UN Convention on the Rights of Persons with Disabilities

Good and Promising Practice Guide

IDEA 12

2017

INCLUSIVE TRAINING ABOUT ARTICLE 12

www.idea12.eu

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2   Introduction

This guide was developed to be used by trainers who are delivering sessions around supported decision-making. The guide contains general information about supported decision-making and some examples of good practice in supported decision-making.

The guide has been developed as part of the IDEA 12[1] project. IDEA 12 is an acronym of the full project title "Inclusive Direction in Education of Adults on Article 12". The project contributes to enhancing the implementation of Article 12 of CRPD, which requires coordinated and transnational intervention.

The project runs for 28 months from 1.9.2016 to 31.12.2018 and is funded by ERASMUS+ KA2 – Cooperation for Innovation and the Exchange of Good Practices, Strategic Partnerships for adult education. The project No. is 2016-1-CZ01-KA204-023975.

The project is implemented by QUIP (Czech Republic) in partnership with Land of Harmony (Slovakia), PLENA INCLUSIÓN ESPAŇA (Spain), RESURSU CENTRS ZELDA (RC ZELDA) (Latvia), CHANGE (United Kingdom), TUYA (Spain), ASOCIACIJA „LIETUVOS NEIGALIUJU FORUMAS" (Lithuania), The Protestant Theological Faculty of Charles University Prague (Czech Republic)

The guide was written based on the review of the reports, academic literature, websites and the descriptions of the practice provided by the Project partners, who have described their examples based on a template proposed by RC ZELDA.

3   Supported decision-making

Supported decision-making is a broad concept that includes a number of legal mechanisms, used as an alternative to restricting a person's legal capacity. The person's legal capacity is retained in full, however in some areas the person requires support, provided by varied means including one or more support persons.

Supported decision-making is a personal decision-making process in which a support person or support network (usually 2 to 5 persons) assists a person with disability to plan his or her future and make decisions about his/her life, health/social care, finances and property based on their will, preferences and rights[2]. The person's supporters usually include persons chosen by the supported person (they may be family members, friends, advocates or support providers). A support person may not be assigned against the wishes of the supported person.

Supported decision-making may be completely informal i.e. provided by so-called natural support providers, or formal i.e. where a support person is formally recognized and assigned by court, notary,

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[1] http://www.idea12.eu/
[2] https://www.alrc.gov.au/publications/will-preferences-and-rights

civil contract etc. The spheres and scope of supported decision making may be set by a court[3], based on and following the person's rights, will and preferences.

Relations between the supporting and supported persons must be based on trust. The support person must fulfil his duties only in accordance with the supported person's rights, will and preferences. The support person helps the supported person to understand information and make decisions based on his/her rights, will and preferences, and also explains the position of the supported person to third parties and assists in communicating with them.

The main benefits of supported decision-making are defined as following:

1. It protects individual autonomy and the universal nature of personhood.
2. It benefits individuals, families and society.
3. It helps individuals to be less isolated, increases their independence and enables them to be better integrated in the communities where they live.
4. Individuals are more likely to be happy with outcomes when opportunities to express their views are provided in the decision-making process.[4]

Why do we need supported decision-making? – A story from the United Kingdom (CHANGE, UK)

This is a story told by Joanne on the blog of the CHANGE organization (UK)[5]. Joanne had a fiancée, whose name was Lee and they were very much in love with each other and were going to get married. Lee lived with his parents till 18 years old, when he moved into respite care to prepare for independent living. Afterwards, he moved into Supported Living, where he did not have a possibility to make choices, was told by the staff what to do about his life. He was not happy. The staff also did not allow Joanne to stay at Lee's place, and it felt horrible for them, because they wanted to have a normal sexual life and intimacy, but the care home had all the power and made the decisions instead of them.

Only at Lee's brother's wedding they got a chance to stay together for the night. A month later Lee died.

Joanne felt devastated and she decided to tell everyone who works in health and social care about this story, how important it is for people with learning disabilities to have loving relationships, intimacy, and spend time together if they want to.

Tips and thoughts for trainers:

Even though Joanne's story is not about good or promising practice, you can tell the story when speaking about the necessity of supported decision-making in the life of other people. Joanne

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[3] The models differ from country to country. In some countries court is involved in deciding if person needs support in decision-making. However several countries are just beginning to develop supported decision-making models through a number of pilot projects and in many cases these pilot projects are implemented without respective legal regulation and without involvement of the court.

[4] Supported Decision Making. Good practice guide:
http://www.mwcscot.org.uk/media/348023/mwc_sdm_draft_gp_guide_10__post_board__jw_final.pdf

[5] https://changepeoplephilipa.wordpress.com/2017/05/

wanted to make her story public and heard around the world, so please share it, whenever you meet professionals who have a power over other people's lives.

In the recent article "Future Directions in Supported Decision-Making"[6] the authors state that the most important element in supported decision-making is "taking the time to listen and communicate", as people with cognitive and intellectual disabilities need more time to process information and to communicate.

It is important to have a clear overview of good practices implemented in the field of supported decision-making, because, as the authors continue, despite the call for a shift from substituted to supported decision-making, countries see a big "implementation gap", because their legal systems are built around guardianship based concepts.

4 What is the best, what is good and what is poor practice in supported decision-making?

Even though nowadays we can find that the usage of the terms it pretty vague, we think there are definitions we should be taking into account in order not to confuse trainers and practitioners who would later on use this paper.

First of all, we believe, that it is better to avoid the term "best practice", because it technically means that something is better than anything else, which also needs to be proven through systemic research and generally accepted as the best. So we need a sufficient body of evidence to use this term, corroborated with proof that such practice can be generally used in most other contexts and settings.

Secondly, "good practice" (or "promising practice") is a more accurate term for all practices connected with supported decision-making, as it is relatively new and we cannot claim that its application has been systematically reviewed and researched. Using these terms does not mean that we claim that our practices are the one and the only ones, but assumes that such practice has some evaluation behind, solid evidence of good outcomes and could be trailed in other settings. Therefore we suggest that while providing examples of good practice, trainers refer to evaluation that might have happened (including the supported person's feedback, for example).

There is an even more accurate term that will be more suitable in some cases - "emerging practices". This is to be used where trainers are not even sure whether the results of the practice are good, but the evaluation is more based on ideas, opinions or very limited data.

For the same reason, in the "Guide of promising practices on legal capacity and access to justice" the term "promising practices" is used: most of the described practices are innovative and experimental,

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[6] Anna Arstein-Kerslake, Joanne Watson, Michelle Browning, Jonathan Martinis, Peter Blanck. Disability Studies Quarterly Volume 36, Issue No. 4 (2016), http://dsq-sds.org/article/view/5070/4549

but have not been researched and proven to be effective or have not been replicated. Also most of these practices have a possibility to be developed further to reach their aims more fully[7].

