, color, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status". Furthermore, Art. 15 of the Convention on the Elimination of All Forms of Discrimination against Women (adopted and opened for signing, ratification and accession by virtue of Resolution 34/180 of the UN General Assembly on 18 Dec. 1979) stipulates that States Parties shall accord to women, in civil matters, a legal capacity identical to that of men and the same opportunities to exercise that capacity. In particular, they shall give women equal rights to conclude contracts and to administer property and shall treat them equally in all stages of procedure in courts and tribunals.

-Disability is perceived as an issue in the interaction with the external environment, which is an obstacle and a barrier to people's participation. Therefore, any restrictions justified by the disability are discriminatory, as the environment has the obligation to ensure access.

-It is for the first time that a mandatory obligation to ensure universal design and reasonable accommodation has been laid down, the accessibility to be secured being not only physical but also informational.

- The new vision and legal paradigm are most strongly developed in the provision of Art. 12 Equal recognition before the law which obliges the states to ensure a system for the autonomous exercise of rights, including by individuals whose legal agency (the ability to run their affairs independently) would otherwise be questioned.

Philosophy and standards of Art. 12

The most important highlight in Art. 12 concerns the link between the concepts 'legal standing' (the ability to hold rights) and 'legal agency' (the ability to independently exercise these rights). In practice, as the legal provision makes it clear, legal agency cannot be restricted even for the purpose of protection. Protection can be justified only by ensuring safeguards that relate to the conditions explicitly set out in Art. 12, para 4:

"... respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests..."

This interpretation is also confirmed in the General Comments on Art. 12 of CRPD adopted in 2014. According to these comments, the concept 'legal capacity' has two inseparable stands:

- 1) the ability to hold rights and duties, called 'legal standing',
and
- 2) the ability to exercise those rights and duties through one's own actions, called 'legal agency'.

While national legislations usually recognize the first stand (legal standing) in respect of persons with mental disorders or intellectual disabilities, they deprive them of or impose limitations in terms of the second stand (legal agency). In this respect, the General Comments explicitly point out that these two stands: the 'passive' one (legal standing) and the 'active' one (legal agency) are intrinsically linked; they constitute an integral part of the concept 'legal capacity' and can be neither separated nor limited.

Any individual has legal standing and legal agency by virtue of being human, and this is an inalienable right of theirs. The General Comments distinguish between the concepts 'legal agency/capacity' and 'mental capacity'. **Legal agency/capacity** is the key allowing independent participation in the society, while **mental capacity** relates to the individual's ability to make decisions. **Mixing these two concepts** in legislations contributes to limitation/deprivation of legal agency on the grounds of: (1) medical circumstances; (2) prevention of any potential negative consequences from the individual's decisions; (3) the existence of deficits in decision-making. The right, as enshrined in Art. 12 of the Convention, applies to everybody, in all areas of life. It is the key to ensuring participation in the society, hence it is the tool for the exercise of the other rights.

The reason why this legal text had to be explicitly included in CRPD is that medical and legal characteristics are often combined in the context of people with ID. Mental or cognitive capacity concerns decision-making and people's capability to make decisions that vary between individuals, and depend on a number of other factors, including the environment and social circumstances. As indicated in the General Comments on Art. 12, the concept 'mental/cognitive capacity' is highly controversial. Mental capacity can hardly be defined as an objective state. It is contingent on the social and political context in which the individual is at a certain point in time.

Man is, first and foremost, a social being that accumulates, within their own life, social experience and knowledge affecting their coping abilities and skills, and their strategies to this end. We all, whether we have disabilities or not, build up our unique social experience which teaches us: how to make decisions, how to share them (in what context) and before/through/with whom. Opportunities are continuously emerging for us – new ones, opportunities repeating our experience directly or in a similar manner. However, if we think about this more deeply, we will become aware of being faced with an ongoing choice. We make choices with almost any actions of ours: in some cases – automatic and emotional, in others – better conceived, and yet others – better informed. This is true of any human being.

In addition, making a mistake or taking an incorrect or just an unreasonable decision is something that many of us provoke consciously or unconsciously – acting in this way is determined by a variety of subjective and objective factors (related to the environment), without being directly related to cognitive abilities. Nevertheless, it often happens that we are not objective in our assessment of the actions performed by “normal” individuals and those with ID; we are tolerant to the erroneous decisions and incorrect choices made by persons without disabilities, on the one hand, but, on the other hand, we set extremely high criteria in respect of decision-making by persons with disabilities. Moreover, this stereotype is further complicated by the fact that, whether we have a disability or not, the complex contemporary world requires that we use specialized assistance when making certain decisions – for instance, in relation to the medical treatment, finances or other matters that require specific competence. The very fact that we do not have an in-depth understanding of the particular matter or of the various consequences from potential choices due to the lack of special knowledge cannot serve as grounds for limiting our legal agency.

This is why Art. 12 also lays down the irrebuttable presumption that any individual can make decisions in line with their personal wishes and preferences. Under the standards set out in Art. 12, it is not admissible that this be refuted based on an assessment of the individual’s mental/ cognitive capacity. **If a person has difficulties, they are entitled to support through measures whose purpose is helping them not make the decision but receive information and support whereby they can make a choice in accordance with their wishes and preferences.** For certain, the support for communication is part of this process of support for sharing the choice.

Legal agency as an opportunity to exercise one's rights through autonomous actions, is, in practice, a legal tool, **the key, whereby legal standing and any right is implemented.** The autonomous exercise of rights allows people to independently build and manage their world, as they link the legal opportunity (the right) to self-evocation – the action driven by individual understanding, perception and wish. What is objectively possible (legal agency) is linked to the subjective realization, which opens up a space for free choice and provides protection against interference by third parties in decision-making. This is the way for us to realize our freedom. The exercise of rights not via independent actions, except for the assumption of empowerment, always results in or implicitly involves substitution of a person's will (guardianship). Therefore, the restriction of legal agency in terms of the outcome and consequences for the individual contributes to the factual deprivation of rights and the impossibility to control one's own life.

An important standard laid down in CRPD is that having difficulties does not serve as grounds for restriction; on the contrary, this gives rise to the right to receive support which will enable the individual to make decisions and autonomously exercise their rights. These support measures should not include substitution of decision-making and substitution of the supported person's will and preferences. All forms and measures of supported decision-making related to legal agency, including measures with less intensive support should be based on the individual's will and preferences, and not on what is assumed to be their best objective interest as understood by the third parties. Including people with intellectual disabilities or mental disorders in supported decision-making measures cannot be grounds to restrict fundamental rights of theirs such as the right to have their voice heard, the right to contract a marriage, to create a family, the right to freedom, etc.

Art. 12 sets out standards with regard to the measures. The measures have to be:

- 1. proportional and adapted to the person's circumstances,**
- 2. applied for the shortest time possible,**
- 3. subject to regular review under supervision; and**
- 4. determined by a competent, independent and impartial authority or judicial body.**

The safeguards are **proportional to the degree** to which they concern the rights and interests of the relevant individual. The topic of proportionality is extremely important, as it relates not only to legal interventions, but also to medical and social ones. Being proportional means that the support measure proposed should be the most appropriate one (person-centered, individual), and any other measure, in particular those of less intensity, should be less appropriate not only because it will not be efficient enough (to achieve its aim) but it might also put the person at risk compared to the measure proposed which will be more efficient for him/her.

The last standards set out in paragraph 5 refer to **eliminating any legal barriers** to the autonomous exercise of rights and introducing explicit possibilities for persons with disabilities, including the right **to own or inherit property, control their own financial affairs and have equal access to bank loans, mortgages and other forms of financial credit, and ensure that persons with disabilities are not arbitrarily deprived of their property.**

Placement under guardianship in conformity with the Bulgarian law

(The Persons and Family Act of 1949)

The concept of placement under guardianship as “protection”

The existing regime of guardianship⁴ (guardianship and custodianship) with respect to adults aims to provide (in theory) protection at three levels: for the person with disabilities; the third parties; and the whole society. The concept of guardianship in terms of people with intellectual disabilities incorporates the following principles and views:

- The medical model of the disability perceived as a deficiency and an issue of the individual themselves; due to the person’s deficiency and their inability to make up for it and, thus, become “normal”, they need to be protected even if this would imply being treated as an object of rights and care;
- Persons with mental health problems and intellectual disabilities are placed under guardianship in order to protect them against making “wrong decisions” and the unfavorable consequences from such decisions;
- The protection of these persons should be provided in conformity with the concept of “the best interest of these persons”, as this best interest is understood by the society and the third parties;
- Persons with mental health problems and intellectual disabilities are unable to form a legally valid will; therefore, the law does not consider and does not respect their wishes and preferences.

This rationale is at the core of the Persons and Family Act whose latest version of this particular part dates back to 1949, and does in no way reflect the contemporary understanding of human rights, nor does it take into account the achievements of social science and approaches. While our modern so-

⁴ *Approved in its now effective version in 1949, without any changes ever since.*

ciety has become mature enough to eliminate physical barriers before persons with disabilities, the denial or restriction of their legal agency on the grounds of a mental disorder or an intellectual disability is still a fact, which creates communication barriers.

The very essence of guardianship is that the person placed under guardianship has a substitute in the legal world who makes decisions for them which are in conformity with their best interest, as understood by the third parties and the society. The concept of guardianship as protection is contrary to the approach which is based on rights and is incorporated in contemporary international legal instruments, including CRPD; this approach implies, on the one hand, empowerment and achieving independence for persons with disabilities as active subjects, holders of rights and, respectively, ensuring the responsibility of the institutions and third parties that are obliged to guarantee the effective and real exercise of rights by people with disabilities.

Over time, guardianship (through the prism of the **medical model of the disability and the rational exercise of rights**) has been perceived as a **form of protection**. Based on the numerous cases we have dealt with so far, we can question to what extent **guardianship does indeed provide protection or is rather a tool for deprivation of rights and abuse of the interests of the persons placed under guardianship**.

In practice, as a final result, the institution of guardianship equates the "protection" of the individual with the preservation of property (also controversial, because if it is taken away from the person to whom it belongs and managed not according to his/her wishes and preferences, then it is not clear to whom it is "preserved") and to safeguard the interests of other parties and civil turnover. The destiny of the individual, the subject of rights, does not constitute a value and a focus of guardianship.



Shtukaturov v. Russia case before the European Court of Human Rights. Shtukaturov's mother who suffered from ordinary schizophrenia lodged an application with a Russian court requesting that her son be deprived of legal agency. The arguments therefor were that he was inert, passive, rarely left the house, and, after inheriting property from his grandmother, had taken no action to see to the property rights acquired. This revealed his inability to have an independent and autonomous life, and the need to have a guardian. Shtukaturov was not informed about the claim lodged by his mother. Neither did he participate in the court proceedings of which he had not been notified. The mother had been notified. She did not appear but informed the court in writing about sustaining her claim. The court hearing was attended by a representative of a psychiatric hospital which had conducted a medical assessment of Shtukaturov. The representative of the hospital, described as an "interested party" in the case, submitted a claim to the court for depriving Shtukaturov of legal agency. The court hearing took just 10 minutes. At the end of the day, the court deprived Shtukaturov of legal agency on the grounds of the medical assessment conclusion; his mother was appointed guardian, and in 2007 she placed her son in a psychiatric medical facility.

The ECHR holds in its decision that the judgment whereby Shtukaturov was deprived of legal agency constitutes interference in his private life, and hence a violation of Art. 8 of the European Convention on Human Rights. Furthermore, the Court holds that Shtukaturov's placement in a psychiatric medical facility for indefinite time is a violation of Art. 5 (protection against deprivation of liberty) of ECHR, and amounts to deprivation of liberty.

Pursuant to the Bulgarian Persons and Family Act, guardians and custodians, being guided by the principle of **the best interest** (which is laid down in the law), make decisions instead of the persons concerned. In the Bulgarian context, this is also applied with respect to individuals who are placed under partial guardianship. It is not by chance that in *Stanev v. Bulgaria* (2012) the European Court of Human Rights found that in Bulgaria placement under partial guardianship often compares, in terms of the legal consequences, to full guardianship.



In *Stanev v. Bulgaria* case the European Court of Human Rights found that any placement of a person who is legally deprived legal agency or has partial legal agency in a specialized institution for social services amounts to “deprivation of liberty” within the meaning of Art. 5, para 1 of ECHR. It is in the same case that the Court has defined the assumptions of the concept “deprivation of liberty”: (a) when the individual was legally incapacitated, and was placed in a psychiatric ward upon the request of their guardian; (b) when the individual initially consented to placement in a medical facility, and subsequently attempted to escape; (c) when the individual was incapable of giving consent to placement in a psychiatric ward, and never attempted to escape. In addition, according to the above judgment of ECHR, guardianship played an essential role in terms of Mr. Stanev’s deprivation of liberty. The Court explicitly holds in its reasons that **if he had not been placed under partial guardianship, he would not have been placed in a specialized institution for residential social services**, without respect for his will, and, respectively, he would not have been deprived of liberty.

The conclusions made by ECHR in the second successful case *Stankov v. Bulgaria* are similar. Mr. Stankov was placed under partial guardianship in 1999. The judgment was delivered on the basis of his medical diagnosis. The mental illness that he had had for years was the only reason for the restriction of his rights. After being placed under partial guardianship, Stefan Stankov was placed in a specialized institution in the village of Dragash Voyvoda where the living conditions were humiliating and extremely harsh. Survival was just a matter of personal resilience, and, as Mr. Stankov said: "of a healthy mind". After the institution was closed, Mr. Stankov was simply moved "as an object" to a similar institution in Rusokastro. On 17 March 2015 the European Court of Human Rights delivered a judgment against Bulgaria for violation of the rights of Stefan Stankov. In its judgment, the Court finds a violation of Mr. Stankov's rights under Articles 3, 5, 6, and 13 of the European Convention on Human Rights and Fundamental Freedoms (the right not to be subjected to inhuman and degrading conditions and treatment; the right not to be subjected to torture; the right to freedom and security; the right to a fair trial; and the right to effective remedy). Similar to the case of Mr. Stanev, Stefan Stankov would not have found himself in such a situation, had he not been placed under guardianship.

According to statistical data (Civil Registration and Administrative Services for 2018⁵), as of the time of providing the information requested, the persons placed under full guardianship were 7,355, and those under partial guardianship were 1,035 or a total of 8,390. Approx. 3,500 of them were placed in specialized institutions, being deprived of the opportunity to have an independent life in dignity.

⁵ Data gathered by the Ministry of Justice within the framework of the WG for the assessment of the impact of the Natural Persons and Support Measures Act.

The practical and legal consequences from guardianship are that the persons placed under guardianship are deprived of all rights. They cannot choose where and with whom they will live; cannot exercise the right to receive education of their choice and preference, nor the right to additional training and qualification, the right to employment, the right to an independent life in the community, the right to contract a marriage, and a number of other rights.

Support measures for ensuring access to justice and legal protection under the Persons with Disabilities Act (PDA)

A new Persons with Disabilities Act was passed in 2018 (effective as from 2019). The law offers the first clear and systematic attempt to introduce some of the standards of Articles 12 and 13 of CRPD in relation to changing the paradigm for people with disabilities.

The law sets out the first legal definition of SDM, and clarifies that any person with a disability who has difficulties with the **autonomous exercise of their rights** in performing specific legal actions, shall have the **right to supported decision-making** which shall be determined following the procedure laid down in the law by providing support measures.

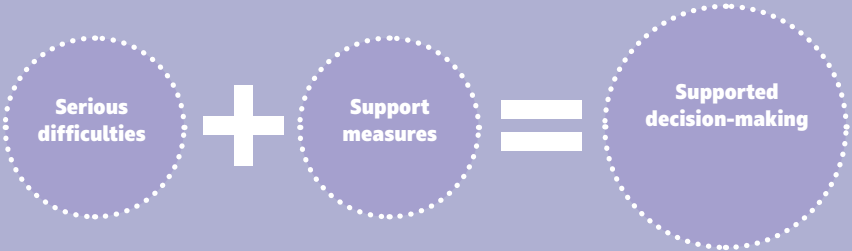


Fig.1 Formula of the need for SDM

It is explicitly explained that supported decision-making is a combination of **social interventions** whose purpose is support for making decisions which have **legal consequences** and produce **specific results** for the person with disabilities.

It is pointed out what **serious difficulties** are – these are the cases when the person with a disability:

- 1.** does not understand the information on which the decision for the specific legal action is based;
- 2.** does not assess the nature and the consequences of the potential decisions concerning the specific legal action;
- 3.** is unable to link the information under point 1 to the assessment under point 2 in the specific decision-making.

It is particularly important to note that the person's inability to independently express their wishes and preferences via the usual communication means does not constitute serious difficulty, if the person uses ways and means that are appropriate for their circumstances, including non-verbal forms of communication, visual presentation, etc.

It should be highlighted that the PDA introduces the possibility for people with ID to receive special support via social interventions, and thus be assisted in communicating their wishes and preferences. Other legal provisions explicitly stipulate that the aim of support measures is facilitating the **autonomous exercise** of the rights of the person seeking support.

To sum up, a support measure will be made available, when the person:

a) has difficulties with understanding the information, expressing this information, being understood in the communication with a third party, and

b) support measures provide them with alternative (to the usual means) ways of communication the message or help them better understand the information.

A very important point is ensuring that the support provided excludes any undue influence by the supporting person, and substitution of the supported person's will with the supporting person's one. This means that if there are relatives who support the individual, special attention should be paid to the extent to which other circumstances would cast doubt on whether the decision being communicated is independent of influence, which in this case would be unacceptable to take into account, or they are in a particular hypothesis of a conflict of interest (for example, subject to support a decision to sell the property that will be transferred to the very supportive which helps communication). Secondly, when communication is supported via communication measures, what should be also avoided is that, instead of communicating the message, the supporting person communicates their personal opinion which is presented as the supported person's one.

Support measures are social interventions which include:

- 1.** Consultations with a trained specialist;
- 2.** Provision of specialized services for supported decision-making;
- 3.** Ensuring a mentor to facilitate decision-making;
- 4.** Drafting an Anti-crisis plan;
- 5.** Supported decision-making through appropriate supporting networks;
- 6.** Applying protection measures⁶.

Therefore, we can sum up that these interventions are aimed at assisting the individual concerned with communication or with communicating their message.

Support measures have the following objectives:

- 1.** Explaining the meaning of the legal action and its consequences;

⁶ These are presented as social interventions with more details in CHAPTER TWO "COMMUNICATION".

2. Helping the supported person understand the other participants involved in the legal action or affected by it;
3. Helping the supported person express their wishes and preferences in a way understandable to the others;
4. Providing other assistance related to carrying out the legal action.

Support measures are determined in compliance with the following principles:

1. **Need** for each measure;
2. **Respect** for the wishes and preferences of the supported person;
3. **Proportionality**, timeliness, and flexibility;
4. **Avoiding conflicts of interest**, and undue influence;
5. **Exhaustiveness** of the support measures compared to the application of the protection measures.

The supporting person shall only be a person with whom the supported person has a trusted relationship⁷.

At the end of the section "Access to Justice and Legal Protection" of the PDA lays down the general obligation for the judiciary bodies, and all the public institutions to provide people with disabilities with access to justice on an equal basis with any other persons, including by ensuring procedural and age-oriented support measures in view of their role at all procedural stages. The National Institute of Justice and the Academy with the Ministry of Interior have training programs for working with people with disabilities.

⁷ You can read more about establishing a fiduciary relationship in CHAPTER TWO "COMMUNICATION".

Legal proceedings in which a SDM Interpreter can participate

PLACEMENT UNDER GUARDIANSHIP (CIVIL CODE OF PROCEDURE)

Commencement of proceedings

The placement of a person under full or partial guardianship can be sought by means of a claim from a spouse, close relatives, the prosecutor or any person with a legal interest vested therein. The participation of the prosecutor in the proceedings is mandatory. These cases fall within the competence of **district courts** with jurisdiction over the residence address of the person in respect of whom guardianship is sought.