In the academic literature, the terms "good practice" and "promising practice" are synonyms, therefore in this guide we will continue to use the term "good practice".

If we are talking about poor practices in supported decision-making, there are major concerns stated by researches that the participatory research in this sphere is not fostered by those who implement practices, that supported decision-making becomes a mere social service and not a transformative practice, and that there is a big challenge when applying supported decision-making practices with people with complex support needs or those whose communication is complicated due to their disability, and where special safeguards are needed[8].

5 Possible criteria for good practices in supported decision-making

In the framework of "Access to Justice for Persons with Intellectual Disabilities project", implemented by five partners[9], the handbook "Guide of promising practices on legal capacity and access to justice" was published. The handbook includes the promising practices that are based on the values and the philosophy of supported decision-making, and include elements such as supporting people in making their own decisions and accessing justice directly, therefore recognizing autonomy and control over their lives. In such cases, the process is based on discovering the rights, will and preferences of a person[10].

> **What is it good support in decision-making? – A story from the United Kingdom (CHANGE, UK)**
>
> Jane: "Good support is when people give me choice. For some carers, I am just a job, they don't ask me the right questions. For example, they step into my room and say it's time for your bath. They do not ask me when I would like it. I have no decision to make. When I get the right support and get to make my decisions, it makes me feel great."

The Reference document of the IDEA 12 project outlines the main crucial elements of supported decision-making, based on the concept and principles that are used for the implementation of the Article 12:

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[7] Guide of promising practices on legal capacity and access to justice, http://www.ajupid.eu/images/documents/promising_pratices/BAG_AJUPID_UK_2015_BV.pdf, p. 4

[8] Anna Arstein-Kerslake, Joanne Watson, Michelle Browning, Jonathan Martinis, Peter Blanck. Disability Studies Quarterly Volume 36, Issue No. 4 (2016), http://dsq-sds.org/article/view/5070/4549

[9] Five partners were: Foundation NET (Bulgaria); Service Foundation for People with Intellectual Disability (Finland); National Federation of Service Providers for Persons with Disabilities (France); Hand in Hand Foundation (Hungary); National Federation for Voluntary Bodies (Ireland).

[10] Guide of promising practices on legal capacity and access to justice, http://www.ajupid.eu/images/documents/promising_pratices/BAG_AJUPID_UK_2015_BV.pdf, p. 4

1. People with disabilities have the right to enjoy legal capacity on an equal basis with others in all aspects of life. In practice, it means that people make decisions and their decisions are respected. Article 12 (2) CRPD

2. States have an obligation to provide supports (where needed) to help someone exercise their legal capacity. Article 12(3) CRPD

3. States have an obligation to provide safeguards to prevent abuse and 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, are applied for the shortest time possible and protect the person from exploitation, violence and abuse. Article 12(4) & Article 16 CRPD

4. States shall take all appropriate steps to ensure that reasonable accommodation – adjustment that enable persons with disability to exercise on an equal basis with others all human rights – is provided. Article 5(3) CRPD[11]

As supported decision-making is often incorporated as a social and legal service, it is also important to understand what is the criteria for good practices in service provision. The Good Practice Project of good practice in services for people with learning disabilities (2012) has defined the following indicators of good practice:

1. Co-production – involving service users in planning their services and in some cases delivering them.

2. A capability based approach to disability – looking at people's strengths and what they can do, rather than looking at what people cannot do for themselves.

3. Community capacity building – where people can gradually rely more on community based support.

4. A move towards more integrated services, bringing in care, health and often housing and leisure together.

5. A commitment to personalisation, not as a cost-cutting measure.[12]

Based on these indicators, but taking into account that supported decision-making is not a service provided but the needed support to exercise the right of a person, we believe that the criteria for good practices in supported decision-making could be the following:

- should be participatory;
- should be based on a person's strengths and skills as well as on will, preferences and rights;
- should not be limited only to service provision, and oriented on it, but should be oriented on life in the community;
- should include personal stories where possible.

Taking all this into account, while inviting the partners of the project to prepare descriptions of good practice, they were asked to include in their descriptions things such as the areas of decision-making, and if the description included personal stories, then a detailed and personalised description of the

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[11] Inclusive training about Article 12 Reference document of IDEA 12 project, available at:
http://www.idea12.eu/

[12] http://nationalforums.co.uk/uploads/docs/21/good-practice-project.pdf

example: objectives, background; the strengths, talents, hopes of supported person etc. and his/her active role, who took part (especially what was the role of the community), what were the activities or steps (with a focus on supported decision-making activities and principles), what was the most important thing or element that should have been in place (e.g. communication charts or inviting a special person etc.), what resources were needed. We also believed that these personalised descriptions should have involved people of different gender, culture, ages, etc. If the practice has undergone some research already, we asked that some outcomes and evaluation should be included and we also asked that the example should be describing the practice that could be used or replicated in other countries.

In those examples where we found a good personalized story, we preferred to use it as a description of the good practice, rather than putting general information about various pilot projects of supported decision-making, so that this material would be more useful and illustrative for the trainers on supported decision-making in future.

6 Areas of support in decision-making

6.1 Decision-making concerning access to the justice system and legal protection – examples of good practice

One example of promising practices based on the principles of supported decision-making as described by "Guide of promising practices on legal capacity and access to justice" is the project "Supporting a person with disabilities in a court setting"[13] implemented in 2011 by the National Advocacy Service for People with Disabilities (NAS), in Ireland. Within the project, a free representative advocacy service was launched, based on the principles of supported decision-making. Within the service, the advocates helped persons with criminal and legal matters; they helped them to attend court and other meetings, to understand the documents, the proceedings and decisions being made. They also provided consultations about other legal matters. This project has a special focus on child protection issues, to ensure that parents with disabilities have an equal access to justice.

The "Guide of promising practices on legal capacity and access to justice" provides the following personal story of how this good practice worked:

> **Example of good practice in supported decision-making regarding access to the justice system and legal protection – National Advocacy Service for People with Disabilities (NAS)[14], in Ireland**
>
> John was referred to the NAS by his employment support service as it appeared that he was experiencing domestic violence in his family home. It became clear that John was having money taken from his bank account without his consent by a family member.

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[13] Guide of promising practices on legal capacity and access to justice,
http://www.ajupid.eu/images/documents/promising_pratices/BAG_AJUPID_UK_2015_BV.pdf, p. 49-52
[14] Ibid.