The person in respect of whom guardianship is requested shall be examined in person, and, if the need be, the attendance thereof shall be compelled. Where the said person is placed in a medical-treatment facility and the health condition thereof precludes that he or she be brought in person to a court hearing, the court shall be obligated to obtain an immediate impression of the condition of the said person. If, after the examination, the court deems it necessary, the court shall appoint a provisional curator to take care of the personal and property interests of the person.

The court shall pronounce on the statement of action after an examination of the person sought to be placed under guardianship and of the family members thereof. If this proves insufficient, the court shall proceed with taking other evidence and hearing expert witnesses. If the person is placed in a medical-treatment facility, the court shall procure information on the condition of the said person.

Both the theory and the practice recognize that the court **has to establish the existence of two types of criteria** within the framework of these proceedings: a) **medical criteria** – the person has a weak mind or a mental illness, which is established through an expert opinion by expert witnesses-psychiatrists, and b) **legal criteria** – as a result of the existence of the medical criteria (i.e. a weak mind or a mental illness) the person is unable to take care of their affairs.

It often happens that in such proceedings the expert witness establishing the medical criterion pronounces on the legal one, which is inappropriate.

After the entry into force of the judgment whereby the said person is placed under guardianship, the court shall notify thereof the guardianship and custodianship body in order to institute the guardianship. The plaintiff shall not be entitled to costs in the guardianship proceedings (i.e. he/she pays the costs incurred – remuneration for the lawyer, expert opinion, court fees, etc.). If the action is dismissed, the plaintiff shall owe the respondent the costs incurred thereby in connection with the case.

In cases of guardianship claims, neither judgments by default, nor judgments upon admission of demand shall be delivered. The provisions of this chapter shall also apply to lifting guardianship. The lifting of guardianship can also be sought by the guardianship or custodianship body, and independently by the person placed under partial guardianship.

Giving consent for placement in residential care (Social Services Act)

The Social Services Act lays down a very important prerequisite for using social care – the wishes of the persons placed under guardianship shall always be taken into consideration and shall take precedence (here we also include the experience gained from the first envisaged procedure in accordance with Art. 16a from Social Assistance Act, which provision was repealed after the entry into force of the SSA).

Art. 91 of the SSA stipulates that the provision of social services to an adult under guardianship and the termination of the use thereof shall be in compliance with the person's wishes and the opinion of their guardian or custodian, and, in the event of a conflict, the wish of the person in need of a social service shall take priority. Where the wish to terminate the use of the social service for residential care has been stated, the Social Assistance Directorate shall immediately take the actions referred to in Art. 100 if the person is under full guardianship, and if the person is under partial guardianship, paragraph 1 shall apply, i.e. in compliance with the person's wish and the opinion of their guardian or custodian.

A particularly important point is that the law explicitly provides for the possibility for the Social Assistance Directorate to request support from social services providers with a view to examine the wishes of persons placed under guardianship, which shall be carried out in conformity with the support measures referred to in the PDA.

The guardian or custodian of a person placed under guardianship must take into consideration the person's wishes and assist them with the referral to and the use of the social service chosen by them.

Placement in residential care

Section 3 of Chapter 6 of SSA sets out a special procedure for the placement of persons under full guardianship in residential care. The placement in residential care of adults under full guardianship shall be done by the **regional court** with jurisdiction over the current address of the person concerned.

The procedure shall be initiated with a request for placement to the relevant regional court submitted by the Social Assistance Directorate on the basis of the person's consent declared in writing and the guardian's opinion in accordance with Art. 91.

The following documents are attached to the request:

- 1.** A report which also contains an opinion regarding the possibilities to provide care for the person in a home environment;
- 2.** A preliminary assessment under Art. 73;
- 3.** Information about the existing appropriate social services for residential care within the region, and vacancies.

The Social Assistance Directorate (SAD) with jurisdiction over the current address of the person under guardianship may carry out only temporary placement in a social service for residential care in an administrative procedure in cases when no other options to ensure care for the person are available pending the court ruling.

Temporary placement under paragraph 1 shall be carried out by an order issued by SAD's Director on the basis of the person's consent declared in writing and the guardian's opinion in accordance with Art. 91 (explicit consent).

Within one month from the issuing of the order, SAD shall submit a request for placement in a social service for residential care to the regional court with jurisdiction over the person's current address. The acts of Directors of SAD are issued and are subject to appeal under the procedure laid down in the Administrative Code of Procedure.

Legal proceedings

The requests for the placement of a person under full guardianship in a social service for residential care shall be within the competence of the regional court with jurisdiction over the person's current address. In the procedure under paragraph 1, the court may collect evidence at its own initiative, and shall examine the will of the person whose placement is sought, including via expert witnesses.

The court shall immediately examine the request in an open hearing with the participation of the Social Assistance Directorate, the person and their guardian. In case the person whose placement is sought is unable to participate in person in the hearing under paragraph 3, the latter shall be held outside the court building.

It is the obligation of the court to examine the will that predetermines the need for an "assistant" in this process; the appropriate person for this role is the expert interpreter of communication (hereinafter "SDM Interpreter").

The court shall deliver, within one month from the date of the request referred to in Art. 96, para 3, a judgment which shall be notified to the parties, and shall be immediately enforced.

The court may grant the request for placement in a social service for residential care in respect of a person under full guardianship only in cases when the procedure does not establish the existence of any possibility to

provide support to the person in a home environment and in the community. The judgment shall indicate the time limit for the placement which cannot exceed three years.

The judgement for placement shall be appealable before the district court within a 7-day time limit. In the event of an appeal, the court shall appoint a hearing within max. 7 days. The district court shall deliver a final judgment.

The placement of a person under full guardianship in a social service for residential care shall be terminated under the placement procedure by the regional court at the request of the Social Assistance Directorate on the basis of a wish declared by the person and an opinion of the guardian in conformity with Art. 91.

Before the court delivers its ruling, the termination of placement shall be ordered temporarily by SAD's Director on the basis of a wish declared by the person and an opinion of the guardian in conformity with Art. 91.

When the placement time limit in the judgment under Art. 98 has expired, para1, and in the event of death of the person, the above two assumptions shall not apply. The judgment of the regional court shall be appealable before the district court, and the appeal shall not suspend the enforcement. The judgment of the district court shall be final and shall not be appealable at the cassation instance. The decision for the termination of the placement of a person under full guardianship in a social service for residential care shall be enforced in an administrative procedure.

The extension of the time limit for placement in a social service for residential care and for the transfer into another social service for residential care of a person under full guardianship shall be effected following the placement procedure by the regional court. The time limit for the placement of a person under full guardianship in a social service for residential care may be extended if the provision of support for the person in a home environment is not possible.

Conclusions:

The placement procedure under SSA and PDA is controversial administration of justice – the court conducts the proceedings, and can act *ex officio*, i.e. it can take actions on its own initiative, can seek additional evidence, etc.

The court has a more special function – it does not play the usual role of independent arbitration between the parties to the dispute, it safeguards the lawfulness of the restriction of freedom for persons with disabilities, and performs this role by conducting a fair procedure.

An analysis of the causal relationship: disability – communication – expression of wishes and preferences – should be carried out, and this is of paramount importance to the court, as it needs to get a direct impression of the person's consent to use the service or, respectively, terminate the use of the service.

If the person is unable to unequivocally express their wish through direct communication, the social support provided should help them make not simply a statement but a clearly reasoned one, so that this statement can be interpreted with the other facts in the case and the direct impressions of the court.

Within the interventions proposed, those making the proposal should submit convincing reasons to justify that these are the most appropriate and efficient ones for the person concerned (this will provide the court with relevant information in relation to its opinion on proportionality and necessity). This requires, as a minimum necessity, examining the person's functional abilities, the existing circumstances of communication and relationships and the missing ones.



The supporting person should simultaneously:

- Have a proven trusted relationship with the person (it has to be mutual, durable, without any history of manipulation, abuse and violence). When examining the existence of a trusted relationship, the court can either use an expert opinion by a psychologist or request once again an assessment regarding the existence of a trusted relationship from the social service. Furthermore, it is recommended that oral and written evidence tools be used to establish and prove the existence of this relationship, which will ensure avoiding a conflict of interest and abuse.



- Be able to understand the communication, and interpret in a reasonable and logical manner the person's will and preferences, and use this interpretation in specific decision-making situations. If the court does not feel confident in terms of assessing this circumstance, the assessment could once again be assisted by a social service provider, the issue being included in a potential assessment under the above point. An impartial specialist with experience in working with the relevant target group can assess whether the potential supporting person adequately understands the person's will and, respectively, communicates and interprets it in accordance with the person's preferences.

- Be committed to the person's well-being, be able to interpret their will and preferences, and provide them with support in making the decision based on this interpretation.

CHAPTER TWO



COMMUNICATION

The analysis in this part starts with four axioms. These are not just statements but a deep conviction and belief that the big step towards the change in the attitude towards people with intellectual disabilities should be taken by all of us.

Any individual, irrespective of whether he/she a disability and how serious it is, has wishes, preferences and will;

The wishes, preferences and will should always be respected, regardless of any issues with communication;

Any individual, irrespective of whether he/she a disability and how serious it is, is capable of building a trusted relationship with another individual;

Any individual, irrespective of whether he/she a disability and how serious it is, at some point in time needs support for making decisions, and receives it from the people whom he/she trusts.

Any reader holding this handbook in their hands has to agree with the four axioms before reading further.

Theoretical considerations for communication

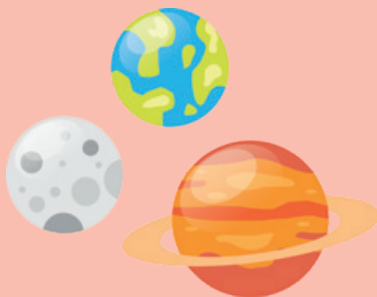
Interaction and communication

There is a huge variety of definitions of the concept "communication". All of them convey a broader or narrower meaning. The term "communication" is of Latin origin: the noun "communicatio" means "sharing, notifying", "dividing", "transmitting". Frequent synonyms are the concepts "interaction" and "communication".

Interaction can describe any process in which the action of a participant affects the action of another participant. These participants are not necessarily people or even animation. One could describe the interaction between chemicals (although this usually results in a chemical reaction) or the interaction between the sun and the planets.



EFFERVESCENT TABLET



PLANETS

Communication is a specific form of interaction which includes exchange of information. We do not need human actors. Two computer programs communicate when they send information to each other.

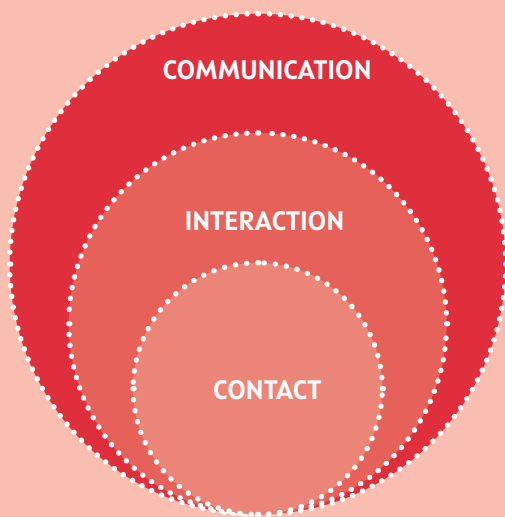


Fig. 2. Communication, interaction, contact – specific connection

The connecting factor for both forms of information exchange (contact and communication) is the interaction, but the contact is a lower level of interaction, while for the communication we have an expectation for the exchange of ideas. Communication among people is the superior form established for the exchange of information. It takes place through all the senses, but mostly through human language and speech. Language and speech are a very important criterion in terms of how we introduce ourselves to the world and to the others, and often determine our quality of life – the environment in which we develop, our profession, our relations with people, etc. Language and speech are always two-sided: one side relates to our ability to understand the message we have received, and the other one to our ability to respond to the message received, express ourselves, show that information has reached us. Probably, the variety in these processes of understanding and expression is as large as the number of people on the earth.

Intellectual development disorders



**INTELLECTUAL
FUNCTIONING**



**PEOPLE WITH POTENTIAL
INTELLECTUAL DISORDERS**

In 2009 World Health Organization (WHO) set up a working group which was tasked with the classification of intellectual retardation. The working group reported the revision of ICD-10 intellectual and behavioral disorders in the 11th Revision (ICD-11) to the WHO International Advisory Group. It should be noted that this working group was the first international and multidisciplinary expert group set up by the international organization which addressed this issue in the last 40 years.

The debate on whether intellectual disability (ID) should be conceptualized as a health condition or a disability intensified after the completion of the revision of the International Classification of Diseases (ICD) of the World Health Organization.

It was proposed that the concept Mental Retardation (MR) from ICD-10 (at present Bulgaria is using ICD-10, and looks forward to ICD-11) be replaced with the concept Intellectual Developmental Disorders (IDD) in ICD-11. These disorders are defined as *“a group of etiologically diverse conditions originating during the developmental period characterized by significantly below average cognitive functioning, related to limitations in learning, adaptive behavior, and skills”*.

It is recommended that Intellectual Developmental Disorders (IDD) be included in the category of neurodevelopmental disorders and the current classifier of severity (mild, moderate, severe, profound) continue to be used. The term "Intellectual Developmental Disorders" (IDD) proposed by the WHO expert group was approved and included in brackets in DSM - 5 ID (IDD), with a focus on the conceptualization of IID as a brain-based health condition, and not as a disability. The new diagnosis criteria of IDD should be based on a developmental approach. The underlying elements of the IDD definition are not only the impairments in the degree and level of cognitive development such as knowledge, reasoning and symbolic representation, but also the functioning related to them. These limitations in the functioning relate to difficulties in learning, adaptation, and acquiring and using language.

Intellectual Developmental Disorders (IDD) is a life-long condition. It is examined in all phases and at all stages. A development approach taking into account the complex causal factors that are known to affect the acquisition of cognitive abilities and adaptive behavior is required in order to understand IDD and ensure appropriate interventions and long-term care which will help the individual attain their development potential (Hodapp and Burak, 2006).

The Diagnostic and Statistical Manual of Mental Disorders – DSM-5 defines intellectual disabilities as neurodevelopmental ones which have an onset in childhood and are characterized by disorders in the intellectual functioning, as well as difficulties in the conceptual, social and practical areas of life. There are three DSM-5 diagnostic criteria for intellectual disabilities:

- 1.** Deficits in intellectual functioning – "reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and experiential learning" - confirmed by a clinical assessment and individualized standard testing of IQ ([APA, 2013, p. 33](#));
- 2.** Deficits in adaptive functioning, which makes it very difficult to observe the standards for development and social culture, for an individual's independence and ability to meet their own social responsibility;
- 3.** The onset of these deficits is in childhood.

DSM-5 definition of intellectual disabilities provides more comprehensive information about the individual compared to the 4th edition, DSM-IV. DSM-IV definition includes impairments of the general intellectual abilities which affect the individual's functioning in conceptual, social and everyday areas. DSM-5 has abandoned IQ-specific results as a diagnosis criterion, although it has kept the general functioning concept at two or three standard deviations below the general population. DSM-5 has a stronger emphasis on adaptive functioning and the usual life skills. Unlike DSM-IV which envisages disorders in two or more areas of skills, DSM-5 criteria indicate disorders in one or more super-dominated areas of skills (for instance, conceptual, social, practical) (Papazoglou et al., 2014).

The terms "mild", "moderate", "severe", and "profound" are used to describe the severity of the condition. This approach is useful when the aspects of the mild to moderate degree differ from the severe to profound one. DSM-5 has maintained this grouping with a stronger focus on everyday life skills than on the specific IQ scope.

Mild to moderate form of intellectual disorder

Most people with intellectual disorders are classified as having a mild form. Persons with a mild form are slower in all areas of conceptual development and social and everyday life skills. They are able to acquire practical life skills, which allows them to function in ordinary life with minimum support. Persons with a moderate form are able to take care of themselves, travel to familiar places within their community, and learn basic skills related to safety and health. Persons with a mild form of intellectual disorder are able to talk and perform a variety of activities (arranging stands, cleaning, working in a kitchen, etc.). Their difficulties pertain to limitations in terms of their adaptability to new situations, and they need to be accompanied to new places and in new situations, need support in making fast decisions. These individuals do have a good understanding of the context in many situations in the language spoken by the others (except for rather abstract topics and situations). They could perform very well in carrying out an activity for which they have mastered all the steps.

Severe form of intellectual disorder

This form is manifested through bigger delays in development, and the persons often have the ability to understand speech, but have more limited expressive skills (Sattler, 2002). While they can learn to perform ordinary everyday procedures and ensure basic care for themselves, they need stronger support in their everyday life. As these people find it more difficult to express their thoughts, hence using augmentative and alternative support is very important. They also have the ability to carry out very simple repetitive activities. This group work worldwide in social enterprises for people with disabilities in a protected working environment, while the above group can work with support (in some cases without support) in a real working environment.

Profound form of intellectual disorder

cannot live independently, and need ongoing care and help to perform regular daily activities. They have a very limited ability to communicate, and often motor limitations, too. People with a mild to moderate form are less likely to have related medical conditions than the ones with a severe or profound form. This group are faced with serious communication limitations. Some of them have learnt onomatopoeia or words which they use in a specific context in order to communicate something. Others do so by means of their behavior. Whatever the case, however, we can understand them after we get to know the function of the behavior or gesture through which they communicate.

The International Classification of Diseases (ICD) is the diagnosis tool used in Bulgaria. Here is some data from ICD:

While “intellectual disorder” has broadly replaced the concept “*mental retardation*”, the debate on whether it is to be regarded as a health condition or a disability intensified with the revision of the WHO International Classification of Diseases (ICD-WHO). The working group proposed that mental retardation be replaced with *intellectual developmental disorders* defined as a “group of conditions characterized by significantly below average cognitive functioning, related to limitations in learning, adaptive behavior, and skills”. In accordance with their viewpoint on persons with disabilities, the American Association on Intellectual and Developmental Disabilities (AAIDD) developed an exhaustive definition, classification, and a support system. According to AAIDD intellectual developmental disorder is a disability characterized by “significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills”. This disability originates before the age of 18. This is an obvious impairment of basic cognitive functions needed to develop knowledge, reasoning and symbolic representation at the level expected by adult peers, the cultural and community environment. Nevertheless, there are a large variety of models of cognitive disabilities for specific conditions.

By and large, people with intellectual developmental disorders have difficulties with understanding verbal communication, the perception of reasoning, their work memory, and the speed of processing. In addition, these people could have related difficulties in various areas of acquiring knowledge, including academic and practical knowledge. They usually have difficulties with their adaptive behavior, and often find it challenging to manage their behavior, emotions and interpersonal relations, and to maintain their motivation in the learning process.

The two instruments for disease diagnosis (ICD and DSM) offer a similar definition of the concept “Intellectual Developmental Disorder”. The disorder is present in the various levels of intellectual development, and each of them sets limits in the development of all areas of human functioning in medical terms. The limits of functioning in each area of life can, by and large, be attained to a greater or smaller extent. Communication abilities are one of these areas.

The issue regarding cognitive capacity and whether a person with intellectual disability has reached its limits is being constantly raised and discussed. This capacity concerns both a person’s ability to live autonomously and independently in safety and their participation in the community and in communication. We assert that the intellectual capacity is not relevant, and the person develops with the support of social interventions and measures. For persons with impaired vision, the white cane and the Braille alphabet are the way to independent movement and communication; for persons with motor disabilities – the wheelchair or the crutch, sign language systems for persons with impaired hearing, etc.

People with intellectual disabilities also use various means to communicate and acquire knowledge and understanding about life: a network of supporting persons; a trusted person; communication through augmentative and alternative communication systems.

Myths and facts about people with intellectual disabilities

Myth №1: All people with intellectual disabilities are the same

Fact №1: People with intellectual disabilities function and develop differently. They all have different interests and preferences. In a popular video, more than ten people with Down Syndrome talk about how they like to spend their time. One feels good in company, another with his beloved, a third one in front of the TV. One likes spaghetti, another chocolate, a third one - fruit.

Myth №2: Their behavior is childish

Fact №2: People with intellectual disabilities understand when someone violates their rights, they can ask questions about their lives as adults: "Why am I different?", "What is my diagnosis?", "Can I have children?"

Myth №3: This is a disease

Fact №3: Intellectual development disorders are not a disease. Many of the people with intellectual disabilities are physically healthy and strong, and even when they work, they maintain a good attendance at their workplace.

Myth №4: They can't make decisions

Fact №4: They can decide if and how to vote, with whom to live, where to live and what to spend their money on.

Myth №5: They can't work

Fact №5: People with intellectual disabilities are working in various fields of work as waiters, cooks, office administrators, cashiers. They also take various working positions in the civil sector, in production and supply, and many others. Many of them can boast with many years of experience - over 20 years.

Myth N°6: Intellectual disabilities are an inherited problem

Fact N°6: Intellectual disabilities are only sometimes inherited. It is most often caused by external influences, some of which can be prevented.

Myth N°7: Intellectual disabilities are contagious

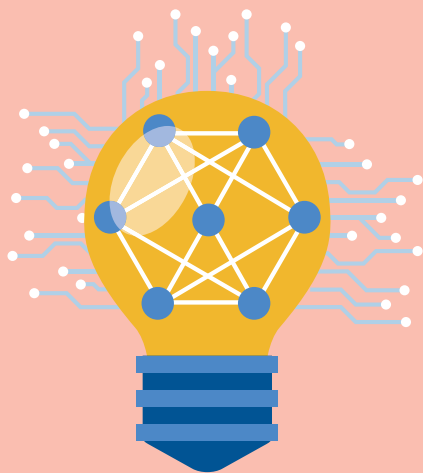
Fact N°7 This is completely untrue, as intellectual disabilities do not spread through any kind of contact.

Myth N°8: Adults with intellectual development disorders can pose a sexual danger to others because they have poor sexual control

Fact N°8: Adults with intellectual disabilities tend to be sexually abused.

Myth N°9: Bad deeds (karma from a previous life of parents) can cause intellectual difficulties

Fact N°9: This is completely untrue. Beliefs like these only add to the already increased burden on parents. Intellectual disabilities are a medical condition and parents and careers need community support. People with intellectual disabilities perform very well with sufficient support and encouragement from family and community.



Communication

This part focuses on the specifics of communication of people with intellectual disabilities and/or other groups of people with developmental disorders whose symptoms of lack or very difficult use of language and speech hamper the possibility for them to be understood in the relevant context and by persons, other than the ones closest to them, as well as for their will and wishes to be understood and respected by the court - people with different and varied difficulties such as genetic syndromes. The group of people with communication difficulties affecting comprehension and expression is large and diverse. It includes people with autism spectrum disorders, people with language and speech disorders and intellectual development disorders, people who have experienced trauma, various mental conditions, or people living in institutions, and the range of their language and speech development can vary widely.

Within the framework of social interventions, the following formula can be applied with respect to persons with similar communication difficulties as a starting point for ensuring efficient communication:

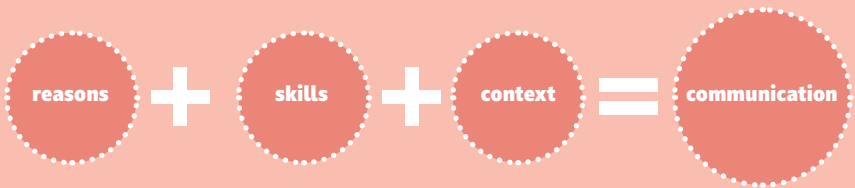


Fig.3. Efficient communication formula

This is a universal formula for each of us. It contains the necessary "components" in order for communication to be efficient. The absence of any of these components makes the process difficult, reduces its efficiency and quality and/or makes it impossible.

Each of these components contains generally accepted (standard) elements. When communicating, we do not think about them all the time, but we are aware of and react to any disruptions in communication.

Reasons

It is generally accepted that, firstly, we have a collocutor, secondly, we wish to share thoughts and feelings or an interesting fact, thirdly, we seek information, express a need for something or seek help, etc. This is how communication emerges:

Castaway finds himself on a lonely island. Is the ball with the painted human face he talks to enough to say that he is communicating effectively?

The reasons are the provocateurs in communication. These are the occasions needed to start/initiate/address a signal or message to the other person. The reasons for initiating communication are tens and hundreds: share a feeling, learn something new, show that we are interested in someone, express the need for food or fun, seek attention, etc. They are connected and directed to something or someone.

The main functions of communication pertain above all to the reason or the intention due to which we communicate, and can include:

- **Request** – the possibility to request something allows the individual to express their wish for an object, help, rest, etc. One can use an image – a photograph/pictogram – when asking for something.

- **Reject / Protest** – this allows the individual to show that he/she does not want a certain object. For instance, one can push away an undesired object.

- **Comment** – this allows the individual to communicate information on a specific topic. An example would be the use of assistive devices for making a statement about what the person likes or does.

- **Greet** – the individual can interact in a social way. For example, saying good-bye at the end of the meeting, the event, the day.

The function of communication for persons placed in institutions tends to be more limited, mostly communicating wishes and needs through requests and protests, and not communicating with the aim of social interaction, which includes greetings and comments.

The communication skills of a person participating in a specific situation (a court hearing) are assessed by means of an Evaluation Protocol. A person's ability to use their way of communication in a functional way is assessed with the aim to determine if he/she is an efficient communicator and what his/her individual abilities and skills are.

Skills

We start developing them right after our birth; they are hierarchically built and deeply linked to the reasons we have for communication, and the context (the environment, the people surrounding us, etc.). These are our skills – mimics, facial expression, gestures, behavior, speech, writing a speech, etc. Skills are related to the way in which the message is communicated. Others are simultaneity, shared attention, time, and interest in communication. It often happens that the process is not that efficient with people with intellectual developmental disorders who have not developed communication skills understandable to the others (words, mimics, behavior, etc.). The issue is finding ways to think beyond the existing limitation, to identify what is missing in the components (reasons, skills, and context) in order to ensure conditions for supporting the persons's abilities. The truth is that we are not aware of what abilities a person receiving permanent support can develop.

Skills also have standards, and the participants in communication have expectations in terms of them. For example, communication requires that we use words, keep eye contact with our collocutor, share a common space during the meeting, etc.

When do we notice that our collocutor communicates in a different way? When we notice that the skills he/she uses to communicate are different: he/she does not use words to produce speech, loses his/her distance, bumps into an object in order to say that he/she has a headache, etc.



Faya was placed in a specialized institution in early childhood, at the age of approx. 3-4. She communicates in a specific manner. She has not developed her speech well enough for her age, but she can utter specific vocalizations which communicate some meaning, and probably her relatives/friends can understand them and respond to them. A couple of days and weeks after her accommodation, the child started communicating with her caretakers by vocalizing, "calling them", directing her eyes at them. The institutional care model was unable to respond to this call for communication by the child the way this happens in a family environment. The child lost interest in doing it. Several months later, Faya stopped making any sounds, closed herself in her own thoughts and world, and thus the others were no longer the source of knowledge and the gate for her development.

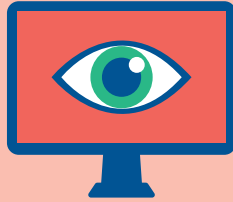
An extract from a French documentary about the changes occurring in a child's personality as a result of institutionalization

Context

It relates to the practice of communication, the environment in which we have the necessary conditions to develop a certain communication topic. It is about communicating in a real practical environment. Whatever we are told about or however we imagine how you choose and order your meals, and pay the bill in a restaurant, we cannot make sure that we have developed our communication on this topic unless we go to a restaurant, order from the menu, unless we have real contact with waiters/shop assistants and pay our bills, etc.

All these “components” are interrelated, and efficiency in communication is contingent on their existence, and how they are supported in respect of the person with intellectual disability. In case we take one single component out of the formula, we can in no way achieve the expected result -however, our experience shows that even if we keep them all, it is essential that we “secure” them for this group of people on an ongoing basis, that we assist them with initiating communication, with developing their skills and ability to communicate in various situations.





Augmentative and alternative communication

People with impaired intellectual functioning can be supported at the same time to develop their communication skills, and to express themselves and be understood (to communicate by means of the skills they currently have).

The support for people with impaired intellectual functioning in court hearings is about identifying, in particular, the ways in which they communicate and how they use their ways of communication in order to be heard. This support is about the use of the so-called alternative (substitute) and/or augmentative (complementary) communication which involves visual tools for facilitating and supplementing communication.

Visual tools can be used to facilitate the dialogue with people who have difficulties communicating. These tools are adaptive, portable and can be used in numerous and various situations.

Visual communication tools can be instrumental in ensuring structure and routine, encouraging independence, building confidence, improving understanding, avoiding dissatisfaction and anxiety, and providing the possibility to communicate with the others. They can contribute to making communication physical and visible, instead of being inconsistent, which could be the case when words are uttered.

Visual tools facilitating communication:

- tactile symbols / benchmarks, for example: food packaging, labels;
- photographs;
- short video clips;
- miniatures of real objects;
- color pictures;
- drawings;
- symbols;
- written words.

The tools can be real objects, printed images or can be shown on the screen of a laptop, smartphone or PC.

Augmentative and alternative communication (AAC) is an area of clinical practice which is in line with the needs of individuals with considerable and complex communication disorders – impairments in producing and/or understanding speech, including oral and written forms of communication. Augmentative and alternative communication is an assistive tool which facilitates acquiring linguistic competence and using the language.

The beginning of the use of AAC is described by Zangari, Lloyd, & Vicker according to whom the AAC evidence-based practices whose purpose is maintaining the communication of persons with acquired disorders developed substantially in the 50's (Mirenda, 2017). It is **augmentative** because it provides additional information about the situation, and alternative – it uses all perceptions, with the aim to facilitate the understanding and conveying of a specific message, specific information.

AAC consists of all available options to ensure a conscious and targeted feedback from the person with impaired intellectual functioning which can be used in hearings as an assistive augmentative and alternative tool

whereby the person can express themselves, can be understood by the others: gestures, photos, painted images, stylized pictures – pictograms, including picture communication boards, linear drawings, speech-generating devices, material objects, manual signs, and fingerspelling in order to help the individual express their thoughts, wishes and needs, and ideas. We all use this type of communication in our everyday life – an example of AAC are all boards in public spaces indicating exit, WC, lift.

The definition of *Communication*, as approved and laid down in CRPD, is based on the same understanding. Communications includes any languages, visual presentation of a text, the Braille alphabet, tactile communication, enlarged fonts, accessible multimedia, as well as any forms of written, audio, simplified language, announcer speech, augmentative and alternative means, devices and forms of communication, including accessible ICTs.

The use of the means of augmentative and alternative communication meets the criteria of universal design and reasonable accommodation for the benefit of people with intellectual development disorders or communication difficulties worldwide. This is a quick, easy and accessible way to catch up with others and a prerequisite for full communication on important topics.

AAC is an area of clinical practice and education whose purpose is compensating temporarily or permanently losses in receptive and expressive communication (ASHA, 2002). AAC is the *umbrella* term which encompasses all ways of communication used to augment or replace the speech of those who have difficulties understanding or expressing themselves via oral speech. AAC is a multi-modal system for facilitating interaction which uses the verbal, non-verbal and visual aspect of communication to support understanding and expression. There are several efficient ways to use AAC. These are the natural ways of communicate which consist of non-verbal forms – guiding, gestures, mimics, body language, and facial expression.

Other AAC forms are based on the use of real objects, photos, drawings or stylized symbols – pictograms. There are visual symbol systems requiring the use of a device, a book or a table (Bedwani at all, 2015). Such communication systems are PECS, MAKATON which are used worldwide – they are universal and do not depend on the specific language. The differences relate to some symbols or pictograms that are relevant to the specific language – for instance, the word “banitza” or “lyutenitza” are examples for the Bulgarian language. Therefore, AAC comprises all kinds of communication which are used cumulatively or as a substitute for speech with the aim to improve the communication of an individual.

This Handbook will use AAC with a view to proposing that an Interpreter’s Dictionary be used as a tool in the SDM Interpreter’s work in order to improve communication in court hearings. The purpose of the Dictionary is developing and supporting an individual’s existing communication skills in the context of a court hearing. The chapter about the Interpreter as a professional offers a theoretical description of the *Interpreter’s Dictionary*, while the Annexes (Annex 1) cover the practical aspects.



INTERPRETER’S DICTIONARY PERSON SUPPORTING COMMUNICATION

Specialized literature describes various levels of communication abilities, the criterion being the individual’s communication skills.

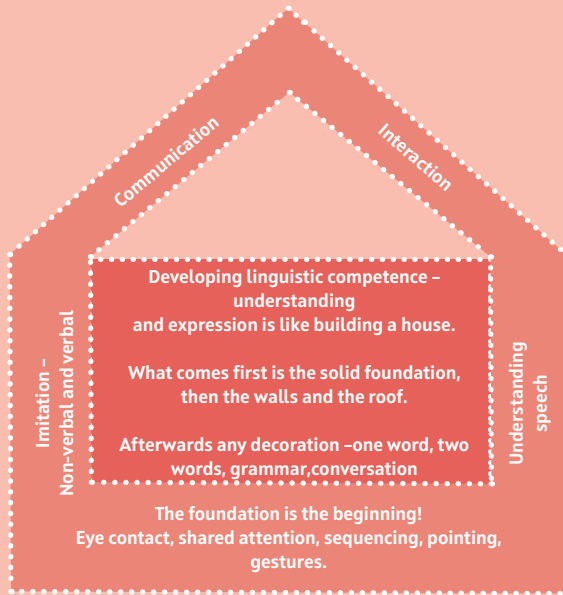


Fig. 4. Hierarchy of linguistic skills 1

Fig. 4 shows an example of a hierarchy of communication skills.

For us, practitioners, this house enables us, for example, to locate the position of a person with intellectual difficulties in terms of communication (what their skills to communicate are). Different criteria are used (age, living environment and context, conditions, social relationships, support, etc.).

The lowest level of communication abilities is often referred to in specialized literature as **basic, pre-symbol-based or emerging** (in terms of understanding and expression), and the **highest level as speech**. In the figure above, this is the foundation of the house – eye contact, shared attention, etc. There are, no doubt, other terms used with the same meaning.

When communication abilities are at this level, communicating with the individual is a real challenge; however, communication does exist. The person can signal and/or initiate communication through their behavior in a non-traditional, unspecific manner.

Communication levels can also be presented via scales – see Fig.5.

Another way to present the communication skills of people with intellectual disabilities is by means of a pyramid structure. This structure consists of three broad categories: **pre-symbol-based (the lowest level), symbol-based, and verbal (the highest level)**. By focusing on symbol-based and verbal communication, the reader can conclude that symbol-based language, whether its expression is speech or symbols, is at the basis of a clinical meeting. However, there are meaningful and therapeutic encounters in the transmission of affect and affective resonance of basic signals from the clinician to the patient. Some would argue that most of what is happening in the human context is non-verbal and non-symbolic.

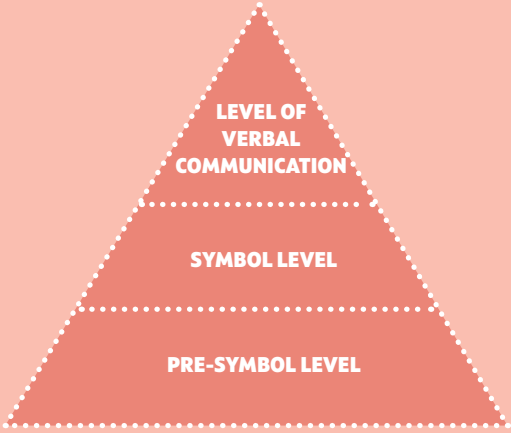


Fig. 5. Hierarchy of linguistic skills 2

Communicating with persons with the lowest level of communication skills is a challenge. Persons who can use only symbol-based communication (they are classified in medical terms as persons with very severe or profound intellectual disabilities on the foundation of the house in Fig. 4) will not be able to understand or use symbol-based forms of communication such as speech, photos or signs. This means that these persons understand and express themselves through objects, actions and a familiar context. For example, such a person will know that it is time for a meal when he/she sees a group of people heading for a certain room in the building. We have come across a large number of persons at this communication level in specialized institutions.

Such a group of people will mostly rely on the people in their surrounding environment in order to foresee their needs and interpret their vocalizations, facial expressions and body language (Coupe O’Kane, 1998).

Another similar classification (Fig. 6) offers a hierarchy of skills in four categories: **basic, non-verbal, verbal, and alternative.**

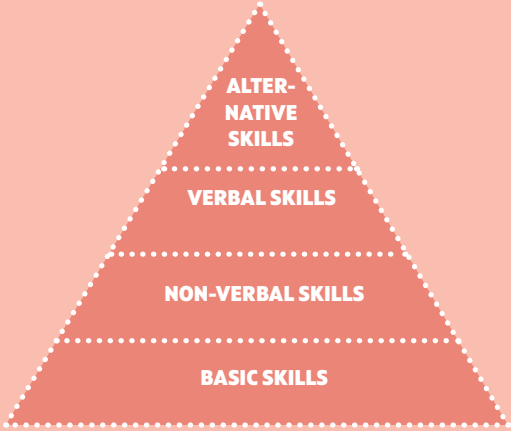


Fig. 6 Hierarchy of linguistic skills 3

This pyramid offers a better distribution of skills. Basic communication skills are the ones to appear first - they are acquired and developed right after the baby was born – facial expression, eye contact. They are a necessary prerequisite to initiate interaction and the first manifestations of interaction.

Non-verbal skills are the ones used before speech emerges, but they facilitate understanding. They are instrumental for communicative expression through behavior, body language, chewing, facial expression. Talking over the telephone is not the preferred option for evolving communication; they are instrumental for an expeditious transmission of a message, for instance.

Verbal communication skills often need clarification, even in the interaction between persons without intellectual disabilities. It is accepted, however, that concepts stand for precise objects, features, actions, etc. in

any language (including sign language). Alternative communication skills, however, are any type of communication using all available opportunities for ensuring a conscious and targeted feedback from an individual with an intellectual deficit. There are tens of examples for alternative communication: expression via a speech book which contains a picture vocabulary of the concepts the person needs at the particular point in time; a map with letters; cards with gestures, and many others.

It often happens that persons placed in a specialized institution (Homes for people with intellectual disabilities) have not developed their communication skills in these two forms. The reasons are institutionalization and the lack of social services for developing skills. The non-verbal forms used by many of them to communicate may be incomprehensible to the parties involved in judicial proceedings.

All classifications and degrees determining communication offer relevant information to professionals. Any person with an intellectual disability can be positioned in these classifications in accordance with the level he/she has. This step could determine the person's future development, namely with limited opportunities or serve as the gate to development or success. Our position is that the medical model imposes limitations on people, and often they are not just restrictions on paper but become real social ones. When we think through the prism of social interventions, we could contribute to the widespread viewpoint that persons with an intellectual development disorder, if supported in an individual and specific way, will be able to step over the established medical limitations.