The advocate supported John to contact the police and report the abuse, and then to make an application to the local district court for a safety order which was granted. John was then supported to identify new accommodation and put a plan in place protecting his chances so that only he could access his bank account.

Tips and thoughts for trainers:

This story could be used while speaking about seeking justice for people with disabilities. The story resembles similar experiences in various countries, because the challenges people with disabilities face are similar regardless of cultural or geographical difficulties.

You can also use John's story to role-play the talk between the supported person, support person and the police while reporting the crime (for training purposes, use a minor crime as an example), if in the training there are advocates and lawyers present. The small group should also include the observer who can then give feedback for the support person around the elements of the supported decision-making that have been present in the talk. In this case it is important also to get feedback from the supported person and the policeman - how was it different for them?

6.2 Decision-making concerning financial matters – examples of good practice

Financial issues for people with disabilities are among most important ones. They demand a number of skills and also specific knowledge about the value and meaning of money. At the same time, financial issues is an area where exploitation and abuse can very likely occur, as it was mentioned above in the description of John's story, therefore a lot of substituted decisions are made for people with disabilities in this field.

The supported decision-making process concerning financial matters should be carried out taking into account several factor: the person's previous history of managing finances and relationships with money, what works and what does not work for him or her when making financial decision, etc. It is also very important to remember that every person can improve his or her skills after some time (see the example below).

Example of good practice of supported decision-making regarding financial decisions in everyday life – RC ZELDA (Latvia):

Anton is a young man with a disability and with full legal capacity, who has just started to live in the community. He receives support concerning financial decisions from his support person, who is a social worker from the RC ZELDA. Anton has been living all of his life in various institutions and was never given an opportunity to learn how to manage his money.

Anton is very responsible while paying bills, so that, if he has his social benefits coming on his account, he pays the bills first. The money left he could spend very quickly, in one day, buying sweets, nuts, very expensive food or some clothes. While living in institution, he could survive later on by getting some food from the employees or other residents of the institution, but it was no longer an option when he started living in the community, and he realized that.

To manage the process of supported decision-making, several steps were taken:

1) Though Anton has been paying his bills, he has done some mistakes with sums and accounts and did not feel self-confident about using Internet banking on his own - he asked the support person to help him pay the bills.

2) At the beginning, together with the support person, he made several visits to the shops, where the decision was made about each and every thing the young man bought. It turned out, that the young man never looked at the prices per kg, only at the prices per pack, so he has been overspending money while buying food.

3) Then together with the support person he started to make lists of the things to buy and to define the amount of money that could be spent during each shopping visit, which helped avoid unnecessary purchases. Anton has mastered the skills of reasonable shopping (food for one week).

4) Anton asked the support person to transfer the money that he did not need for the shopping on that day on a separate account that was not connected with his card. This was a decision made by Anton, based on Anton's self-assessment on how he uses his money "I will overspend!". This meant, that:

    a) a lot of purchases are made impulsively, because they bring him joy and relieve from stress;

    b) on the other hand, if he does not have money left, the level of stress is growing.

Thus it was quite difficult for Anton to manage his finances for long term (not one day of shopping, but one month) at that time.

By this point, the support person had access to his Internet banking, as well as Anton. Anton asked that only the support person can do transfers between the accounts on his request, but Anton can also access his own money and make any kind of transfers at any time.

After a year Anton and his support worker saw a great deal of improvement in his management of finances: Anton has recently started to log into his Internet banking and pay the bills by himself. He has also decided to have some spare money on his card for the weekends, and it turned out that this money could stay on his card for two day if he decides that there is nothing important to buy.

Tips and thoughts for trainers:

The story of Anton can be used for educational purposes as an illustration of how support in budget planning can be done in the scope of supported decision-making. After you tell Anton's story you might give the trainees small exercises on budget planning, so that participants in small groups together with one person acting as a person with a disability could work out a plan for budget planning, based on supported decision-making principles.

Among the tasks, you could include - to plan a certain sum of money that constitutes pension or benefits for the month using the mechanisms of supported decision-making. The supported person can speak about typical problems with finances: credits and debts, spontaneous or expensive purchases, problems with various addictions that can be financially burdening. It is useful to have an observer in the small groups, so that the support person can receive feedback.

As each and every person, people who are supported through supported decision-making might have complex financial issues, where several financial decisions should be made at one time - for example, deals concerning immovable property (buying, selling, renting housing), investing or saving money, or

spending money on everyday needs, with not only one person involved in the decision-making process. Here is a personalized case of a person with complex needs from the Slovakian experience:

Example of good practice of supported decision making regarding decisions about complex financial matters – Land of Harmony (Slovakia):

Paul and Leo are brothers with disabilities, their father has recently died. Leo was living with his father in three rooms' apartment and his brother Paul was living in supported housing, provided by an NGO Agency of supported living. The staffs of this NGO were also informed about supported decision-making, so the process concerning financial matters was launched. First of all, the circle of support was created to include some friends, staff from the NGO and their father's sister. As the brothers could not read, the members of the support circle provided help with understanding all of the needed documents.

In this process, several important decisions concerning finances were made by the brothers:

- Father's funeral - the costs were covered by the father's sister, but the brothers later on repaid the costs, when they received their inheritance.
- Charge to the administrator of the real estate (notary) – with the support from the NGO the brothers made a contract for a minimum payment per month and about all requirements in the procedure of inheritance.
- Father´s debt to the bank – this decision was a very difficult one, and demanded a long process of individual understanding and processing of the risks – what will happen if the bank will implement an execution? At the same time the brothers did not want to lose the apartment. Their decision was to sell the three rooms' apartment and to buy a one room apartment.
- Budget planning - both brothers found support persons for themselves, who were helping them with managing everyday costs and expenses (one friend, one member of the NGO staff).
- Selling an apartment and choosing a new one – with the support from the NGO staff the brothers have chosen the best option for the new apartment for them and paid for it from the money they got after selling the larger one.
- Paying the bills (father's debt, administrator of the property) – the NGO staff made a clear detailed bill that included all the sums, and the brothers made a decision to pay this bill.
- Ownership of the flat – the brothers decided that both of them will own the flat, with Leo living there and Paul continuing to live in supported housing.
- Money in their accounts – they decided that there will be money on their separate accounts, so that they can make decisions on how to spend it.