INTELLECTUAL DEVELOPMENT



INSTITUTION



INSTITUTION FOR ADULTS

Let us imagine some individuals outside the community (placed in a specialized institution). These are social services where a large number of people with intellectual disabilities are placed. The facilities and the infrastructure are obsolete – they lack modern equipment, private space, coziness. The institution does not have adequate medical and social services. The location is remote, and the inmates live in a limited social environment. Almost all of them are under guardianship. They are usually at the basic level (the lowest level) of communication development – in most cases, these are people who are non-verbal, have not acquired repetitive gestures that they can address to the others to communicate in a specific situation. Most of them do not initiate communication, as they often do not have a reason to do so due to the prolonged social isolation in which they have lived. There are others who communicate via basic means – a look, a touch, mimics, a smile, etc. They often do not have persons who are close and relevant to them, and the information gathered about them is limited and imprecise.

Which cases do we define as “challenging” or “the most serious” ones in terms of the practice of the judicial proceedings in relation to placement under the provisions from Section 3 of Chapter 6 SSA:

- persons with a basic communication development;
- predominantly placed in a specialized institution, and have a heavily institutionalized profile;
- living in social isolation;
- often do not have people who are close and relevant to them; the information that can be gathered about them is limited and imprecise;
- do not have a vision for their life – absence of person-centered planning;

- the institutional model limits or deprives people of opportunities to make choices and decisions.
- the specialized institution does not ensure a vision for an individual's life, a plan and opportunities for the individual to make choices and decisions.

Similar to the child's story in the documentary above, the institutional machine has modified the formula for efficient communication (see Fig. 7) for hundreds of others.

Our experience has identified the following issues regarding persons with the most severe forms of difficulties in communication:

- Is there any communication with these persons?
- Do they have anything to communicate to us?
- Can they address a message?

When speaking about persons with severe communication difficulties, we have very often been confronted with the following perception: "they don't have anything to tell us", "they don't communicate", "they don't have any communication skills", and "they are unable to develop such skills". This perception has a very strong relevance when it concerns adults, and not children. This is what the formula looks like:

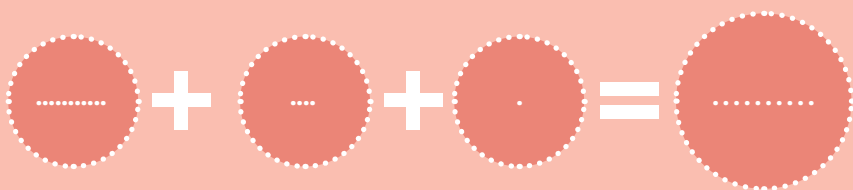


Fig.7. Modification of the efficient communication formula

To sum up, we would point out that as far as people with severe and profound intellectual development disorders are concerned, the formula seems unclear and unstable. The efficiency of communication is questioned. In more specific terms, the reason for this relates to the expectations regarding communication "happening" as a two-way process whereby various messages are sent and received. The communication process occurs when a person has reasons to communicate with another person in a specific context by using the means available.

The components of the formula contain some important conditions, and people with intellectual development disorders cannot meet these conditions, as they: often do not have a reason to communicate outside the limits of their basic needs; they have given up communication, as no one has listened to them and has understood them for a long time; they cannot find their way around in the context; the means they have are insufficient and remain incomprehensible; they need specific support for developing their communication skills, etc.

We have often encountered the view according to which a person, by way of principle, cannot communicate their basic everyday needs and wishes. The components are either missing or are unclear. The assumption that any individual communicates and sometimes has a style of expression that is unique and difficult to identify. This prompts the specific way of communication.

The next reference is another perspective in our practice with the communication capacity of people with intellectual disabilities. It is about their life in the community. A small part of these persons are accommodated in family-type residential care in the vicinity of cities and towns, with access to all social services and specialized health care. Another large part live with their families or if not – they keep in touch with the family. They build friendships, make choices, learn things from the positive and negative experience of communicating with people.

A comparison is more than necessary, as community-based social interventions and support are not focused that much on where a person ranks in classifications and degrees of intellectual and/or communicative development, but rather on how the person will develop in all areas of their life.

Pipilota is a girl. She has been diagnosed with Down Syndrome and Deep Mental Retardation. She has lived all her life in a specialized institution. She is currently living in the family-type residential service where she has been accommodated during the process of deinstitutionalization in Bulgaria. The girl was crawling low down to the floor "like a spider". She was not communicating with anybody and was afraid of most people. She had aggressive behavior and eating problems. It was impossible for anyone to touch her. A few years after she was placed in the residential social service, she is moving on her own, standing upright. She has very good control over her diet and taste preferences. Pipilota developed close relationships with the people who take care of her, and a specific trusting relationship that has allowed her to put aside many of her fears by allowing someone to do her hair, to choose her accessories. She travels accompanied to the Day Care Center, where she expects to see a boy she likes. She has already gone shopping, visited the sea ...

Communicating the will and wishes

Communicating rights



COMMUNICATION



DECISION-MAKING

Making choices as to how you will spend your money, where and with whom you will live, whom you marry ... These are issues that are taken for granted by many people. In reality, these choices are part of our human and civil rights. The individuals placed under guardianship are deprived of these rights. The diagnosis “Intellectual developments disorders”, and peculiarities in the intellectual development, difficulties in terms of communicating with and understanding people with intellectual disabilities are a prerequisite for restrictions and deprivation of rights.



Fig. 8. From the National Joint Committee for the Communicative Needs of Persons with Severe Disabilities (1992). Guidelines for meeting the communication needs of persons with severe disabilities. Asha, 34 (Suppl. 7), 2-3, adapted by K.AL.

All persons, regardless of the extent or severity of their disabilities, have a basic right to affect, through communication, the conditions of their own existence. Beyond this general right, a number of specific communication rights should be ensured in all daily interactions and interventions involving persons who have severe disabilities. These rights are summarized in

a Communication Bill of Rights developed by National Joint Committee for the Communicative Needs of Persons with Severe Disabilities in 1992.

These basic communication rights are as follows:

- The right to request desired objects, actions, events, and persons, and to express personal preferences, or feelings.
- The right to be offered choices and alternatives.
- The right to reject or refuse undesired objects, events, or actions, including the right to decline or reject all proffered choices.
- The right to request, and be given, attention from and interaction with another person.
- The right to request feedback or information about state, an object, a person, or an event of interest.
- The right to active treatment and intervention efforts to enable people with severe disabilities to communicate messages in whatever modes and as effectively and efficiently as their specific abilities will allow.
- The right to have communication acts acknowledged and responded to, even when the intent of these acts cannot be fulfilled by the responder.
- The right to have access at all times to any needed augmentative and alternative communication devices and other assistive devices, and to have those devices in good working order.
- The right to environmental contexts, interactions, and opportunities that expect and encourage persons with disabilities to participate as full communication partners with other people, including peers.
- The right to be informed about the people, things, and events in one's immediate environment.
- The right to be communicated with in a manner that recognizes and acknowledges the inherent dignity of the person being addressed, including the right to be part of communication exchanges about individuals that are conducted in his or her presence.
- The right to be communicated with in ways that are meaningful, understandable, and culturally and linguistically appropriate.

From the National Joint Committee for the Communicative Needs of Persons with Severe Disabilities (1992). Guidelines for meeting the communication needs of persons with severe disabilities. Asha, 34 (Suppl. 7), 2-3, adapted by K.A.L.



Support in decision-making

Any individual, irrespective of their functioning, receives support from other individuals in their life. Speaking of the environment in which we live, there is a variety of groups of people whom we rank hierarchically against our personal social experience. Some of them stand close to us, others even closer. Some of them provide us with support on financial matters, others on health issues, and yet others are our “buddy” when we live through separation or fall in love. This dynamic network of people has its natural presence throughout our life. In spite of the turnover – people coming and going, there is a permanent nucleus to whom we can refer as persons supporting us.

Support in decision-making is informal help which people use all the time in their life – for instance, discussing a variety of issues with friends and acquaintances. Support can be also provided in the form of social intervention in the community. For example, Sweden has the institution of the “personal ombudsman”. Support in decision-making could also be offered by peer support groups of persons who have been faced a specific challenge. This is a social intervention that helps you deal with a specific situation because you can’t find your way around or are in a difficult situation.

A variety of social interventions are used in practice (*we made an introduction into them* in the Chapter "The LAW setting the frame"), and these are support measures:

1) **Peer groups**

Peer groups consist only of persons who have a specific (identical) issue in small or larger groups in which they share their experience, success stories, and challenges. Group members are supported with information, advice and encouragement.

2) **Counselling**

Professionals from various areas (lawyers, psychologists, speech therapists, finance experts, etc.) who provide counselling on specific matters. It is important that these professionals be trained in SDM and working with the relevant group of people.

3) **Social service**

In some of the cases the person needs specific social support in order to be able to restore some of their skills, to improve their functioning and communication.

4) **Mentor**

This is a professional (a social worker, speech therapist, psychologist, special/social pedagogue, educator, teacher) with specific training whose task is supporting the person in gathering the necessary information, understanding it, assessing the consequences, and making decisions.

5) **Anti-crisis plan**

One may have serious concerns about having, at a certain point in their life, an idea about life and the consequences from their actions which differ from what matters most, namely their wishes and preferences. Under such circumstances, a good option is the Anti-Crisis Plan (preliminary declarations/powers of attorney). The Anti-Crisis Plan is drawn up by the person themselves with the support of a trained professional (facilitator). The plan

is a tool whereby the person concerned expresses their will, voluntarily renounces their autonomy by empowering persons chosen by them – trusted persons.

Supported Decision-Making



**I MAKE A DECISION
ABOUT MY JOB**



**I MAKE A DECISION
ABOUT SOMETHING**

Communication via the process of supported decision-making – SDM ¹ (which is different from support for decision-making) may be the only option for people with intellectual development disorders to communicate their rights, choices and decisions. This can take place through a whole network, a part of it or just one trusted person.

¹ "Persons with Disabilities Act" – Supported decision-making is a combination of social interventions that aim to provide support to make decisions which have legal consequences and lead to concrete results for the individual with disabilities.

"Natural Persons and Support Measures Act" – Supported decision-making is a support measure in which the court-approved supporter, under conditions of trusted relationship, assists the supported person to express his/her wishes and preferences in making decisions for specific legal actions.

The Bulgarian model of SDM is based, first and foremost, on trusted relationships (Fig. 9).

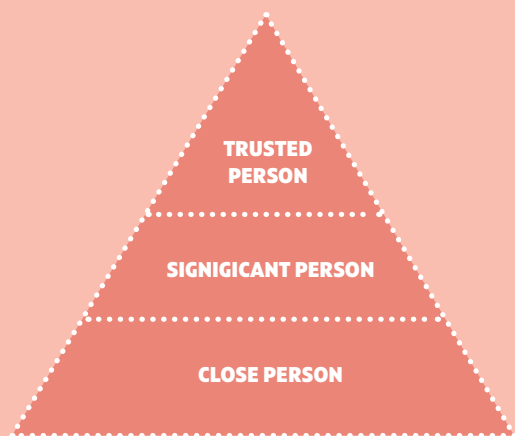


Fig. 9 Trusted relationships

6) SDP through supporting networks

Supported decision-making through supporting networks is, in essence, a process in which supporting networks assist adults with intellectual, psychological or cognitive difficulties in planning their future life in the community and in making decisions about their private life, health, and finances/property. The supported person himself/herself chooses the people who will help him/her by including family members, friends, and advocates whom he/she trusts in his/her network.

To sum up the above, people with intellectual developments disorders need support to make decisions and exercise their rights:

1. This may be due to the fact that they have their unique communication style, and this style is not familiar and comprehensible to those who do not know the person;

2. The need for support is also identified due to the difficulties some people have understanding and analyzing the information relevant to making a decision;

3. Such persons can make the decision with the support of another person whom they trust.

SDM is an instrument which allows people with intellectual developments disorders to improve the quality of their life, weakens stigmatizing attitudes, and makes access to justice effective.

In 2018 the Bulgarian court – a small group of judges – recognized the need to appoint an **SDM Interpreter** whose task will be to help a group of people with intellectual developments disorders communicate their consent/lack of consent regarding the place to live (a specialized institution – a Home for Elderly People with Intellectual Disabilities).

The legal framework uses the concept “Interpreter” with the meaning of a natural person who uses their expertise to help the investigator, prosecutor, judge and the parties to the proceedings understand what a mute or deaf accused person or witness wants to say, and convey the meaning of the questions asked to such a person.



INTERPRETER



SDM INTERPRETER



COMMUNICATION

The SDM Interpreter is a professional with special knowledge who acts as a mediator in the court in relation to understanding the consent/ disagreement to be expressed by the person in responding to the questions asked by the court; the SDM expert is defined as an Interpreter – the term currently used in the Civil Code of Procedure. This type of Interpreter differs from the expert doing sign translation. He/She has specific knowledge and experience with understanding the ways in which people with intellectual developments disorders think and communicate, and applies specific tools and methodology.

The following groups of persons are most often identified as persons in need of an Interpreter by the court:

- persons with a diagnosis related to an intellectual disorder (in some cases, the persons have co-morbidity – epilepsy, cerebro-cranial traumas, etc.);
- all persons under guardianship;
- persons with limited communicative abilities (non-verbal or verbal; the court does not understand them, however).

According to our professional perception the group of persons that can use an Interpreter for communicating their rights is broader:

- all people with intellectual developments disorders in specialized institutions or in the community;
- all people with intellectual developments disorders who need support for their communication in other judicial proceedings in relation to other matters – financial decisions, violence, etc.;
- persons with other type of communicative disorders – autism without intellectual disabilities, expressive speech disorders.

Tools based on which the Interpreter develops their expertise

The first tool developed for the Interpreter has been named "Communication Evaluation Protocol", and the second auxiliary tool - "Interpreter's Dictionary".

The two tools serve as a basis for developing the SDM Interpreter's expertise, and provide assistance/support to all parties involved in judicial proceedings with the aim to improve communication:

Communication Evaluation Protocol (in short, the "Protocol")

is an auxiliary tool that is part of the Interpreter's expertise, which aims to provide the court with information on the specifics of communication for a person with intellectual disabilities to express his/her will. The Protocol was developed in connection with the need for:

- following a procedure and complying with certain conditions for the development of a special expertise by an Interpreter, which is based on a Communication Evaluation Protocol;

- developing specific guidelines for harmonization of the processes for the examination of consent and expression of will in the court for people with intellectual development disorders, as at this stage they are significantly different.

Objectives in developing an universal and individual protocol:

- 1.** To ascertain what are the means and opportunities of man to communicate at this point in his development in order to express his will;
- 2.** To contain objective and impartial information;
- 3.** To contain scientifically substantiated information.



Universal protocol - contains general data about the profile and communication skills of the person, collected from interviews and observation. It is a common framework, the basis for developing an individual protocol.

Individual protocol - provides specific information about the person, the means by which he/she communicates in relation to questions and topics, the situations in which he/she communicates these issues, the relationship with the people supporting him/her and any other important information. If, for example, the information gathered in the general protocol proves that the person communicates in a non-verbal way, the specific protocol provides information on the type of non-verbal communication (facial expressions, gestures, writing, etc.) in relation to the question or topic. The individual protocol is developed on the basis of the observation of the expert Interpreter, his/her specific knowledge and verification of the information collected from the general protocol. In order to prepare a motivated conclusion, an analysis is made between the general and the individual protocol.

Interpreter's Dictionary (see CHAPTER THREE for details)

is a tool that meets the current need of the situation - communication during a lawsuit. The Interpreter's Dictionary is based on the principles of augmentative and alternative communication (AAC) to support the communication in a court hearing situation. Through AAC the communication process is supported by photos, pictures, drawings, written text and real objects in the context of the situation and all non-verbal forms of communication such as gestures, facial expressions, body posture for more detailed and concrete understanding and expression on set topics.

Chapter Three focuses with details on the profile, the overall methodology and the toolkit of the Interpreter (**see CHAPTER THREE for details**). Allowing the role of the Interpreter in judicial proceedings has a number of positive effects:

- 1.** Develop a new understanding in terms of the communication of people with intellectual development disorders;
- 2.** Prove the thesis according to which if a person with a disability does not have their life ensured in the community, most of their rights are limited, and the person is not just excluded but restricted in such a way that he/she is unable to benefit from and exercise their rights;
- 3.** Develop the understanding of the need for special social intervention in providing support for decision-making;
- 4.** Recognize this special expertise – the SDM Interpreter.

Types of support from the SDM Interpreter

How the Interpreter assists with communicating rights?

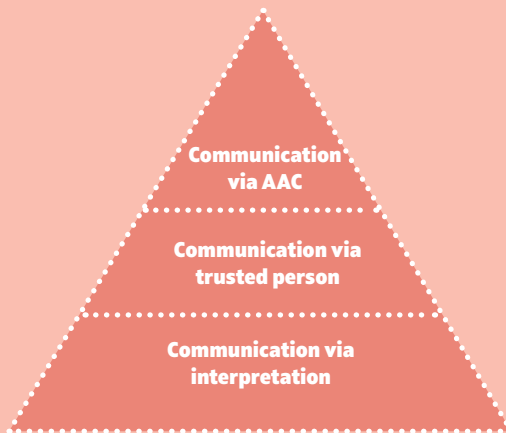


Fig. 10 Communication with the assistance of an SDM Interpreter

The Interpreter accompanies the person with intellectual development disorders and other communication disorders (supports them) in the process of communicating their wishes in accordance with their abili-

ties. In practice, the Interpreter provides assistance in the process of understanding the information, evaluating it, and sharing the decision. Our practical experience (Fig. 10) has shown that the Interpreter can be efficient in facilitating the communication of persons with various degrees of intellectual development disorders. People with intellectual development disorders who have a higher level of speech and language competence express their will via AAC. The higher the degree of speech and language impairment, the lower the communication level of the pyramid, i.e. the Interpreter needs to ensure trusted persons who are best able to understand the relevant individual; if such persons cannot be ensured, interpretation can be applied.

Supporting communication via AAC



I UNDERSTAND



I EXPRESS MYSELF

The person communicates directly and independently through Augmentative and Alternative Communication by making choices, clearly manifests their will by means of an individualized way of understanding, expression, participation in the communication process. The messages between the person with ID and the court **are transmitted through a variety of means and techniques for creating alternative ways** to ensure a two-way process.

The SDM Interpreter examines, evaluates and supports the individual's skills, first and foremost, in their regular everyday environment, and facilitates their hearing before the court in accordance with their communication abilities in the best possible and supportive manner for the individual.

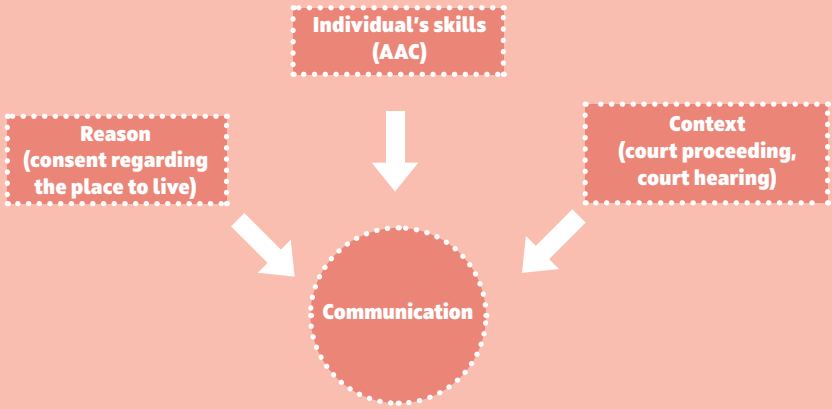


Fig. 11 Equation for efficient communication with the Interpreter's support

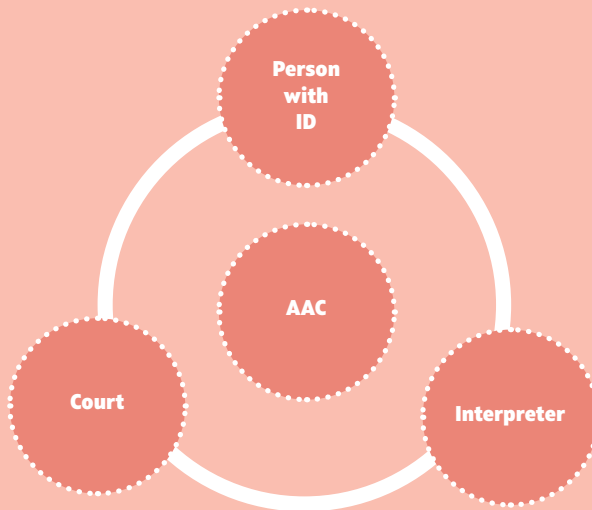


Fig. 12 Communication of a person (via AAC) in a court hearing of people with intellectual development disorders within a judicial procedure

Supporting communication via trusted person

The judge asks a question: "Do you want to stay in (name of the institution)?" – Makedonsky answers: "No."

He does so by means of a head and hand gesture of negation.

The judge asks the next question, a direct one: "Could he live on his own?"

The Interpreter interprets the judge's question by means of several probing questions:

"Can you take care of yourself?", "Can you do your shopping... cook your meals...?", etc.

The hearing is supported via projective techniques and questions with the aim to understand if the person can cope on his own. In the course of the hearing, the judge adapts his way of speaking to the person's ability to understand.

In response to the questions asked, Makedonsky gives short answers: "No". When a more complicated answer is needed, he has difficulties. What follows is the stage of clarifying the choice options that Makedonsky has. The Interpreter uses projective techniques and drawings to depict the three options to the person – living with his guardian; living in an institution; and living out in the street. The Interpreter crosses out the option with the guardian, and, in practice, hides it. The person understands this limitation right away, and focuses on the other two options. He decides that he is unable to take care of himself, hence makes the difficult choice of staying at a place which is not to his liking, as he has no other alternative at this stage.

Hearing in a blue room

TRUSTED PERSON

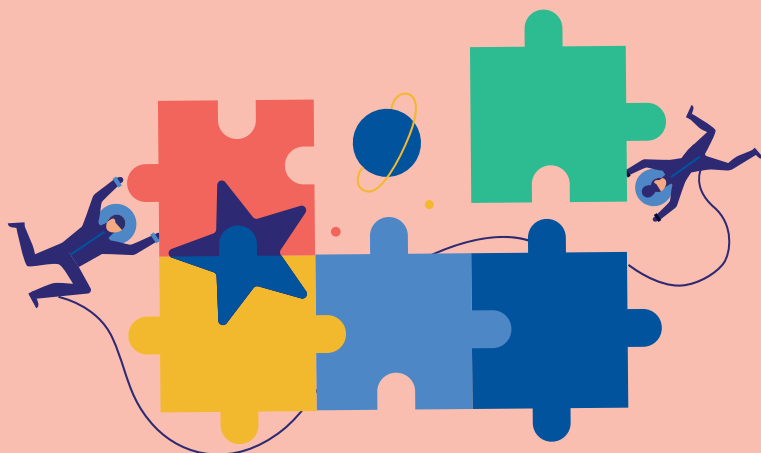
The individual communicates through a trusted person who 'translates' the message. The Interpreter may verify the translation. The forms of verification depend on the area of activity. The process is conducted in conformity with legal rules and procedures. The Interpreter is certified (in terms of special training and knowledge) and acts as an independent figure; the verification he/she carries out includes any activities (written and oral expert opinions, recommendations, certificates, evidence) that will certify the veracity of the outcomes from the tasks assigned. **This type of hearing a person with intellectual development disorders is based on the SDM trusted relationships.** A 'trusted person' is a term that we have to clarify according to how we understand it. We want to highlight the concepts "close person", "significant person", "trusted person" so that they can be clearly and understandably used in their specific context further in the handbook.

We use the term 'translation of the message', as when the 'Communication Evaluation Protocol' has been drawn up, the Interpreter cannot propose that the communication support be through AAC.

For the following reasons:

- **At the current point of their communication competence, the person's abilities to communicate are at a level related to pre-symbol understanding;**
- **The person needs to be trained to use AAC in order to use it for communication.**

When AAC cannot be used, the Interpreter will seek another resource. In this case, SDM can be serve to introduce a support measure whereby the supporting person (a person from the supporting network) approved (by the court), under the conditions of a trusted relationship, assists the supported person (a person with communication disorders) with expressing their wishes and preferences when making a decision in relation to specific legal matters.



The trusted relationship is at the basis of the way in which we all function. When an individual with an intellectual development disorder has a narrower or broader social environment and various circles of people, there must be a way for us to find at least one person whom we can identify as a trusted person.

The Interpreter can identify the trusted person. In methodological terms, this identification is done in a number of ways – most often by gathering information from interviews held with various circles of people; studying the person's personal story (people in their past); and by using a special toolkit for studying and describing the person's behavior, their reactions (answers) in a specific context and/or in the presence of a hypothetical trusted person:

- *Where the person lives;*
- *What is their circle of people;*
- *What is (was) the hierarchy of their relationships with each person from that circle;*
- *Who is interested in the person and how, what are their actions in this respect.*

The communication of the person with intellectual disabilities with the hypothetical trusted person – the history of their communication, current communication, reactions, behavior in different contexts (in the person's presence, before that, when he/she is told the person is coming, when the latter leaves, etc.), etc.

At the beginning of the hearing, the man is sitting on his mother's lap. The hearing begins and the judge asks questions about his life. He asks the man: „Do you want to live here?“. The man moves around in the same spot, snaps his fingers and makes sounds and does not show much skill. He starts doing something else. He gets up and goes to the judge and the secretary. The Interpreter warns - this is a greeting with a touch and that this is a big step forward, because until 2-3 years ago he did not recognize that someone was entering the room. Shortly afterwards, the man began to gnaw on a toy module, which is probably a sign of tension after 40 minutes of standing in the hall. The judge is still not convinced what is the man`s wish regarding the place to live.

The Interpreter reacts and says that by biting the toy module, the man is calming down. After a while he stops, gets up and stands behind the social worker for a few seconds, then behind the director for a few more.

The judge asks: "His mother is here, too?!". In practice, the man shows security and connection with these people (the social worker and the director). The man gets up, goes to the refrigerator, takes milk, drinks from it and puts it away; he takes out cookies, gives them to the social worker to open them, eats some and puts them away. He shows what he has learned and that he feels at home, as well as how he communicates with other social service users. In the preliminary statement, the Interpreter noted that he had visited the service on a day when the man returned from his home to the resident service where he lives - he had been smiling while he ran to the sheltered housing. The judge stopped the hearing and said that he "felt the whole situation". Man`s consent was taken on the basis that he showed that he likes the place.

Hearing of a 38-year-old man with intellectual disabilities

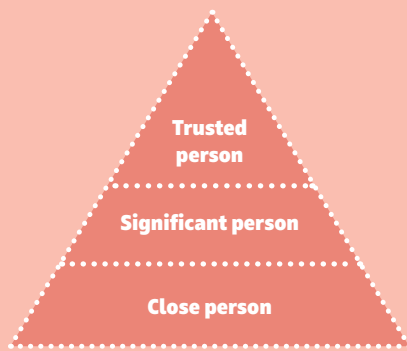


Fig. 13. A trusted Person

A close person is the one whom the person with intellectual development disorder recognizes as such, and vice versa. The criteria for observing and assessing this two-way recognition and closeness can be: body language, gestures of a smile and excitement, history of relations, common topics and event, and many others.

A significant person is the one who is ready to act in the person's interest – shows interest in the person and their life; declares readiness for support in the future; the two of them have close relations and one of them maintains these relations; they are responsive to each other (or only the significant one).

The trusted person acts – in addition to being a close and significant person, the trusted one acts in the individual's interest in the long term; provides continuous support through actions improving the individual's well-being; initiates actions to either protect the individual's human rights or prevent fraud/abuse against them.

Prerequisites for trusted relationships:

- awareness of the relationship and its long-lasting nature;
- the trusted person is able to communicate the individual's will by conveying as precisely as possible the essence of this will, and the individual's real wishes and preferences;
- the trusted person is able to act in the interest of the supported person while taking into account their personal wishes and preferences;
- there are no relations of unlawful influence, violence, abuse or manipulation of the supported person by the supporting one in a trusted relationship.

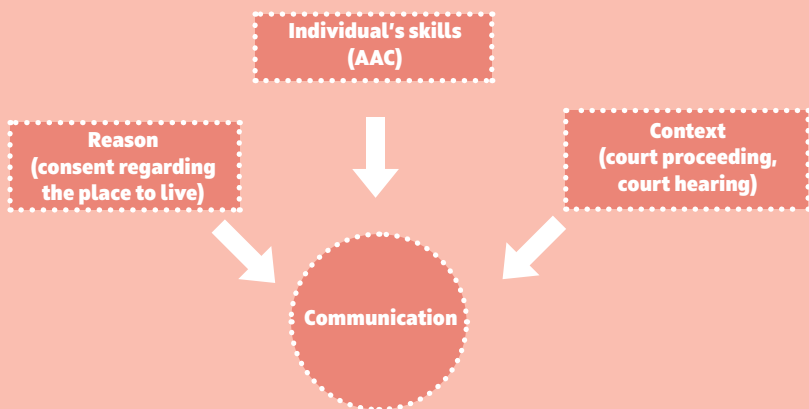


Fig.14. Communication via a trusted person

The strong positive effect of judicial procedures, in which the communication via trusted person was recognized as reliable and was validated, allowed that SDM be acknowledged as having the effect of a judicial decision (a precedent). This experience predetermined the outset of changing attitudes, namely that the source of the limitation is not the disability itself, but the challenges in communication and the absence of an adapted environment.

*Support for communication via **interpretation of the best will:***

Interpretation of the best will is applied in the absence of close and significant persons whom the individual identifies as such, and in the absence of people who know the individual and their means of communication. Prior to an assumption for this measure, a communication evaluation protocol is drawn up – skills and context, close and significant persons; communication behavior, and responses to the environment and in a specific context.

There is still no working definition of this type of interpretation. The interpretation of the best will and wishes of people with intellectual development disorders is a process whereby explanation and/or clarification is provided for what the person says/the will the person expresses.



Two possible assumptions are considered:

The first assumption - is about identifying people who will interpret together the person's best will. These can be, if necessary, officially appointed professionals (treating physician, social workers, occupational therapist, human rights organization, placement authority, organization working with people with ID). Interpretation can be applied if the following cumulative conditions are met:

- a) the officially appointed persons are specially designated, with a specific task and role in terms of implementing the person's rights and interests;
- b) the court raises a common issue for all of them;
- c) following a discussion, all the persons appointed agree on a common position and proposal to the court regarding the interpretation of the person's best will and wishes. This relates to the possibility for them to express their view and impression as to where the person wishes to live (in our practice it is the place to live, and other matters).

Under this assumption, all the officially appointed persons get together to make a specific decision, work in a team using the expert opinion and experience of each professional. They all enjoy equal rights in terms of expressing an opinion, making proposals, and they have to be unanimous in the decision taken.

In practice, this concept was proposed in regard to several individuals in judicial proceedings; however, it has not yet been accepted as possible. While it looks like substitution of the person's will – similar to what happens with a person under guardianship, the group of officially appointed persons ensures better safeguards for interpretation to take place.

The second assumption - makes a turnaround back to the pyramid of trusted relations. As it has been established, however, that such a person cannot be identified by the individual concerned at the specific point in time, the latter could simply name a close or a significant person, and this will be an indication of authorization for decisions to be taken on the individual's behalf. The questions arising are: how does the individual understand this authorization, and how will the court be assured of it.

This concept upholds our overall view that it is always possible to identify a person who knows the individual well enough. This concept takes us back to the individual who has difficulties communicating, but has close and significant persons who can interpret their best will and wishes.

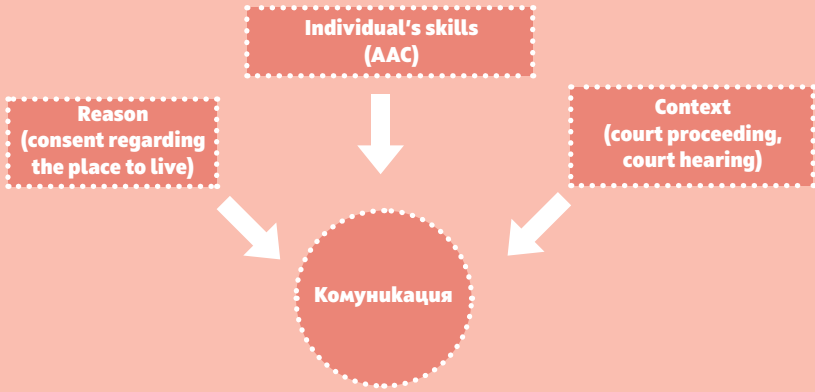


Fig. 15. Communication via interpretation

CHAPTER THREE



THE INTERPRETER AS A PROFESSIONAL

The Interpreter is a professional with special knowledge who acts as a mediator helping the court understand the consent expressed by the person in relation to the questions asked by the court.

The SDM expert can be defined as an Interpreter – the term used in the now effective Civil Code of Procedure. This type of Interpreter differs from the expert who performs sign translation. He/She has specific knowledge and experience with understanding the way people with intellectual development disorders think and communicate, which is based on the Communication Protocol which he draws up.

The experience of the Interpreter provided us with the great opportunity to pioneer the change in the attitudes towards people with intellectual disabilities, and we set the following goals:

Specific:

1. Draw up a communication evaluation protocol (general and specific);

2. Verify the communication evaluation protocol drawn up by another person – for instance, a professional working in a social service, another expert.

Objectives of verification:

- Check the content and the validity of the information in the protocol drawn up by another person based on the special knowledge acquired;
- Establish a wish or preferences expressed by the individual concerned;
- Document the process against standards, in a reasoned manner, and based on scientific arguments;
- Ensure sufficient time for the verification of the protocol.

Additional goals related to the change in attitudes:

- 1.** The individual is at the center of the process in SDM, as it is in the judicial procedure;
- 2.** Main approach: humane attitude, humane process – the individual as a subject, not as an object!;
- 3.** Safeguard respect for the individual – their abilities and rights, regardless of their capacity;
- 4.** Improve the individual's life and daily routine – in the short- and long-term. In case someone, when visiting the service/the institution witnesses an offence – an inmate being beaten or otherwise abused – the incident should immediately be reported;
- 5.** Establish a rapport between the judge and the individual – in judicial proceedings this rapport is about getting to know each other, presenting “two worlds” which know little, next to nothing, of each other, and are divided by the gap of attitudes and prejudices accumulated over time. The communication between the judge and the individual becomes possible, a less scary, and even pleasant encounter;
- 6.** Achieve changes in the attitudes of all the parties involved, all the participants in the process.





What does interpretation mean?

Interpretation consists in **communicating the content** of what the individual wants to say. The Interpreter finds the content of the information in the **means of communication** used by the individual, irrespective of their degree and level of expression.

It is generally accepted that any individual can express themselves in their specific way which can be understood against various criteria as repetitiveness of the means of expression used in respect of the people they target, repetitiveness in different or identical situations, etc.

Tasks assigned to the Interpreter by the court:

- Is the individual able to communicate;
- How does the individual communicate, and how will the court understand this communication;
- How will the individual be informed in a way he/she understands about the alternatives available in terms of the place to live – what will the person expresses.

Profile of the Interpreter

Statements based on experience:

- Education and experience are a factor for the special knowledge and competences - professionals in the area of the humanities: psychologists, speech therapy, pedagogy, special pedagogy - can draft a communication evaluation protocol, and verify it in their capacity of experts designated by the court - Interpreters;

- It is important that the Interpreter has, in addition, practical skills for analytical research and observation;

- Given the small number of professionals with specific knowledge who are familiar with SDM, a pool of experts with such expertise needs to be developed; the interpreter should be included in the category of expert witnesses - in practical terms, this would ensure a higher level of objectiveness, and a broader scope for the measures and decision proposed;

- The need for ongoing discussions on the topics and arising issues, and the need to study the actions taken and the change achieved.

Specifically concerning the Interpreter:

1. A professional/An expert with special knowledge in examining and evaluating specific communication abilities in relation to specific tasks assigned by the court;

2. Experience in communicating with people with intellectual development disorders;

3. Draws up a communication evaluation protocol; or

4. Verifies a communication evaluation protocol drawn up by another expert;

5. The existence of a trusted relationship with the individual with regard to whom the protocol is drawn up or verified is not necessary, as the interpreter is a professional whose task is about observing and verifying a certain process;

6. SDM expert for people with ID (applies in practice support measures as social interventions).

Communication Evaluation Protocol

Purpose of the tool and types of protocols

- A tool for efficient support in judicial procedures concerning persons with communication disorders of a different type;
- Identifies the specifics of communication;
- Allows or facilitates the communication of people with ID in judicial proceedings;
- Drafted on an individual basis.



What is the Communication Evaluation Protocol?

The Protocol is a tool for studying the communication development which is drafted in the form of a single document. The content of the document consists of two parts: a universal protocol and an individual protocol for the person concerned (see Fig. 16).

The expert opinion drafted by the Interpreter is based on the Communication Evaluation Protocol, and, respectively, on his/her specific knowledge and experience.

The universal protocol can also be called general, as it contains general data about the person's profile and communication abilities gathered in interviews. It serves as a framework, a basis for developing the individual protocol.

The individual protocol contains specific information about the person concerned, the means used thereby to communicate on the issues and topics raised, the situations in which the person communicates on them, the relationship with the supporting persons, and any other relevant information. If, for example, the information gathered in the general protocol shows that the individual has non-verbal communication, the specific protocol informs about the type of non-verbal communication (mimics, gestures, written form, etc.) in relation to the issue or topic raised (for example, how the individual gives their consent regarding the place to live). The individual protocol is drafted on the basis of the observation carried out by the expert-Interpreter, their specific knowledge and the verification of the information gathered in the general protocol. The reasoned conclusion is drafted on the basis on the universal protocol and the specific one.

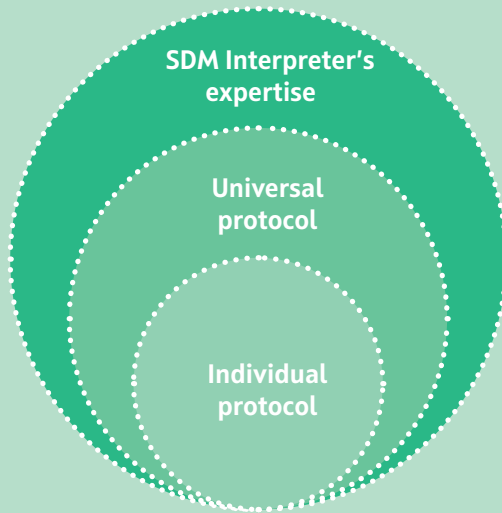


Fig.16. Communication Evaluation Protocol

Purpose and use of the Communication Evaluation Protocol

Who can draw up the protocol?

The experts (interpreters) may have various professional backgrounds (language therapists, psychologists, social workers, and special pedagogues), but they all should:

- have specialized skills to conduct an evaluation of the communication of people with intellectual disabilities;

- be neutral, independent employees of the court appointed by virtue of the law (similar to translators), even though their role is much broader;

- swear an oath and bear criminal liability; however, they submit an expert opinion, and do not testify.

When the individual has a combination of disorders, the interaction of experts from various groups may be needed (for example, an expert with experience in working with people with ID, and an audiological and speech rehabilitator).

When is a communication needed?

1) For what persons:

- Persons with a broad spectrum of intellectual development disorders;
- Persons with autism;
- Persons with acquired communication disorders;
- Dementia.