The circle of support was very important for Leo and Paul – there were moments when the procedures and legislation, rules and contracts were difficult for them to understand.
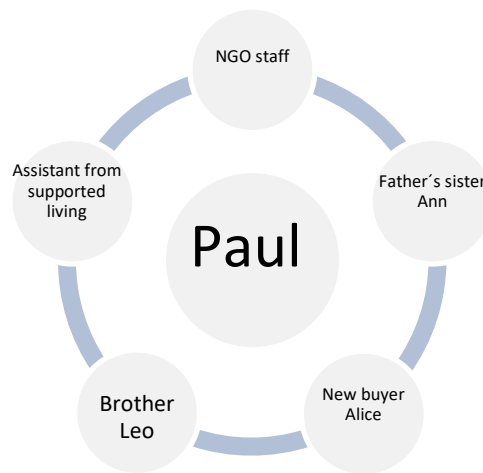
Here how the circle looked like:

The lesson learnt while working with these decisions was about how important it is to split the big decision to smaller ones and prepare a plan of different actions.

1. How to pay for the flat

2. How to pay the debt

3. How to sell the flat

4. How to buy new a flat

5. How to pay for life cost

It is also very important that the members of the support circle have the option of consulting with the lawyer while working with financial decisions.

Tips and thoughts for trainers:

Paul and Leo's story is a good chance to practice supported decision-making, when there are more than one person involved. For your presentation, you can make one group of four – two persons with a disability and two supporting persons. Imagine that they have to make a common decision about inheritance, and then give out to the supported person two cards that they are not supposed to show to anyone. The cards should include the opposite points of view (like "I want to sell the apartment" or "I want to keep it as it is"), then some reason for that (selling – to buy food, to pay debts, to give presents, not to worry about the future; not selling - for the pleasant space, feeling of home, sweet memories), and some tips on how that person could agree with another ("I could move

to live with my brother in this flat, it could save some money on rent", or "By selling the apartment I could help out my brother").

6.3   Decision-making concerning everyday living – examples of good practice

It is important to understand that the decisions concerning everyday living constitute the core of the life of every person and can dramatically influence the way we feel about ourselves in the world. When people lose any control of their life, they will naturally get angry or depressed, which sometimes can be the case with people with disabilities.

I really wanted to do this for myself instead of my brother doing it for me! – Shaun's story from the United Kingdom (CHANGE, UK)

Shaun: "I needed help to set up a bank account. My support worker asked me what I needed more support on, what concerned me most. I really wanted to do this for myself instead of my brother doing it for me. It was my decision which bank I wanted to use. My support worker helped me by showing me the options of bank cards. I had never used a bank card before. My brother loves me but he's more like a parent. I wanted to do shopping on my own, but he would say I might get it wrong, get the wrong change. We used to argue about it and in the end, I had to go with him, and he would make the decisions for me about what food I would have. It made me feel angry and frustrated because I felt I had no power. He had the power. I now live on my own and I make all my decisions, I go to the bank on my own, I travelled to Thailand on my own, I cook on my own, and I work. When I need support, I will ask for it, but on my terms."

Tips and thoughts for trainers:

Suggest to the group it divides in pairs – support person and supported person. The support person wants to go shopping. Give the pair five minutes to prepare the list of "do's" and "dont's": what both of them should do together and what they should not do in order to achieve the aim – the supported person made the purchases he or she wanted for the money he or she could afford spending.

Ask the small groups to present the lists to the whole group. Point out similar things and different things – what makes this support individual for each and every person?

We also need to keep in mind, that everyday living of people with disabilities has different dimensions. One important dimension is the services that people receive and that are aimed at supporting the daily living of people with disability. Unfortunately, in cases where there is no space for the decisions made by the person themselves, the services often are no longer a support for the person, but serve interests of others.

The "Self-Directed Support" project was aimed at promoting supported decision-making especially in the sphere of service provision, so that a person with a disability could by him/herself choose how and what kind of support they receive on a daily basis and take part in organizing it. This project was implemented by the Service Foundation for People with an Intellectual Disability in Finland in 2010-2013. The project put people with disabilities in the centre and included the following steps: 1) person-centred planning, 2) evaluation of support needs, 3) creation of the personal budget, 4)

making a support plan, 5) personalizing support, 6) evaluation. The project has shown very inspiring results, with achieving better results at the same costs as traditional service provision models.

The "Guide of promising practices on legal capacity and access to justice" provides the following story of a person benefiting from this good practice:

Example of good practice in decision-making regarding everyday living – Self-directed support, Finland (the Service Foundation for People with an Intellectual Disability)[15]:

Sirpa lived in different group homes for almost 30 years. She suffered because the housing and services were too institutionalised: "We had schedules for eating and other daily routines. Service was not personalised," Sirpa complained. She didn't want to live in a group home anymore and that is why she was seen as a 'difficult customer'. Her life changed in 2012 when she moved to her own home: "It was a huge change. I've slept better than ever, because it is so quiet. I can do what I want. It is my home, my rules. I get personal assistants and they do what I ask them to do."

Sirpa receives services from the South Karelia Social and Health Care District (Eksote). Eksote was one partner in the pilot project for developing self-directed support in Finland. Because of the project, Sirpa finally had the chance to say what kind of services she really wants: "For the first time in my life I felt that I was listened to. At first I hesitated – can I manage it on my own? But then I thought that it can't get any worse."

Sirpa gets personal assistance – several hours per day – as much as she needs. "My services are even cheaper than before. At the same time the quality of my life has increased significantly. Why did it take such a long time? Why did we need a pilot project to make this all happen? When I moved away from my childhood home the only possibility was a group home. After that, the system of personal assistance had developed. Because of the self-directed support people are better listened to," Sirpa says.

Because of support in decision-making, Sirpa is able to direct her own services. She decides on how she wants to live her life and what kind of services she needs.

Tips and thoughts for trainers:

Ask participants to divide in groups of three persons each. One person will interview the other about the support and services that he or she feels they need in their life, their contents, intensity, general description. The third person would draw a map/scheme of the support this person needs in his/her life.

Put all the drawings together. Allow several minutes for the group to walk around and write down at least five similarities and five differences between the drawings. Invite people to reflect on the importance of the person-driven, individual-oriented support in their lives.

Another important part of everyday life is the skills that are needed to live a healthy, safe and happy life. Supported decision-making can contribute to the life of people even if some of the decisions

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[15] Ibid, p. 9-13

seem to be minor or not that important – for example, choosing some clothes together, or choosing which kind of food they want to eat that day. Andrey's story can show how a "minor" decision of a person can lead to the development of essential skills.