2) Potential indications identified:

- It is not possible for the persons to express their will without support due to obvious communication difficulties;

- The person's interaction with the court is difficult, as the person is unable to independently give comprehensible answers to the questions asked by the court;

- The court finds it difficult to receive from the person comprehensible answers to the questions asked due to the person's specific way of expression;

- The person gives unclear or unspecific answers;

- It takes the person a lot of time to react, he/she hesitates;

- The person does not seem to understand much from what concerns them or what is being said.

Drafting a Protocol – essential requirements

Drafting a Protocol – essential requirements

Requirements for drafting the Protocol:

- Appoint an Interpreter as soon as possible;
- Sufficient time (specific for each individual);
- Access to the information the Interpreter needs.

Requirements for the Protocol:

- Contain only the necessary information;
- Observe the principles of neutrality and impartiality;
- Be based on scientific arguments;

- Have a clear conclusion regarding the functionality of the individual's communication, i.e. how the individual will express their will using the communication means available, and will be understood by the court;
- List special measures and recommendations in support of the individual in the judicial proceedings (in relation to the language or the arrangements to be put in place for the hearing).

What support can the Interpreter provide via the Communication Evaluation Protocol?

1) Assessment of the level of the person's communication development (Universal protocol) as of the time of drawing up the Protocol and the conditions (the criteria determining this level);

2) Assessment of the specifics in the person's communication and their functional communication abilities with a view to identifying communication means to support the person in the judicial proceedings (individual protocol):

- The reasons why the person communicates - they either exist or don't;
- The specific means whereby the person communicates - verbal, non-verbal, basic (alternative communication system, written language, words, gestures, mimics, behavior, etc.);
- The arrangements put in place or the absence of such arrangements for the person to communicate.

3) Assessment of the person's interaction with the environment in terms of communication or how the environment influences or creates possibilities for the person to communicate and make choices.

- Communication with close, significant, trusted persons;
- Communication with familiar and less familiar persons;
- Communication with officially appointed persons;
- Possibilities for making choices.

4) Conclusion regarding the specifics in the person's communication development and an assumption regarding a hearing measure;

5) Assistance with the communication throughout the judicial proceedings, recommendations to be made in the Protocol on:

- The time and the venue of the hearing;
- The frequency of the hearings and their duration;
- The need for preparation, breaks for the person;
- Help with the communication (supporting the language/understanding) – specific and individual incentives for each person: photos of places and people, words, gestures, pictures, symbols, etc.;

- Other visual means such as, for example, signs for "Yes/No/I don't know";

- Permission for close, significant or trusted persons to attend and assist with the communication;

- Re-word questions when they are asked in a complicated or inappropriate way;

- Other individual means of support, specific and identified in the course of drafting the Protocol.

6) An assumption regarding the person's hearing by means of one of the three recommended measures:

1. Direct communication – independently, with alternative support from the Interpreter:

- Under this measure the person can be heard independently or with alternative support from the Interpreter. In both cases, after a Communication Evaluation Protocol has been drafted. The alternative support from an Interpreter is minimum support for the person's language and speech in order for him/her to express his/her will and to be understood by the court;

- The minimum support consists of all alternative means (including specific ones for the person identified on the basis of communication evaluation).

2. Conveying the individual's will through a close person; however, if the Interpreter does not identify such persons, measure №3 is proposed):

- Identify close, significant and/or trusted persons who know the person best and can convey their will;
- Draw up a Communication Evaluation Protocol;
- Verify the information from close and significant persons.

3. Interpretation of the best will - identification of persons who will act together in interpreting the individual's best will - officially ap-

pointed persons (the first assumption) or we revert to identifying a significant person:

- Absence of a trusted person;
- Draw up a Communication Evaluation Protocol;
- Examine and evaluate the behavior and the person's interaction with the environment where he/she lives - the possibilities created or the lack thereof for communication development; the person's communication behavior and responses to the environment, the person's choice in terms of the possibilities offered by the environment.

In the most serious cases, when, after making considerable efforts, the expert opinion has found that it is practically impossible to identify the individual's will and preferences, the concept "the best interpretation of the will and preferences" will replace the concept "the person's best interest". This means that the will and preferences of the specific individual will be interpreted in the context of their story, the will expressed in the past, behavior, usual practice, gestures, existing non-verbal communication. The aim is providing support for decision-making in view not of the best interest - as it is understood by third parties, but of reaching a decision which will reflect as much as possible the information and the knowledge about the wishes of the specific individual.



INTERPRETER'S DICTIONARY

Purpose of creating the tool

The text to follow describes the objectives of the "Interpreter's Dictionary", and how its use could facilitate your communication as a participant in a court hearing, and improve the communication of all the participants in terms of sending and receiving specific messages and questions.

The Interpreter's Dictionary is a tool which applies the principles of Augmentative and Alternative Communication (AAC). It complements the communication on topics directly related to the choice of decision on the place of residence and accompanying and specific aspects of the court case. The Interpreter's Dictionary includes a number of pictograms, as alternative of words, organized by topics and in terms, with the aim to improve communication in the context of a court hearing between all communicators: a person with difficulty communicating, an Interpreter, judges, lawyers and everyone else - from the preparatory phases and meetings to the hearing itself before the court.

The use of the Dictionary is not obligatory in every case from beginning to end, but it can be useful in any difficult communicative situation.

The purpose of developing the tool:

- In case you need a different, alternative way of communication. The Dictionary aims to supplement the communication with information to make the message clearer;
- When the person is unable to speak but is willing to express himself/herself;
- When the person's speech is not understood by the others or speaking might be more challenging than the other ways of communicating – the dictionary may help;
- Improve the individual's communication in terms of identifying wishes and needs, prioritizing them and analyzing alternative ways for meeting these needs by making specific decisions.

The Interpreter's Dictionary is a tool meeting the current need of the situation – communication in the course of judicial proceedings. The Dictionary is based on the principles of AAC for facilitating communication in the context of a court hearing. AAC ensures support for the communication process by means of photos, drawings, written text, real objects, and objects in the context of the situation, and any non-verbal forms of communication via gestures, mimics, body language for a more detailed and specific understanding and expression in relation to the issues raised.

The Interpreter's Dictionary is a tool whose purpose is to assist the communication process in court, and generate and facilitate, in a fast and targeted manner, communication on a specific topic among persons with or without communication difficulties who do not know each other, and facilitate meetings within a limited time frame. The use of the Dictionary can be tailored to the individual communication abilities of each person with a view to ensuring the best possible communication. One of the main objectives is for the Dictionary to assist the court by helping the individual express themselves, and thus assist with the hearing of an individual with difficulties so that the latter can be supported, heard and fully understood.

The Dictionary may:

- Facilitate the process of gathering information and the communication thereof in the court;
- Support and assistance for understanding and expression in the interaction between the individual and the Interpreter during the period prior to the hearing itself, and for achieving efficient communication among the individual, the lawyer and the court.
- Support the communication of person's desires and intentions in order to improve the expression of desires, but also to get better understanding of the proposed choices.

The Dictionary aims not only to facilitate the process of gathering information and assisting the person in the court, but also to support and develop the communication among the individual, the interpreter and the officials before and during the hearing itself. Gathering a substantial amount of important information within strictly fixed meetings is a challenging task when these meetings are held with a person who has difficulties communicating. The Dictionary can be beneficial to the situation at the very first meeting by mediating the communication among strangers by means of AAC which is closest and understandable to persons with communication disorders; it will continue to serve as a tool for the interpreter in gathering information and developing the person's communication profile.

The Dictionary aims to develop and support the functions of a person's existing communication skills in a court hearing.

The term „functional communication“ or what are the main functions of communication refers mainly to the reason or intention for which we communicate and may include the following:

Request - the ability of a person to express a desire for an object, help, rest, etc. The person can use an image - a photo / pictogram to ask for something specific;

Reject / protest - this allows the person to indicate that he/she does not want an object. For example, a person may push away an unwanted object.

Comment – this allows the person to convey information on a topic. An example of this is the use of assistive technologies to make a statement about what he/she likes or does;

Greeting – the person is able to interact in a social way. For example – he/she can say goodbye at the

end of a meeting, an event, a day. The function of communication for people from institutions tends to be more limited, mainly to communicate desires and needs through demands and protests, rather than to communicate for the purpose of social interaction, including greetings and comments.

The communication skills of the person involved in a specific situation (court hearing) are measured using the Evaluation Protocol. A person's ability to use their way of communicating in a functional way is assessed to determine whether they are an effective communicator and what are their individual abilities and skills.

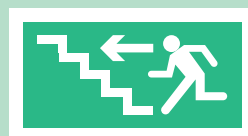
The Interpreter's Dictionary aims to assist with the two communication functions – UNDERSTANDING and EPXRESSION. Firstly, the individual should understand, and then be able to express themselves on a certain matter in the court in a way that reflects their best will

Purpose and use of the Dictionary

Pictograms or picture signs are widely used for the visual representation of information. Pictograms are usually exhibited in public spaces – airports, museums, big retails, international events, seminars, etc. In a nutshell, their wide use is due to the fact that they enable communication among cultures and among generations without the need for a common linguistic system. Words vanish in space, while pictograms remain visible and unambiguous – the meaning does not change depending on the communication situation.

Using the Dictionary is a way to coordinate proposals, make an informed choice, share an opinion, and reach a final decision in a court hearing. The individual has the possibility to apply yet another channel – the visual one – for expressing their will, intentions and wishes, which offers augmentation and alternatives to words. The court and the judge, in their role of a real partner in communication, participant in a specific form of conversation, can benefit from augmentative and alternative communication which facilitates the person's understanding and expression, and thus will use yet another channel, in addition to words, to confirm the person's wishes and will.

EXAMPLE:



EXIT

Rules of use of the Dictionary

The Dictionary includes a number of pictograms grouped by topics that are close man and everyday life. Each symbol corresponds to a word. The words presented consist of verbs and nouns which describe various situations in the fastest, easiest and unambiguous manner. The consecutive presentation of pictograms conforms to the interpretation of ideas and statements in response to the question asked.

The pictograms proposed in this Dictionary are related to communication among individuals in a specific and foreseeable situation. Such pictograms represent the consumer's intention and state, and facilitate communication in the court. Pictograms have the following features:

- Pictograms can be used in a flexible way: for asking a question, helping understand the specific question, but also for assisting with the answer through a visualized choice of one or more options. Example: the question is supported by a pictogram depicting the most important word. The answer is supported by a wider choice of pictograms in order to provoke an oral answer or indicate a choice depending on the skills and condition of the person to whom the particular question is addressed.



HOUSEHOLD

Question:

Where do you live now?



Answer:

Flat with close persons.

Answer:

Home/house.



PARENTS



FLAT



HOUSE



HOME

The pictograms have the following characteristics:

- They encourage communication by making words visible. Research in this field shows that communication via symbols augments verbal expression;
- They are used to improve the understanding of a question, a statement;
- They are used to improve expression - when answering a question or making a statement.

- They are used not only by people with disabilities, but are generally used for a variety of communication styles in various situations and contexts: ranging from daily routine activities to specific, unusual situations such as court hearings;

- The symbols of augmentative and alternative communication can be used separately or can be arranged in communication boards by topics. All the symbols available can be used as printouts or via a device –laptop, tablet, telephone.

The choice of the specific and individualized means of augmentative and alternative communication depends on the degree of cognitive functioning of the individual to be supported, and the Interpreter's skills. The use of AAC in all its forms would be instrumental to all the participants in the communication process in the court in relation to any controversial issue: judge, lawyer, individual, Interpreter. There are a variety of communication programs and applications available in support of people with communication difficulties – MAKATON, PECS, Communicator 5, LetMeTalk, and many others. The systems using pictograms for this purpose are designed on the basis of language systems from the point of view of communication – conveying a meaning. Therefore, they do not reflect the feelings of those involved in communication. Nevertheless, pictograms are, in their essence, of a highly non-verbal nature.

The Dictionary contains pictograms for the purpose of assisting with and/or maintaining non-verbal and/or verbal communication. Pictograms with objects, denoting events, places, people, etc. are used to facilitate the hearing before the court by helping all the partners actively involved – the individual, the lawyer, the judge, the SDM Interpreter. The pictograms can be used, changed and adapted in accordance with the objectives of the specific case and an emerging situation. It is recommended that each pictogram be accompanied by a text in line with the image.

How does the Dictionary operate in practice?



I DON'T UNDERSTAND

I UNDERSTAND

I EXPRESS MYSELF

By creating a SEMANTIC NETWORK for the expected topics, situations, questions, the Dictionary supports the specific communication situation via AAC. Communication has a certain topic which becomes clearer, specific, and targeted.



SEMANTIC NETWORK



I CHOOSE

The Dictionary items can be printed on cards, boards. They fall into a variety of categories: "I and the others", "I accept/refuse", "The Home", "Traveling", "In the Court", "Emotions". The user chooses the appropriate cards for expressing their intention, and denominates, points at, looks at them, puts them in the appropriate order with the help of the Interpreter.

In a nutshell, the Interpreter's Dictionary can serve as a tool to facilitate communication - generating expressions which conform to intentions or situations; expressing opinions; asking a specific question. Other pictograms for words and images related to emerging new situations could be added.

Conclusion

The Interpreter's Dictionary provides examples for using pictograms for communication in the court with the aim to assist persons who have difficulties communicating. It is important for the persons' intentions to be clearly expressed and for the whole communication process to be facilitated with the aim to speed up communication and improve its precision. Developing good communication requires sufficient time in order for both parties involved to understand each other; the use of such a tool would encourage and assist the Interpreter and the court with their activities during the court proceedings, and any additional procedures.

The Interpreter's Dictionary aims to make the necessary and appropriate modification in connection with the court hearing of a person with communication difficulties to be heard in order to ensure that the person with a disability is recognized and exercises all rights on an equal footing with others.

The use of the Dictionary in court proceedings aims to ensure that people with disabilities have access and an equal chance to communicate.

CHAPTER FOUR



ALGORITHM FOR WORKING WITH THE COURT

The SDM Interpreter is a professional who drafts an expert opinion for a court procedure. The main indication of the need for such an expert opinion is the inability of the individual concerned to communicate their rights in the usual way for the court in order for their right to access to justice to be respected, and their will and wishes to be understood. Sofia Regional Court has already had 12 cases applying the special expert opinion of the SDM Interpreter which contains new approaches such as support through augmentative communication means and conveying the will by close/significant persons. These approaches set the beginning for people with intellectual development disorders to be heard in court sessions.

Participants, partners and interaction among them:

- 1.** Individual with an intellectual disability, Interpreter, and judge - the judge allows the lines of communication with the individual;
- 2.** Lawyers of the parties to the proceedings, including the individual with ID and the other party - it should be possible for the relations with them to be well managed;
- 3.** The defense of the individual with an intellectual disability - by way of rule, the defense is designated ex officio by the legal aid;
- 4.** The Social Assistance Agency (SAA) - there is an application requesting the individual's placement in an institution; the Agency supports this request, as they know that the individual has no other place to live; furthermore, they recognize the expert opinion as useful and supporting;
- 5.** Jurists from the Social Assistance Directorate (SAD) - they have one representative, a legal advisor, who, irrespective of what he/she sees and hears and irrespective of the evidence submitted in the case, supports the request for placing the individual in an institution. The caseworker from SAA/SAD does not have any responsibility in terms of the recommendations resulting from the case. It is important for any judgement to require that social workers report on the measures taken based on the recommendations of the expert witnesses;

6. Expert witnesses - psychiatrists (these, however, are prone to discrediting all the other stakeholders, and often stick to their medical diagnosis, which is of no use to the proceedings, and does not offer the necessary answers to the court), psychologists, etc.;

7. Staff, parents of the individual, close relatives, friends, and other persons who are significant to him/her;

8. Guardians / Custodians.

Elements of the Algorithm

The next part presents the steps in the Interpreter's work as a participant in Court proceedings for placement under Section 3 of Chapter 6 SSA, which marked the beginning of the Bulgarian experience.



1. Entry into court proceedings for placement under Section 3 of Chapter 6 SSA;

2. Generating a universal protocol and an individual one for evaluating communication;

3. Submitting the conclusion and hearing the conclusion;

4. Hearing the individual in a court session;

5. Exit from the procedure.

**GOALS AND TASKS
(WHAT DO WE DO)**

The definitions assign the Interpreter's tasks:

- Is the person able to communicate?
- How does the person communicate and how does the court understand this communication?
- The person should be informed – in a way that he/she can understand – about the alternatives he/she has in relation to the place to live: what will the person express.

**METHODS, APPROACHES
(HOW DO WE DO IT)**

A document (a Ruling) is used whereby the Interpreter is appointed. The Interpreter begins working as from the point of issuing the document.



**CHALLENGES, IN PARTICULAR IN
RELATION TO MORE SERIOUS CASES**

- The Interpreter cannot do sign translation, he/she ensures the translation of the content of the communication the person has at the relevant time in the context of the environment and the situation;
- The Interpreter has to prove before the court the difference between a sign translator and a professional who verifies the information gathered about the communication behavior from close and significant persons;
- In challenging cases, the Interpreter tries to find close or significant persons who know the individual best, but in most cases such persons cannot be found.

COMMUNICATION EVALUATION PROTOCOL

DRAWING UP A UNIVERSAL PROTOCOL

Objectives: Ensure that the following elements are present:

1. The individual's profile;
2. Observation;
3. Analysis;
4. Conclusion.

Tasks – evaluating:

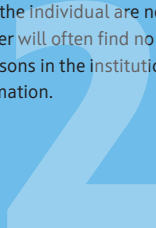
- Specifics in terms of the individual's communication;
- Specifics in terms of the individual's communication with close and significant persons;
- Specifics in terms of how the individual's choice is communicated in the environment;
- How the person expresses consent and refusal.

Gathering information through a variety of channels:

- From documentation;
- From interviews and attaching a questionnaire for interviews, meetings with the individual:
 1. Observing the individual's behavior and the environment in which he/she functions;
 2. Interviews with persons in the individual's environment: caretakers, people supporting him/her, and people in his/her surroundings (this supplements the examination of the environment);
 3. Interview with the individual, and observation of various situations in which he/she reacts with the aim to identifying behavior models (communication level, fulfilling verbal instructions, interpretation of daily gestures).

- The information from these three channels is highly insufficient, unclear, multidirectional, and should always be corroborated;

- It often happens that the persons who are significant for the individual are not the guardians;
- The Interpreter will often find no close and significant persons in the institutions who can give him/her information.



**GOALS AND TASKS
(WHAT DO WE DO)**

COMMUNICATION EVALUATION PROTOCOL

DRAWING UP A UNIVERSAL PROTOCOL

Objectives: Ensure that the following elements are present:

- The individual's profile;
- Observation;
- Analysis;
- Conclusion.

Tasks:

- Is the individual able to give consent; how does he/she give consent regarding the place to live;
- How does the individual communicate consent/refusal regarding the place to live;
- How does the individual communicate consent/refusal in respect of close and significant persons (if any);
- How does the individual make choices in everyday life;
- How does the individual make the choice regarding the place to live;
- Presenting the alternatives in an accessible version;
- What support does the individual need to express their will.

**METHODS, APPROACHES
(HOW DO WE DO IT)**

- Verification of the content of the information gathered on the basis of the Interpreter's observations and evaluation of the individual's behavior and communication (abiding by the scientific reasoning);
- Verification of the observations and building a link between the universal protocol and the individual one reflecting the individual's specifics by applying a standardized questionnaire for evaluating communication.

**CHALLENGES, IN PARTICULAR IN
RELATION TO MORE SERIOUS CASES**

- A major challenge in the analytical part is the evaluation of the communication behavior in the so-called challenging cases;
- What indicators does the Interpreter assess;
- The time available is limited;
- In some cases, assessing specific indicators requires building a rapport with the individual, long training; however, the Interpreter does not have the time for it, and this should be described in the expert opinion;
- Linking the reasons in the justification with existing analytical, psychological, pedagogical theories, which will improve the evidence needed for a reasoned expert opinion.