Example of good practice in a decision-making concerning everyday living – RC ZELDA (Latvia)

Andrey is a young man with a disability. He is living with his family in an apartment. He does not speak and several years ago he refused to leave his apartment. Because of this he did not finish his education, at the same time his support network dramatically shrunk. Andrey likes people and communication very much, he also likes cooking – he is constantly watching cooking TV-shows and asking his relatives to cook some recipes he finds. He often takes part in cooking, when there is some family celebration, but never cooked on his own. At the same time it is important to Andrey, from his family's point of view, that he develops basic skills of self-care (cooking simple meals for himself, putting on his clothes, taking care of his room, washing dishes). Andrey's parents have been searching for some teacher or volunteer to come visit Andrey, however it was very difficult to find someone who would stay for a long time, would be interested in a relationships with Andrey and would understand his communication style. Together with Andrey and his family, RC ZELDA's support workers had a person centred planning meeting and decided to set an aim for a RC ZELDA support worker to visit Andrey, visits during which he would develop his cooking skills and will have the opportunity to communicate outside of his family's circle. During these meetings the support worker tried to build trustful relationships with Andrey and later to understand the nuances of his behaviour, communication and decision-making style. On the first two meetings, Andrey did not communicate with the support worker, he just sat in the next room or nearby, but not looking and not getting involved. During the third meeting Andrey started cooking – he would follow the instructions given in the recipe, but would do only those actions he really liked (for example, chopping and slicing, working the blender). Further on he started expressing his desires and attitude to various activities (washing hands, adding salt), joking (putting ingredients in wrong order). These communication elements made it more clear how Andrey can make small decisions in his life independently or with support, and whether he can communicate those decisions or his attitudes to his family and support network. Thanks to this cooperation, RC ZELDA gathered all the information about Andrey in a person-centred plan and continued to search for an appropriate teacher for him, based on what they learned about him. Eventually they found a suitable person, who started visiting Andrey on a weekly basis and helping him to further develop his everyday skills.

Tips and thoughts for trainers:

Ask each participant of the group to think about their close ones, people who see them every day. What could those people tell them about what is important to them in their everyday decisions? (Morning rituals, first minutes at work, walk with the dog etc.) Make a list of these small important things for each person.

6.4   Decision-making concerning parenting – examples of good practice

Parenting issues for people with disabilities have been brought to wider attention just recently, though this field has not been researched well enough.

The studies show that 40-60%[16] of children are removed from parents with intellectual disabilities, with 10% being removed immediately after the birth. The statistics also show that parents with intellectual disabilities are 15 to 50 times more likely to have their children removed from them[17]. There is a growing concern, that the removal of children in many cases is the result of the lack of sufficient support to the families, rather than the incompetence of the parents.

Supported decision-making can be a good model for parents with disabilities to find a way to keep the family together and care about the child in the best possible way. Nowadays parents with disabilities face various barriers to making informed decisions about giving birth and bringing their children up. While speaking especially about mothers, Sue McGaw and Sue Candy in their article "Supported Decision Making for Women with Intellectual disabilities"[18] have identified the following barriers: opposition from others and low expectations, maltreatment in their own upbringing, social and economic deprivation, inaccessible information and support. The typical decisions these mothers would be involved in are the same as other mothers are: planning pregnancy, decisions regarding child protection issues, providing a safe and peaceful environment for themselves and for the children, developing parenting skills etc.

Example of good practice of supported decision-making regarding decisions about parenting – RC ZELDA (Latvia):

Anna is a young mother with a disability, who came for support to RC ZELDA on her 6th month of pregnancy. She had made an important decision to keep the baby, but this decision was followed by a lot of challenges – more and more decisions she had to make:

- To defend her right to become a mother, as the service provider was threatening to take the baby away the day s/he will be born;
- To find a place to live (as she could not live in the group home with a baby);
- To make a decision concerning her relationship with the baby's father;
- To become a "good mother", which included:
  * Sorting out her problems with aggressive behaviour, learning and communication skills;
  * Developing parenting skills;
  * Learning everyday skills to ensure that the baby will live in a safe environment that included: budget planning, learning how to shop, and learning how pay the bills.

She made a supported decision-making agreement with two support workers – lawyer and social worker from RC ZELDA.

Tips and thoughts for trainers:

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[16] Dr Sandra Baum, Parents with Intellectual Disabilities:
http://www.intellectualdisability.info/family/articles/parents-with-intellectual-disabilities
[17] Ibid.
[18] McGaw, S. & Candy, S. Supported Decision Making for Women with Intellectual Disabilities // Parents with Intellectual Disabilities: Past, Present and Futures. Wiley & Sons, 2010. Pp. 137-154

Ask people to divide in small groups. One of the participants can remember a story of being raised as a child or having a child to raise. Ask groups to discuss these stories and draw on a separate piece of paper a support circle for parent/parents – who offered help, advice, who influenced the style of upbringing. Ask people to reflect how upbringing is happening in their cultures – who makes important decisions in these stories.

6.5   Decision-making regarding healthcare decisions – examples of good practice

Support in decision-making regarding healthcare decisions can involve informal decision making, e.g. like maintaining personal health in a good condition or improving it (e.g. living a healthy life style: having sufficient physical activities, following a proper diet, learning about daily hygiene and maintaining it; learning about sexual and reproductive health; learning about the consequences of smoking, drinking). Formal decision making can also be involved, like decisions around access to a health specialist, various medical procedures, giving consent to treatment, deciding to use or not use medication etc.

For any person (with or without disability) writing an advance directive regarding their healthcare preferences can be very useful. The aim of an advance directive is to help someone express their will and preference in advance – at a moment when the person is able to express his or her will and preference regarding their healthcare in future. In the context of mental health care, an advance directive or statement is usually prepared in written form and it includes the person's instructions on how he or she would prefer to be treated or not to be treated. An advance directive can also indicate which treatments or medications work well for the person and which ones the person does not want.

In the following sections we will describe two models – *patient trust person* and *a network contract* – both of them have been developed before UN adopted CRPD, but nonetheless these models can be considered as precursors of supported decision-making in current sense.

a) Person of Trust in mental health care (Netherlands and Lithuania)[19]

Person of Trust as a support model in mental health care was developed in the Netherlands during 1980's and it has been operating in each Dutch psychiatric hospital since 1994. The main function of a person of trust is to provide people with disabilities, who are undergoing inpatient psychiatric treatment, with advice and assistance regarding any issues regarding their admission and treatment in the psychiatric hospital. The Person of Trust helps the person with a disability have his/her rights respected in case the person has complaints by means of mediation. They can achieve this by providing the person with all the necessary information in order for the supported person to make informed decisions, and by identifying the shortcomings of the system. A Person of Trust is independent from the mental health care provider and he/she must support the person with a disability in his/her relationship with mental health care provider.

A Person of Trust follows several main principles: he/she should investigate each complaint of a person with a disability; he/she should always side with the person with a disability he/she is

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[19] The description is based on the research and materials on person of trust model obtained by RC ZELDA during its study visit in the Netherlands, carried out in 2010 and on written information, provided by the Lithuanian Disability Forum.

supporting; he/she should act only according to the wishes and consent of the supported person and all assistance provided by the Person of Trust should be confidential.