PRESENTING THE CONCLUSION FROM THE COMMUNICATION PROTOCOL BEFORE THE COURT / EXPERT OPINION <i>(this step is not obligatory)</i> ⁹	PRESENTING THE CONCLUSION IN A COURT HEARING;
<ul style="list-style-type: none"> • The expert opinion has to be assigned an official incoming number; • Prepare the judge for the individual concerned and the meeting with him/her; • Describe the conditions that would ensure a calmer, adapted and sparing (for the individual) process. 	<ul style="list-style-type: none"> • Briefly introduce themselves and fulfil to the tasks assigned; • Respond to the task: Is the individual able to communicate?; • Can the individual be heard?; • Decide on when, where and how the hearing will take place – arrangements.
<p>Expert opinion in writing (not obligatory)</p>	<p>Verbal presentation of the conclusion in a court hearing. Respond to the task:</p> <ul style="list-style-type: none"> • Is the individual able to communicate? - YES • Can the individual be heard? - YES • Will the interpreter mediate in the hearing? - YES
<ul style="list-style-type: none"> • Accessibility • Standardization of the document • Reasoned • Scientific arguments <div style="font-size: 48px; opacity: 0.2; text-align: center; margin-top: 20px;">4</div>	<p>Potential for asking aggressive, incorrect, complicated questions (in particular, by the other parties to the proceedings). What matters most in practice, however, is that the court be provided with crystal clear and understandable answers. Therefore, the Interpreter's behavior is very important. Convince the judge that the hearing of the individual be conducted via one of the measures that we propose, and which we consider efficient.</p> <p>Measures to communicate the consent</p> <p>What can we propose to the court?</p> <ul style="list-style-type: none"> – The principle of sequence of the measures: their order always follows a strict sequencing: 1 – 2 – 3; – The principle of timeliness: it is always highlighted that the measures are relevant to a specific time; – The principle of exhaustiveness of the measures: the order in which they follow has its logic. <ol style="list-style-type: none"> 1. Direct communication – independently, through AAC 2. Conveying the individual's will through a trusted person; if, however, the Interpreter has not identified such a person, he/she proposes measure №3; 3. Interpretation of the best will: officially appointed persons or a significant person.

⁹ Submits it with a copy to the parties so that they can get acquainted with the expert opinion. N.B.: It is advisable that the expert opinion be sent as early as possible before the court hearing (min. 7 days prior to the hearing). A request may be filed for the extension of time limit for submitting the expert opinion before the hearing scheduled – with specific reasons and a request for a new deadline. Then the court will hear the other expert witnesses in the relevant session, and will set a new deadline for the expert opinion. Sending the expert opinion in writing: it will be assigned an incoming number by the record-keeper (it is sent by e-mail to the record-keeper, and he/she assigns the incoming No and attaches it to the case file), and thus the judges will be able to get familiar with it and be prepared. The expert opinion in writing contains an assumption regarding the person, the venue. Close communication with the judge is not always possible; hence this is an important step which will prepare the court for what they will hear and see.

THIS MAY BE THE END OF THE COMMUNICATION PROTOCOL, AND THE INTERPRETER'S WORK WILL CONTINUE WITH THE HEARING OF THE INDIVIDUAL, IF THE JUDGE DEEMS IT NECESSARY

HEARING A PERSON WITH ID	EXIT FROM COURT PROCEEDINGS FOR PLACEMENT UNDER SECTION 3 OF CHAPTER 6 SSA
<p>Arrangements for the hearing:</p> <ul style="list-style-type: none"> • Determining the venue: where; • Determining the time: when; • Choosing a measure for communicating the consent: by the court (see stage 5 – How). 	<p>The Interpreter can present their recommendations in case the judge needs them.</p>
<p>Applying one of the “Measures for communicating the consent”</p>	<p>Decision by the judge</p>
<p>Unexpected turnabout and reactions from the individual may occur - refusal to be heard, behavior crisis, etc. Changes in the individual's profile may occur: medication therapy, changes in behavior (there is approx. one month between the hearing the conclusion and hearing the individual in a court session). The court hearing might be cancelled due to the absence of the ex-officio defense of the individual. The judge needs to see and “get a feeling” of how the individual lives when the latter can communicate in no other way but through their behavior (examples from practice).</p>	<p>Each judge has a subjective interpretation of how he/she will take into consideration the individual's wish and choice (in the street or in a specialized institution). The main question judges are faced with: <i>“Can I let this person live in the street? Even if the evaluation shows that the person cannot take care of themselves, even if the person declares so, shall I still keep him/her in the institution?”</i> Judges have their own approaches. The case law gives us examples of judgments which do not confirm the order of the relevant SAD for placement in an institution, and conclusions are drawn according to which the guardian/custodian is obliged to support the individual's life in the community in cases when the guardian is one of the family relatives. This obligation ensues from the provision of Art. 163, para 1, and Art. 164, para 3 of the Family Code. In other words, the choice is not defined as choosing between the specialized institution and the street, but as choosing between the specialized institution and justifying the guardian's/custodian's obligation to live together with the individual in the community, and take care of him/her.</p>

Conclusions and final thoughts

In conclusion, we wish to send across several message to each of you for whom we have lit the spark of changing our attitudes towards people with intellectual disabilities.

Each of us can, individually, by conveying their belief in equality and equal rights, set this wheel into motion, and thus generate huge momentum and create a community of a growing number of people with these beliefs.

We dedicated many pages of our handbook to presenting communication from the perspective of theory and practice, and we hope to have left you with the idea that sometimes it is difficult to even think that communication exists in the minds and wishes of some people; it does exist, however. It just stays there waiting to be discovered. Hence, the following brief conclusions regarding communication:

**Communication is an important factor
for ensuring efficient support
for the individual.**

**Communication is the bridge
to decision-making.**

**Communication is the path
leading to legal agency.**

It is certain that we are not going to change yet another aspect of our beliefs: focusing on the support for these individuals by aiming at trusted relationships, as the latter are often the key to enabling the person with intellectual disabilities to communicate their will, wishes, and rights.

Another lesson learnt is that *building trusted relationships in a specialized institution is disputable: whether this is possible and how it can be achieved. We know for sure that the individuals with ID lose these trusted persons who provide the most important support for communicating their will, wishes, and preferences. This faces each of us, in our role of participants in the court proceedings, with the challenge to assist the person with intellectual disabilities with communicating their rights, without support from a trusted person. We will pursue the goal of also developing and defending this type of support (measure for the hearing) till we successfully ensure it.*

Anywhere across the world the hearing of persons with highly limited communication abilities is a slow and difficult process with many challenges, and this is recorded in a protocol. We do hope that this handbook sets a good beginning towards a protocol for Bulgaria.

"As quite often we do not understand the complexity of electricity and its conduction through the wires, so for people with intellectual disabilities we must create a world in which they only press a switch and the light comes. The light switch!"

Dr. Michael Bach

The light switch

When we press the light switch, we know that it will turn on or off the light; what we do not know and cannot quite imagine, however, is how exactly the electricity flows along the wire to the switch, to the board in the apartment, from there to the complicated board in the building, and from there to the complicated grid of substations and unknown sources feeding the grid. We know that if we press the switch up, the light will be on, and if we press it down, the light will be off. And this is enough for us to make a decision on what we want to do.

As regards people with ID, we have to provide them with a context in which, by using a toolkit, they will be able, similar to the light switch, to turn on and off their wishes and choices.



CHAPTER FIVE

ANNEXES

The forms and content of the Annexes in this chapter are in the process of being developed and (further) developed in order to achieve in practice their most effective form.

III. SURVEY: /the information is gathered from the individual's caretakers/

This survey contains basic questions that can be supplemented, modified (broadened and narrowed) depending on each individual case.

Date and place of conducting the survey:

1. How does the person communicate?

- a. verbally
- b. non-verbally

2. The person uses in communication:

- a. gestures
- b. mimics
- c. sounds
- d. behavior models
- e. augmented communication

Notes:

.....

.....

.....

.....

.....

.....

.....

3. Can the person make choices?

- a. yes
- b. no

If yes, in what situations, in respect of what, and how does he/she express these choices:

.....

.....

.....

.....

4. Does the person express preferences?

- a. yes
- b. no

If yes, in what way does he/she express liking or disliking something:

.....

.....

.....

5. What is his/her usual behavior?

.....
.....
.....

6. Do all his/her caretakers interpret his/her behavior in an identical way?

- a. yes
- b. no

7. With whom does he/she communicate most often, and does he/she initiate the contact?

.....
.....

8. Are there people with whom he/she refuses to communicate, and how does he/she express this?

.....
.....

9. Does he/she share things with the others in the environment, and, if yes, what (emotions, experiences, wishes, suffering). And in what way?

.....
.....
.....

10. How does he/she respond to an unknown environment with strangers?

.....
.....
.....

IV. EVALUATION OF COMMUNICATION SKILLS

The evaluation process shall be conducted using a standardized Silver Silver Communication Assessment Questionnaire.

EXPRESSIVE COMMUNICATION I

E1 1. Does he/she use words or vocalizations?

E2

E3

.....
.....

E3 2. Does he/she use gestures, signs or symbols?

E4

.....

E8 **3. Is there immediate or delayed echolalia? (ie does he/she repeat words spoken by another?)** *(ie does he/she repeat words spoken by another?) Please give examples.*

.....
.....
.....
.....

E3 **4. Does he use individual words?** *Please give examples of the most commonly used words.*

E4

.....
.....
.....
.....

E3 **5. Does he/she name objects and / or pictures?** *Please give examples (You can use the Interpreter's Dictionary).*

E5

.....
.....
.....
.....

E6 **6. Does he/she use any verbs?**

.....
.....
.....

E7 **7. Does he/she compose his/her own phrases?** *Please give examples.*

E8

.....
.....
.....
.....

EU 18 **8. Does he/she pronounce the words clearly?**

.....
.....
.....
.....

EU 19 **9. If he/she uses signals, are they understandable?**

.....
.....
.....
.....

FUNCTIONAL USE OF COMMUNICATION I

EU 2 1. How does he/she show "No" or "I don't want"?

.....
.....

EU 3 2. How does he/she express a desire?

.....
.....

E1 3. Do sounds or actions have a certain meaning such as biting hands, pinching?

EU2

EU3

EU 13

E2 4. Does he/she point a finger?

.....
.....

What does he/she indicate?

.....
.....

EU 13 5. What motivates him/her the most to communicate (eg food, children's movie, computer)?

.....
.....

EU 13 6. What motivates him/her the most to communicate (eg food, children's movie, computer)?

.....
.....

To whom?

.....
.....

Where?

.....
.....

EU4 **7. Is the communication directed in an appropriate way to another person?**

EU 5

To whom?

In what situations?

EU 20 **8. Does he/she initiate communication?**

.....

.....

How? (through words, signs, actions)

.....

.....

Does this change depending on the people or the context?

.....

.....

EU6 **9. Does he/she learn and use words as part of everyday situations?** *(eg breakfast)*

EU8

EU9

EU10

.....

.....

EU7 **10. Can he/she ask for help when he/she is facing a problem?**

.....

.....

EU8 **11. Does he/she manage to generalize the words learned in everyday life into new situations?** *(eg from breakfast to other eating situations)*

EU10

.....

.....

.....

EU11 **12. What does he/she do when he/she is upset?**

EU 16

EU 17

Can he/she show what the problem is or how he/she feels?

.....

.....

EU12 **13. How does he/she attract attention?**

.....
.....

EU19 **14. Does he/she direct the attention of others to things that interest him/her?**

.....
.....

EU 15 **15. Does he/she ask questions, does he/she look for information. How?**

.....
.....

16. How can he/she be helped to use his/her communication skills? *(eg does it respond to a hint as a started sentence or indication?)*

.....
.....

EU 6 **17. Where is he/she the most communicative?** *(eg in front of the computer, at lunch)*

EU 9

EU 10

.....
.....

EU4 **18. Who does he/she communicate with the most?**

EU 11

.....
.....

19. Does he/she use the language adequately to the context?

.....
.....

UNDERSTANDING COMMUNICATION I

U1 **1. Attention control - cComment on his / her ability to focus on a task in a group situation and in individual activities.**

.....
.....

U5 **2. Listening and memorization skills - what is the level of his/her auditory memory?**

U6

U7

U15

U3 **3. Does he/she use gestures, signs, symbols, or written words as an aid to understanding oral speech?**

.....
.....

When?

.....
.....

How?

.....
.....

U2 **4. Does he/she answer a call by name, "No" or "Stop"?**

U4

.....
.....

Does he/she follow instructions related to the specific situation, such as "put on your shoes"?

Please give an example.

.....
.....

U5 **5. Does he/she understand nouns (eg cup, biscuit, car)?**

.....
.....

U6 **6. Does he/she understand verbs (eg run, jump)?**

.....
.....

7. Does he/she understand words as part of simple interrogative sentences related to the specific situation?

.....
.....

U9 What?

.....
.....

U8 Where?

U9

.....
.....

U14 Who?

.....
.....

Please give examples of when / where he/she understands these sentences.

.....
.....

U12 **8. Does he/she understand simple phrases related to an event from the recent past (things that have just happened)?**

.....
.....

U13 An event from the near future (things to happen soon)?

.....
.....

Please give examples of when he/she uses speech in this way.

.....
.....

U11 **9. Can he/she understand language when it refers to things that are slightly out of the "here and now" situation (eg to shift the focus of attention from an instruction related to a table activity to an instruction to bring something from the cupboard)?**

.....
.....

U16 **10. Can he/she understand the language when he/she is directed outside the "here and now" situation to familiar or particularly interesting events or places (eg related to a walk or home)?**

.....
.....

11. Comment on the speed of processing verbal information (eg does he / she need more time to process the oral speech? How much?)

.....
.....

.....
.....

V. CONCLUSION

On the basis of the information gathered; the observation during the period -
.....; the survey conducted for, and the research
based on Kate Silver’s method on....., a conclusion can be drawn that the
person, communicates

.....
.....
.....
.....
.....
.....
.....
.....
.....
.....
.....

Annex 2

INTERPRETER'S DICTIONARY

Topic 1. PEOPLE – I and the others

The topic allows examining the individual's family environment and his/her place therein:

Who am I?

What is my name?

Who are the significant persons in my environment?

What is my relationship with them?

In what way are my choice and my opportunities for choosing the place to live related to these people?

Topic 2. MY HOME – The place where I live

My room, house or flat are an important part of the communication regarding the choice of a place to live. Using this board or a part of the pictograms can help the interpreter establish a contact with the individual at the very first stages, and introduce the topic of the home as an important one to communicate.

Topic 3. CHOISE – I accept/don't accept

The expression of an individual's will can be easily understood and respected – by using the pictogram boards or observing the natural gestures of approval or disapproval, and a negative answer: nodding, waving a finger, a smile, body posture. Offering the choice between two alternatives results in a positive or a negative answer. By asking closed-type questions we can quickly and easily reach an answer with the means proposed. Use some of the pictograms to design the board for agreement or disagreement, depending on the person's individuality, by supporting them in the best possible way for them.

Topic 4. IN THE COURT

Visiting an unknown place and getting away from what we know in our daily routine can be unpleasant for most people. Using pictograms will help explain the situation in advance, and will prepare and calm down the person while looking forward to the upcoming and unknown event.

Topic 5. TRAVELLING

Moving from one place to another may provoke not only unrest but even physical discomfort. By describing the details of the situation we can avoid unnecessary tension and ensure yet another situation for which the individual is prepared. Details such as the color of the vehicle, the time of departure, other passengers can be shared with the individual, if necessary to travel to the court.

Topic 6. CHOICE. I CAN CHOOSE

Providing the opportunity to make a choice can facilitate communication in many and various situations. It can direct and focus the topic of the conversation, can give guidance on solving a dispute or making the correct decision.

Topic 7. EMOTIONS AND STATES

It is sometimes difficult to find the precise word for our current state; however unclear the referral to the emotions or state be, this can help a lot in difficult and emotional situations.

Topic 8. GREETINGS

Greetings are a good start or end of communication; they give the collocutors time to exchange information, to start or end a conversation.

Topic 9. EVERYDAY LIFE

Talking about everyday life and regular activities may be easier by means of pictograms. This can be the starting point of the evaluation of understanding and expression.

Topic 10. QUESTIONS

Asking and answering questions is crucial in the process of communication. It is very important that we make sure the question is correctly understood in order to assist with the answer on a specific topic.

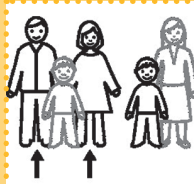
Topic 1. PEOPLE – I and the others



I AM ...



FAMILY/CLOSE PERSONS



FAMILY



GRANDPARENTS



MOTHER



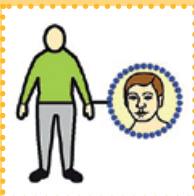
FATHER



PARENTS



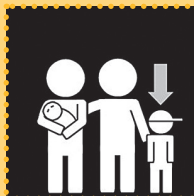
PARENTS



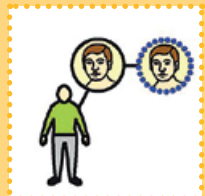
BROTHER



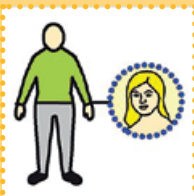
BROTHER



BROTHER



UNCLE



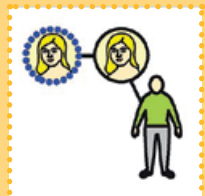
SISTER



SISTER



SISTER



AUNT

Topic 2. MY HOME – The place where I live



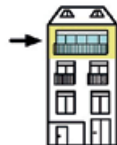
HOUSE



HOUSEHOLD



HOME



FLAT



BEDROOM



HOUSEHOLD



BED



WARDROBE



BEDROOM



BED



CHAIR



CUPBOARD



TABLE



TV SET



BATHROOM / TOILET



AREA FOR HAVING MEALS

Topic 3. CHOISE – I accept/don't accept

YES



YES

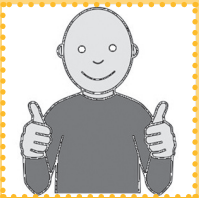


NO

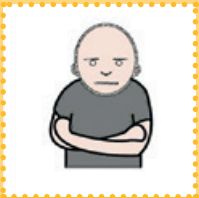
NO



YES



YES



NO



NO



YES



YES



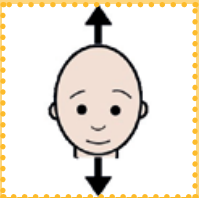
NO



NO



YES



YES



NO



NO

Topic 4. IN THE COURT



COURT ROOM



LAWYER



LAWYER



COURT



HEARING



HEARING



JUDGMENT



LAW



JURORS



INTERPRETER



JUDGE



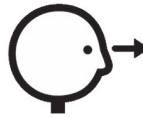
JUDGE



JUDGE'S HAMMER



I LISTEN



I LOOK



I ANSWER
QUESTIONS

Topic 5. TRAVELLING



TRAVELLING



WHEN?



WHEN?