In case a person with a disability, while receiving in-patient mental health treatment, wants to file in a complaint, the Person of Trust can assist them to draft (in writing) the complaint and to submit it to the respective complaints' review body. Additionally, the Person of Trust can arrange the meeting and actively mediate and support the efforts to find a solution regarding issues raised in the complaint. If the supported person desires, the Person of Trust can refer the complaint to an external body or to his/her legal representative.

The Dutch Person of Trust model was replicated in Lithuania and implemented by NGO "Mental Health Perspectives" in Vasaros Psychiatric hospital of Vilnius between 2006 and 2010. According to the Lithuanian Disability Forum the most common areas where a Person of Trust was providing support during implementation of the model in Vasaros hospital, were:

- Voluntary and involuntary hospitalization;
- Questions about daily regimen at the hospital;
- Review of the diagnosis;
- Issues related to legal capacity;
- Lack of personnel, professional ethics of personnel and other structural shortcomings.

This support model has been proven to be effective in safeguarding human rights of people with disabilities hospitalized in psychiatric hospitals. Among the positive benefits, one can mention the empowerment of the person with a disability (power balance is equalized, i.e., in case of conflict/disagreement between the person and staff of the hospital, the person is not left alone dealing with the hospital staff team, but is supported by the Person of Trust).

b) A Network contract (example from Sweden)

This model was developed by Laila Gentzel, who has described her experience in the booklet "A Network Contract A tool for clarity and cooperation in recovery"[20]. After being hospitalized several times because of suffering from manic depression, Ms Gentzel together with her family, friends and mental health professionals developed a network contract, which aims "to prevent manic episodes or make them as light as possible"[21]. The contract includes the responsibility of Ms Gentzel, for whom it has been developed (e.g. to take prescribed medicine without trying to reduce it; to continue psychotherapy on a regular basis). In this case, if Ms Gentzel wanted to change her medication, then the network meeting would be organized in order to discuss this decision and in order for each network member to reconsider their own participation. The network contract also stipulates what happens and what each person from the network should do in case she cannot manage her own responsibilities, e.g. what should be done if she shows possible early signs of mania or if she becomes manic. The network contract also includes clear directives for treatment of a manic episode, including directions for the practical roles of each person in her personal support network, e.g. brother and a friend have accepted to take responsibility to pay her bills and give her some

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[20] Laila Gentzel, A Network Contract, A tool for safe recovery, University of Central England, Centre for Community Mental Health, 2006, pp. 67
[21] Ibid, p.28

pocket money. Other network members have agreed to water flowers, check mail, cancel the daily paper, organize a specific number of visits to Laila (for example every fourth day).[22] The network contract should be evaluated every year. Network members include the person for whom this network is created (Laila); specialists from the healthcare services (doctor, personal carer); a personal network of people who are expected to be active during the acute condition of Laila's illness and associated members whose only responsibility is to signal to the named person within the network if he or she recognizes a sign of mania. In aforementioned publication Ms Gentzel also included stories from her network (stories were shared by her friend, brother, personal carer and doctor), sharing mistakes made and what worked well.

Amongst positive advantages of having such a contract, Ms Gentzel mentions:

- Giving each person the responsibility to do certain things, which are clearly defined in the contract;
- Allowing each person of the contract to break the confidentiality code in order to improve communication about feelings and to agree on things to be done (the code of confidentiality is still valid outside of the network);
- Making communication simple by having the telephone number of all network members listed in the contract.[23]

Last but not least, Ms Gentzel has included in her publication advice for anybody who would like to create a similar network contract. She suggests that the contract should be short, but very clear and should include the person's (for whom the contract has been developed for) responsibility; the responsibility of family and friends and the responsibility of the mental health care service provider.[24]

6.6   Decision-making regarding education and work – examples of good practice

Decision-making concerning education – RC ZELDA (Latvia)

Sofia is a young woman with a disability. She has recently restored her legal capacity and her current support plan was aimed at supporting decisions regarding her education and her future career. The situation was complicated by the numerous conflicts in the family, where she was seen more like an irresponsible person, who cannot and should not live on her own. However, the family always took care of her, and all members have shown interest and eagerness to help with the planning. One of the most important inputs was made by one of her relatives, who while contributing to the plan, said that she admires most of all in Sofia her sewing skills, and that this is important to Sofia. Later Sofia agreed with that and said that sewing might become her future profession.

However, while describing herself, and what is important to her, Sofia constantly repeated that it is important to her to develop and to learn new, more complicated things – for example to study astronomy at school, while at the same time her family members said that it would be a waste of time for her and she needs to go and learn some profession instead. It became obvious when we

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[22] Ibid, pp.28-34
[23] Ibid, p.50
[24] Ibid, p.51

were filling the chart in the plan about negative and positive things in life – how Sofia sees it and how her family saw that: "What Sofia thinks – positive things in her life, what makes sense – to study something difficult and complicated; What others think – negative things in her life, what does not make sense – to study something Sofia cannot understand".

Later on this contradiction turned out to be the core of the family conflict. For Sofia learning difficult things in life was very much connected with her self-esteem – she was just finishing school after a long break in education and did not want to be considered a "disabled child" like her classmates – she was a grown-up woman. At the same time her relatives were having in mind very practical reasons – Sofia needs to get a profession as soon as possible, because she is an adult and all relatives that support her financially are already old.

Tips and thoughts for trainers:

Propose the participants to think for a couple of minutes of the role knowledge has in their life. You can ask some of the following questions: 1) What piece of knowledge was especially important for you to know in your life? (Practical or theoretical, a couple of examples) 2) How did you know that you have mastered this knowledge? 3) Who told you about this, taught you that knowledge? Who put most efforts in you, for you to learn this knowledge? 4) How do you use this knowledge nowadays in your life? 5) What would those people say or feel about you, having mastered and appreciated this knowledge in your life?

Ask participants to divide in small groups to share their experience and stories between themselves.

6.7 Development of a support network – examples of good practice

Appointing not only one support person, but developing a whole network of support is one of the variants of the implementation of supported decision-making. It can be a good option for those people who already have got strong connections in the community, and also if there is an aim of community mobilization around people with disabilities and their needs. As with the case of one support person, it is crucial for the supported person to choose all the members of the support network by themselves on the basis of trustful relationships. The other name for this practice is "Circles of Support" or "Circle of friends", and it was firstly introduced by the advocate for inclusion Marsha Forest. The person places people around him or her in the following circles that are stretching away from the centre, with the closest ones being the more resourceful and supporting for the person:

1. In the circle of intimacy are people who the person loves.
2. In the circle of friendship are the person's friends.
3. In the circle of participation are people the person knows such as colleagues, but who would not be close enough to be called friends.
4. In the circle of exchange are the people who have a paid relationship with them.[25]

One of the good practices described by the "Guide of promising practices on legal capacity and

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[25] http://trainingpack.personcentredplanning.eu/index.php/en/circles

access to justice" is the project "Network of support – Empowering People with Intellectual Disabilities", which was implemented in 2011-2017 by the Regional Society for Support of People with Intellectual Disabilities (RSSPID) in Bulgaria. Within the project, 53 persons with disabilities got the networks of support built around them, with 4 of them having successfully removed the guardianship from them in the court, provided that giving adequate support may be a better option than restricting legal capacity[26].

Another project that uses the approach of Circles of Support was launched by the Irish organization "Brothers of Charity Services Clare". As the organization by itself define the practice: "a circle of support is a group of people who join together in solidarity with an individual in order to work together towards realising the dreams and vision of the 'focus person'. <..> Essentially, Circles of Support are not about paid support. Members of the circle are there because they enjoy directing their time and energy towards real and positive changes in the life of someone they care deeply about".[27] The organization uses this practice in order to build the informal support networks around the families they are helping that will stay in their lives for good. The organization is avoiding paid people in the circles and tries to include people from different generations. The purpose of the circle and the vision of the person should be clear in order to find people who share the vision and are committed to reach this aim. The focus should be that the supporting person would be comfortable with slowly growing the circle, giving people around a possibility and time to know a person with a disability. The "Brothers of Charity Services Clare" are building these kinds of circles not only for one person but also for whole families[28].

6.8 Decision-making regarding the future – examples of good practice

Planning for the future is one of the major areas where people with disabilities need to make critical decisions about their lives.

Example of supported decision-making regarding decisions about the future – QUIP (Czech Republic):

Lucy is a young woman with an atypical form of autism, with learning difficulties and also behavioural problems. She talks or sings, but talking for her has different meanings than for people around her (about communication issues in supported decision-making – see below). Lucy has received a basic education, but could not move forward to secondary school because of her behavioural problems. There were also no possibilities for her to get the necessary everyday support she needed.

Her parents decided to launch a planning process for her, to arrange a support group and organize the best possible future arrangements for her life and studies – all that had to be organized with Lucy and her decisions in the centre.

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[26]http://www.firah.org/centre-ressources/upload/notices3/2015/bag_ajupid_uk_2015_bv.pdf, http://bapid.com/bapid/?page_id=108&lang=en
[27] National Annual Report 2011 Brothers of Charity Services Ireland: http://www.brothersofcharity.ie/pdfs/boc-report-2011.pdf
[28]http://www.fedvol.ie/_fileupload/Sharing%20Innovative%20Learning/The%20Decision%20is%20mine/Circles%20of%20Support%20NFVB%20June%202012%20-%20Martina%20Rynne.pdf

Three hours long planning session took place at Lucy's father's office, because it was a safe place for her. Food and drinks were served and large sheets of paper were attached to the wall and people were writing down: who attended the session and why, what they like about Lucy, what are important moments from Lucy's life, what is important to/for Lucy now and in the future, what kind of support she needs. Then the support persons altogether identified what works in Lucy´s life and what, on the contrary, does not work. Things that did not work according to Lucy´s will and wishes were prioritised and a plan was developed on what to do to ensure a positive shift in Lucy´s life. Tasks were set, including the deadlines for their fulfilment and names of people who would be in charge.

The main decisions that were made:

1) Learning programs were arranged for Lucy, favourite games and DVDs were provided to her, and places outside home to carry out current and new activities were found.
2) Contacts were established with volunteers and assistants who helped Lucy engage in newly prepared activities – fine arts, playing music, and English language. New activities were introduced and developed: dance and drama, learning Polish, employment training etc.
3) Setting up a blog www.svetlucie.wordpress.com was an absolutely key moment. It documents Lucy´s "painting" in the course of time, exhibitions, openings and events that are being prepared. By the time the next major planning session was taking place, 8 exhibitions had been organised (out of which 3 were collective ones). Lucy participated in contests and in the international internet exhibition of authors with autism. She donated two paintings to a charity auction organised in favour of the association which had been helping her for many years. Some of her paintings were sold at the auction of GAUTE real estate agency who has become Lucy´s patron. Some paintings were bought by individuals or organisations. Funds raised by such auctions enabled Lucy to continue her fine arts activities. New activities started in relation to the shooting of a time-lapse documentary "Up in the sky!". Lucy attended its public premiere in October 2013.

Later Lucy´s mum described the planning session as a major milestone for Lucy and for the family. *"For the first time in her life Lucy heard people using the polite form of address when speaking with her. She managed to name things which are important to her, what she needs now and what she will need in the future! She appreciated greatly the encounter of people surrounding her. She listened to what people were saying: what they admire about her, what they appreciate, and what they like about her. She perceived very strongly the presence of people who gathered because of her".*

It became evident that sometimes solutions can be surprisingly simple with minimal costs. By identifying and addressing current needs and goals a number of issues were resolved right on the spot.

All these events helped Lucy reinforce her ties and relations in the community, helped her realize what were her strengths and abilities, and find motivation for further activities. They have had a positive impact on her overall well-being. Lucy´s preferences and needs were identified, as well as her goals and concerns shown by her family and the people close to her. Joint thinking helped direct Lucy´s life to where she feels well and where she can contribute.

Tips and thoughts for trainers:

Here you can run a small individual exercise:

1) Tell the participants of the training to think about their future, all the important decisions they need to make in the next 2-3 years.
2) Then ask them to close their eyes.
3) Ask to imagine the place, where they could feel enough peace, comfort and safety to think about those important decisions in their life. Ask them to imagine that they are in that place. What does it look like? Where is it? What is surrounding them? What objects should be there to provide comfort?
4) Ask them to imagine the people that could be there for them, thinking about those important decisions. Who they are? How many? How would they welcome those people? How would they thank those people for being around for them?
5) Give the participants a couple of minutes to sit in this imaginary people in the safe place.
6) Ask them to open their eyes and share their experience.

7 Managing the supported decision-making process – good practice

7.1 Communication issues

Sometimes the supported individual does not use speech, or sometimes people say one thing, but their behaviour expresses an opposite message. Also people who do not have close contact with a person sometimes misinterpret his or her communication style, which makes it difficult to ensure that supported decision-making is being carried out effectively.