AT WHAT TIME



I PREPARE



I EAT



TRAVEL PILL



TRAVELLING



TRAVELLING BY CAR



TRAVELLING BY CAR



TRAVELLING BY BUS



PASSANGER



TICKET



BUS

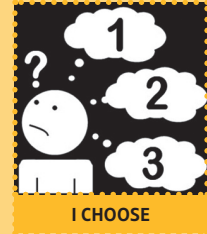
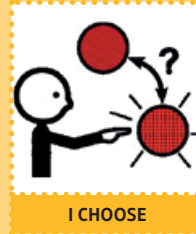


TRAIN

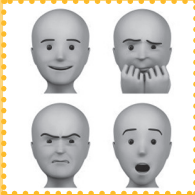


CAR

Topic 6. CHOICE. I CAN CHOOSE



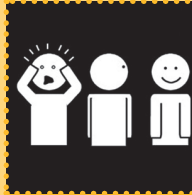
Topic 7. EMOTIONS AND STATES



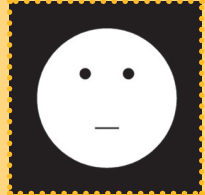
EMOTIONS



FEELINGS



DEAL WITH EMOTIONS



CALM



SATISFIED



UNHAPPY



SAD



HAPPY



CRYING



NOSTALGIC



WORRIED



SCARED



CURIOUS



CONFUSED



ANGRY



ANGRY

Topic 8. GREETINGS



I GREAT



HAND SHAKING



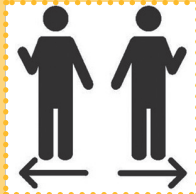
HELLO



HELLO



I GREAT



GOODBYE



BYE



BYE



BYE



GOODBYE



GOOD AFTERNOON



GOOD AFTERNOON



GOOD EVENING



GOOD
MORNING



GOOD
AFTERNOON



GOOD
EVENING

Topic 9. EVERYDAY LIFE



EVERYDAY LIFE



I TAKE A SHOWER



I BRUSH MY TEETH



I CHANGE MY CLOTHES



LAUNDRY



COOKING



CLEANING



I CLEAN



I WATCH TV



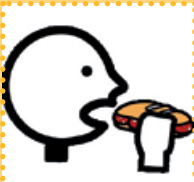
I GO SHOPPING



SHOPPING CART



SHOP



I EAT



I DRINK



I HAVE A REST



FIRST AID

Topic 10. QUESTIONS



QUESTION



I ASK A QUESTION



I ASK



ASK FOR CLARIFICATION



WHAT IS YOUR NAME



WHERE DO YOU LIVE



WHAT DO YOU DO



WHERE IS THAT



WHAT IS THIS



WHAT DID YOU SAY



WHY



WHERE



WHICH CHANNEL



WHAT IS THE WEATHER LIKE



WHEN, AT WHAT TIME



WHAT IS THE DIFFERENCE?

Annex 3

Form for drafting an expert opinion

EXPERT OPINION

For (name)
....., UCN
permanent residence address: city/village, No..... str., conducted by
....., UCN, permanent residence
address: city/village, No..... str., in
(month), (year) in his/her capacity of an Interpreter.

Training and professional experience:

.....
.....
.....
.....
.....

The expert opinion has been assigned by virtue of protocol No
of Court in case No/..... (date),
..... Panel, with the following task:

(this task is indicative and is related to cases for placement in specialized institutions)

1. Make sure that he/she has the ability to mediate in the communication with
....., including the ability to communicate the individual's will in a
reliable way, and to interpret the questions asked by the court and the parties to
the proceedings in such a way that the individual understands them.

2. In the event of an affirmative statement by the expert witness within the
meaning of the above regarding the possibility to carry out communication
with a view to the exercise of
's right independent life in the community within the meaning of Art.
19 of CRPD and the need for the opinion to be delivered as a result of
.....'s informed consent:

- Communicate in an accessible manner the claimant's request for placement in a social service:,

- On the basis of the data on the case, inform the individual about the alternatives available for using social services in the community: residential and daycare in the community, respectively the option for bringing up in the family of a guardian/relatives, as well as independent life in the community, outside the scope of the above mentioned options.

I. DATA ON THE CASE

The proceedings were instituted upon a claim under Art. et. al. of theAct. The claim was lodged by SAD with a request for the placement of, UCN....., at....., in, for a three-year period or till changes in the circumstances occur prior to this time limit which runs from (date).

The court has found that the specifics of the case do not support that full protection of the interests of the person under guardianship will be ensured by the guardian. Pursuant to Art. 13, paragraph 1 of the Convention on the Rights of Persons with Disabilities *"States Parties will ensure effective access to justice for persons with disabilities on an equal basis with others (...) in order to facilitate their effective role as direct or indirect participants..."*. The right of access to the court, including direct access to the right to appeal can be effectively ensured by allowing legal aid in the form of procedural representation, even though Art. of regulating the procedure does not provide for legal defense.

II DATA FROM THE EVALUATION

The evaluation was conducted on the territory of where I gathered the necessary information from the following sources:

- Documentation;
- Interviews;
- Personal observations;
- A communication profile drawn up for

According to documentation data, was placed in social service: "....." in (month), (year). The medical decision issued in defines as a person with intellectual disability. The decision has a lifelong validity. The person is not treated with medication (unless she gets sick).

I had several meetings with the staff of the residential service. It should be emphasized that all the interviewees are involved in the care for, and are familiar with her personal story....

Based on the interview and the documentation, and the discussion with the director and the social worker, it was established that had changed a lot after leaving the social service: in Before being placed at social service: ".....", in, they visited his/her twice.'s way of moving around was similar to a spider's. The procedure required that before being placed in the residential service the future team visit his/her and get acquainted with her while he/she was still in the social service:, in When they were in one of the rooms with his/her, just clung onto one of the women (.....) who would take care of his/her. jumped onto the caretaker, and clutched his/her arms and leg around her body. It was added that now when hears the voice of this caretaker, he/she starts laughing. The only voice to which she he/ reacts is hers.

I learnt a lot about from talks with the caretaker (he/she is called). She confirmed that he/she had known the guy/girl while he/she had been in the social service:, There he/she had witnessed his/her severe behavior crises which kept occurring after his/her transfer to the Center. would shout, turn over the table, and then laugh. According to the caretaker, at present it rarely happens that he/she gets angry, "As he/she has no reason to get angry", and when it does happen, his/her outbursts are not that destructive, he/she may simply shout and then cry. would he/shy away from everybody, and play "like a bear". He/She did not allow anyone to touch him/her. He/She was scared of people, unfamiliar places, and spaces.

The caretaker expressed his/her affection for He/She was speaking about his/her with excitement and showed how happy he/she was with her successes. He/She deeply believed that would be making progress,

and sometimes "he/she had the feeling that they understood each other talking". The caretaker was smiling while telling the boy/girl's story: how he/she gradually started trusting him/her, and now he/she can even touch him/her; he/she lets him/her make his/her hair every morning. The caretaker told me about teaching her things such as – always wear his/her sock when having a meal at the table. laughs when looking at photos of his/hers; he/she likes wearing clean and new clothes, and expresses his/her joy with being beautifully dressed; however, he/she accepts clothes only from his/her close persons; initially, he/she was scared of the lift; he/she fixes her bib himself/herself. took him/her to the dentist, and waited for him/her outside: looked anxious when walking into the dentist's office, but he/she soon calmed down. They went to the seaside together.

I also learnt from the caretaker's story that one of 's legs has a deformity, and he/she usually keeps his/her legs cross when seated. He/She often takes the sock off this leg and twists the leg in such a way that he/she faces it. Then he/she starts moving the foot as if he/she were communicating with a friend. The movements of his/her foot resemble a puppet show.

..... had been through a huge physical and mental transformation since her accommodation in the social service: ".....", in He/She had even grown taller and had put on weight.

I met him/her on the territory of the social service: ".....", in at a time convenient for him/her, without disrupting his/her everyday activities. goes to a daycare center Monday through Thursday, and on Friday a resource teacher works with him/her. According to what the center staff said, spends his/her time there sitting or lying on a sofa; however, the very fact that he/she leaves the social service: ".....", in to get to the daycare center every day is a huge success. It is particularly important for to have a predictable sequencing of activities in his/her everyday routine. He/She has expectations and preferences in regard to various staff members, and food and activities. He/She has his/her rituals, which, if violated, the boy/girl has a negative reaction. He/She has his/her preference for the places to take a seat, and even when the other users of the service see him/her coming and if they have taken one of these seats, they cede it to him/her. Consistency, familiar people and places give him/her peace of mind and comfort. likes working with

the resource teacher: they sing songs, the teacher tells his/her stories, and they play baby games.

Now can move around on his/her own. He/She can climb stairs. He/She is careful when walking, and he/she holds to the rails. When he/she feels unstable, he/she may squat.

..... has not yet acquired independence in his/her everyday activities. He/She receives help for taking care of himself/herself. He/She is still using nappies, even though the staff have made attempts to teach him/her not to use them. He/She laughs when taking a bath. He/She has learnt to make his/her bed. He/She has been to the seaside with his/her caretaker..... There he/she managed to accept the new environment. They visited a shop, and while the caretaker was concerned about 's reaction, he/she behaved quite alright. did not want to get into the sea waters, he/she was afraid of the sand. The caretaker spoke positive about, and was happy with him/her success story.

According to data from the caretaker, uses several gestures to communicate:

- Gesture expressing dissatisfaction – he/she pushes with his/her hand (an object, a person) when he/she does not want to communicate and wants to be left alone;
- Gesture expressing a need – he/she pushes the tap in order to have the shower water fixed for him/her;
- Gesture expressing affection – he/she embraces persons whom he/she likes;
- Gesture expressing protest – he/she gets angry when he/she does not like the taste of the food or the food is not enough.

When we had our first meeting, was in the room for daily activities. When we walked in (with the director and the social worker), he/she started embracing them – first, the director, then he/she sat in the lap of the social worker (a woman). He/She became lively, got up from the sofa on which he/she was lying. He/She wanted to be carried around like a little child.

He/She also noticed my presence, and our contact was at a basic level. He/She looked at me, and turned to me when I spoke. He/She smiled when I introduced myself and extended my hand for a handshake. He/She did not touch me.

After a while, he/she took the social worker by his/her hand and took him/her for a walk. I followed them watching. was choosing the route for their walk around the whole house.

In our next meeting was getting close to me, looking at me, he/she allowed me to touch him/her on the elbow. He/She was listening when I spoke. In one of our meetings he/she turned to me to listen to the song I was singing. Then established contact with me in an unusual way. He/She moved her chair close to me, sat on it, and put his/her deformed leg on me. He/She kept it there for some twenty minutes, while I was sitting, and let me talk to him/her about his/her leg and caress his/her sock. He/She was watching my hands. He/She was smiling. Then he/she tried to take off his/her slipper, but let me put it on when he/she heard the caretaker say that he/she should not take off the slipper. has a deep connection with his/her deformed leg, but nobody knows the story behind it – how come it became crooked. The deformed leg seems to have been his/her only friend in the institution. While was keeping the contact with me, a medical nurse was standing behind him/her and was playing with his/her hair, while the caretaker who was sitting next to us was telling his/her success story. I noticed some stereotype movements of his/her hands (rotating) and his/her tongue when he/she felt entirely at his/her ease. He/She did these movements for a while. This communication took place in the director's office where he/she had been invited and where he/she liked going.

III. ANALYSIS

The following conclusions can be drawn on the basis of the evaluation:

The information about is sufficient with a view to the tasks assigned by the court. The data gathered from the personal file point to a man/woman who is to turn in He/She was born on in, he/she was placed in the social service:, in; before that he/she had lived in an institution for children with disabilities in..... He/She was under full guardianship, and his/her guardian is the director of the social service:, in where he/she lives.

The file contains a decision with a lifelong diagnosis issued by a medical certification board: "severe intellectual disability" and "Down Syndrome". The

degree of intellectual development concerns both impaired understanding of the language and impaired expression (speech). Persons with such a disability are able to understand simple, specific and situational instructions. Their linguistic expression is often at the level of vocalization or isolated sounds. Persons with such a diagnosis can learn to participate in simple activities in their daily routine such as getting dressed, taking a shower, etc. They can also make simple choices and simple decisions in regard to their everyday life. They could develop non-verbal communication in a situational context by means of repetitive gestures.

There are a number of principles that must be at the core of understanding how persons with disabilities function and how you work with them:

- Any individual, irrespective of whether he/she a disability and how serious it is, has wishes, preferences and will;
- The wishes, preferences and will should always be respected, regardless of any issues with communication;
- Any individual, irrespective of whether he/she a disability and how serious it is, is capable of building a trusted relationship with another individual;
- Any individual, irrespective of whether he/she a disability and how serious it is, at some point in time needs support for making decisions, and receives it from the people whom he/she trusts.

From the perspective of my professional experience, I should point out that developing the communication and social abilities of a person with a severe intellectual disability is entirely possible. The individual can build these abilities with the support of people in their surrounding environment or significant persons/officially appointed professionals. An important condition is that those significant persons or officially appointed professionals believe that any individual with an intellectual disability develops in an environment of support, with the following important components:

1. Excluding the medical model which limits the approach in respect of the possibilities for people with intellectual disabilities to develop. Lifelong documents are a record of the person's state over their entire life, but they do not impose limits on the person's development. It is the lack of social services and interventions, the lack of support contribute to setting limitations;
2. Respect for the individual's will, wishes, and choices;
3. Support in the environment where the individual lives;

4. Ensuring support from significant and trusted persons;
5. Ensuring individual and person-centered means of support.

Therefore, in view of the components listed above, the following conclusions can be drawn:

1. communicates in a non-verbal way. He/She has developed situation-based gestures which are recognizable to those who know him/her. The pushing gesture is a signal that he/she should not be disturbed by people who do not know him/her. He/She initiates spontaneous communication mostly with people he/she knows, and, in practice, this is the most efficient communication, as the process is a two-way one: his/her expectations are that his/her close persons understand his/her gesture and will respond, and vice versa – they know when and how to communicate with him/her so that he/she can understand them. As for unknown people, the boy/girl can share space, and communicate with them on a lower level. In a situation with an unfamiliar or less familiar person (the situations of my visits) the boy/girl looks at him/her, shares the attention focused on a certain object. It takes him/her several meetings to get to know the person. The evaluation has shown that he/she develops his/her communication skills at the place where he/she lives. He/She does so at a slow pace, but the changes in his/her development are indeed considerable. The people taking care of him/her have excluded the medical model of raising people with intellectual disabilities, and take advantage of the boy/girl's wish to develop and his/her strengths.

2. understands the significance of a choice made in the context of a certain situation. He/She receives support for expressing his/her preferences and wishes. At this stage of his/her life they concern: his/her pursuit of rituals and predictability in his/her everyday life; specific food; places where he/she can spend his/her spare time (sometimes he/she choose to have a rest in his/her room, sometimes he/she would rather stay in the room for common activities). He/She is able to make choices and take decisions at an elementary level: in a specific social or communication situation, in a familiar and safe environment.

3. The findings show that is actively involved in his/her daily routine, and a person-centered approach is applied to him/her. The people who are close to him/her have been gradually introducing changes in his/her everyday life, and he/she has accepted them when feeling ready for them. The decisions

made are him/hers. The caretakers make use of his/her strengths, and adapt the environment so that he/she feels safe and makes progress.

4. It should be highlighted that is continuing his/her social and communication development. This is due to the resources in the environment where he/she lives and his/her communication potential, as well as to his/her attachment to the people who are close to him/her in the social service: ".....", in

Attachment is defined as "relationships characterized by a strong interdependence, intensive mutual feelings, and crucial emotional contacts". Similar to the way the mother is important for the baby, and the baby begins the process of learning about the world with the support of this strong bond, any child/adult begins this learning process when he/she finds the people to whom he/she gets attached. As regards’s close persons, he/she does have such persons in the social service: ".....", in with whom he/she has a history of relations. It is due to his/her attachment to these people that he/she has made communication and social progress, has dealt with her fears, has accepted new places and activities.

IV. CONCLUSION

..... has lived in an institution since he/she was born. He/She was moved to the social service: ".....", in , and in spite of the features of serious institutionalization (described in the Chapter Data on the Case), has continued his/her development along numerous positive lines.

1. In order to make sure that that he/she has the ability to mediate in the communication with, including the ability to communicate the individual's will in a reliable way, and to interpret the questions asked by the court and the parties to the proceedings in such a way that the individual understands them.

..... can communicate with persons who are significant for him/her on a non-verbal level. He/She communicates on a basic level with persons who are less familiar to her – she can share attention in a common space, can get to know the other person in a specific way after a few meetings.

2. In the event of an affirmative statement by the expert witness within the meaning of the above regarding the possibility to carry out communication with a view to the exercise of’s right to independent life in the community within the meaning of Art. 19 of CRPD and the need for the opinion to be delivered as a result of’s informed consent:

- Communicate in an accessible manner the claimant’s request for placement in a social service: “.....”, in;

- On the basis of the data on the case, inform the individual about the alternatives available for using social services in the community: residential and daycare in the community, respectively the option for bringing up in the family of a guardian/relatives, as well as independent life in the community, outside the scope of the above mentioned options.

The procedure in which can give his/her consent in regard to the place where he/she wishes to live has a hierarchical structure with the following steps:

1. Direct alternative support

- Support via visual symbols with the aim to enhance the understanding ability of the person with intellectual disabilities.

2. Supported decision-making – interpretation of the behavior by significant person who can interpret the individual’s will in a categoric and indisputable way. In this procedure the expert witness-Interpreter can support the interpretation from a professional perspective.

3. Interpretation of the best will and wishes by officially appointed professionals (the placement body, doctors, human rights organization social workers, etc.) – in cases when no significant persons have been identified.

The assumptions described below concern the options for the hearing of at this stage of his/her development, which are directly linked to his/her development.

1. The assumption under which is provided with direct support through an alternative communication system (photos, drawings, etc. which would help her answer the questions asked by the court) is not possible at this stage of her development. has not been trained, and training is a

long process which does not fall in the scope of my tasks and timeframe, in my capacity of an Interpreter.

2. The assumption for supported decision-making is possible

..... would not be able to answer the question **"Where do you want to live?" in the expected verbal way** at this stage of her development. The boys/ girls will be able tell the difference between a residential service where he/ she lives and a place that he/she has not seen and does not know (if any such place as an alternative for his/her choice), if he/she is allowed to accumulate the experience of seeing and living for a while at a different place. Under different circumstances, this comparison would be too abstract for her. The concepts that he/she can understand relate to specific objects, actions or places which he/she already knows.

In practice, an adequate alternative does not exist, and’s choice is between the street and the residential services where he/she is at present. This choice is not understandable to him/her, either, and provokes many controversial issues regarding her abilities to live on his/her own.

..... cannot answer in a verbal form to the **question "Do you want to live here?"**, either; however, given all the data gathered and the analysis in relation to the expert evaluation, her behavior **can be subjected to interpretation. The behavior offers sufficient information for answering this question.**

Supported decision-making is, by way of presumption, a system of measures whose purpose is enabling an individual, with appropriate support, to make their decision and communicate it independently or with support. The purpose of the measures is assisting people with making decisions that are important for them, one of them being the place to live.

In view of the above, supported decision-making can be implemented within the real meaning of this action, i.e. by identifying a significant person for who could interpret her will and wish in a categorical and indisputable way.

City of

Interpreter:

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AUTHORS

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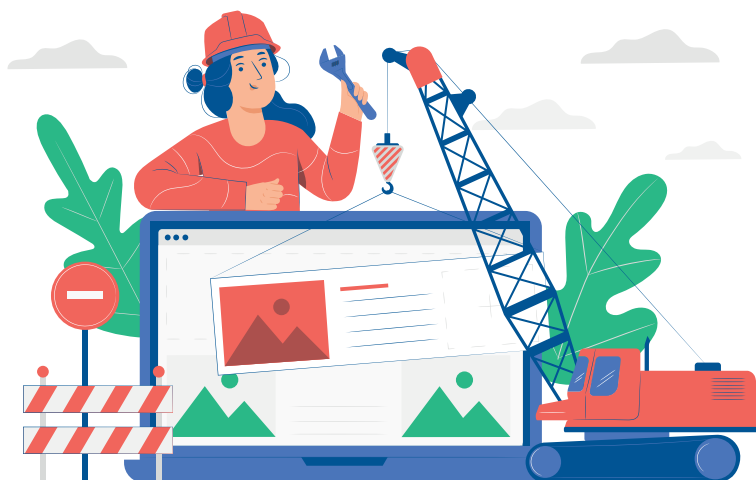
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SUPPORTING DECISION-MAKING

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Bulgarian

FIRST WORKING EDITION



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