I have to shout – Dubali's story from the United Kingdom (CHANGE, UK)

Dubali: "My family, my sister and my mum help me understand things like housing and voting. When it's very important decisions, sometimes other members of the family interfere and don't understand what I mean. It makes me feel stressed and I have to shout! I often get the blame when something goes wrong."

To understand a person's communication style it might be very useful to use communication charts (an important tool from person centred thinking and planning) – both sides of the communication need to be able to comprehend the messages people are sending to those in their environment.

Once the chart is filled, it contains the information about what is happening right now in the person's environment and what message the person is trying to communicate about what he or she wants to do differently. Below you will find the example of using communication charts.

Using communication charts in supported decision-making – QUIP (Czech Republic)

It was decided to develop a communication chart for Lucy (see Lucy's story above), because people who provided support to Lucy often did not understand her behaviour. Lucy´s verbal communication is excellent; she has no problem with difficult foreign words. This ability of hers often confuses other people who automatically suppose that Lucy knows very well what she is saying and why. However, it is not true. We know what she is saying but we do not understand what she really means. This often results in an absolute misunderstanding. We have been training functional communication ever

since. In fact, she speaks continuously and when she is not speaking, she sings.

The goal of the meeting was to understand Lucy´s behaviour in various situations better and to figure out how people around her should behave in given situations to create the best possible conditions for Lucy´s wellbeing.

The communication chart was being developed on a large board. People put their heads together and identified situations in which Lucy does not feel good or her behaviour is not easy to understand for the people surrounding her. Support persons were writing down the description of Lucy´s behaviour – what they were seeing. Then they tried to figure out when such behaviour occurs, what triggers it or which circumstances play a role. They were thinking about what such behaviour can mean, how Lucy feels in those moments and whether she wants to tell others something. The last thing the support persons wrote down was how they should react in such situations so that Lucy feels comfortable. It was interesting how often different people interpreted the same behaviour differently and how their reactions differed. The discussion helped to clarify many things and they began to make sense. After agreeing on the meaning of a certain kind of behaviour the working table was turned into a communication chart which helps comprehend Lucy´s behaviour in various situations.

Communication chart:

Situation, circumstances:	Lucy is doing:	Lucy experiences and tells us:	We, people around Lucy, do:
In the evening or at night, especially before a full moon	Lucy is saying: "I will never sleep!"	Inner uneasiness signalling that she cannot fall asleep	We do not force Lucy to go to bed at the usual time, we try to create a calm and comfortable atmosphere, we are patient, we offer her calming tea, we put on calming music, gradually dim the lights, lower our voices until we stop talking.
Sudden noise, rustle, vibrations, unpleasant sounds in the vicinity (from neighbours or from outside), e.g. chopping, tapping, squawking, cracking in the radio	She says: "Pull him out from the wall by his legs!" "Put the furniture back and leave!" "Get out!"	Lucy is disturbed, upset, she does not like the sounds she hears.	If possible, we [prevent the sounds. If possible, we and Lucy go somewhere else. If it can't be done, we drown the sounds down by making a sound screen – radio, dishwasher, washing machine, extractor fan, vacuum cleaner – switching them on separately, then, depending on the situation, combining them.

Anytime	Lucy asks: *"When will I have my Prague Peace?"*	Lucy needs to be assured that she will see her lady doctor in Prague who helps Lucy tune up her body and mind.	
Anytime	Lucy asks: *"Can I take it from him?"* *waits for an answer, then: "No, just to borrow!"* *and then she goes: "And then give it back to him!"* *"You know it, you've seen it, I don't want to think about it, not imagine it..."*	Lucy needs to know that there is somebody there who she can speak to. She is starting a conversation.	She begins and is waiting for us to finish the conversation. When we don't react, she prompts the conversation.
Anytime	Lucy says quite vehemently: *"I'll swallow No.9!"* *"I'll swallow No. 1!"* *"Without 8 hours!"* *"It can't be done without time!"*	Lucy is uncomfortable; there is tension in her which is growing.	We answer: How would X know when he/she should come and see you?
During an activity (most often when painting)	Lucy says strongly: *"I do not leave the subject!"* *"I do not retreat from the subject!"*	Lucy tries to concentrate on the activity	We don't do anything

The support persons also developed a dictionary of words that explains the meaning of some expressions Lucy uses:

Expression:	Meaning:
Hedgehog	Uncle Jirka (his hair is cut short so that he reminds her of a hedgehog)
Ferdyš	Uncle Jirka´s tom cat
I am OK	I can work, paint, learn, I am fine
Don´t look at the back!	Hair cutting at the hairdresser´s
Podivín (stranger)	A place where something is wrong

Tombola /Tomboluňk (raffle)	Šternberk – the town where grandma Marie used to live for several years

The communication chart and the dictionary are living materials, which are being added to and updated in line with changes that occur in Lucy´s communication and behaviour.

The family has created a virtual space for Lucy where the above documents can be accessed by all the people who are in contact with Lucy. Each of them has access to the data to be able to share relevant information about Lucy. They can learn there what Lucy is doing, what is her activity plan and the places where she would be during the next period.

Tips and thoughts for trainers:

Lucy's story is very vivid. After you have told it to the group, it is the best time to practice in making communication charts. Divide the group in threes, one person is an interviewee (who is ready to tell about how his or her relative or close friend communicates), one is an interviewer, and one is filling the chart while listening to the interview. After filling the chart give it back to the interviewee, so that he or she could check if the information is relevant.

7.2 Dealing with risks and mistakes

Everybody has the right to make his/her own decisions, including the right to make mistakes. Support people or networks can have an important role in explaining possible risks of potential decisions a person would like to make.

Example of identifying and managing risks in supported decision-making – QUIP (Czech Republic)[29]

Elena, 34 years old, has experienced two major mental health episodes in the last twelve years. This resulted in long term hospitalisation in a psychiatric institution. During the second episode especially Elena spent all her saved money and even had to borrow an additional sum. Most of Elena's expenses were for goods and services unnecessary to her needs at the time. Elena´s parents successfully returned a portion of the ordered goods and cancelled contracts to some of the services. Consequently, her parents applied in court to limit her capacity to handle large financial sums. However, the court went a step further and instead limited Elena's capacity to act in all legal transactions and contracts except for managing a maximum sum of CZK 1,000 per month. Her father was accordingly appointed her legal guardian. Nonetheless, Elena still continues to pay back her debts in connection to her excessive and unnecessary expenditure to-date.

Following the last five years after the decision limiting her capacity, Elena's health condition stabilised. She followed her medical prescriptions and regularly contacted her psychiatrist. Because of her improved condition Elena decided to apply in court for a restoration of her capacity. The main reason for her application was that she felt stigmatized in her attempts to look for a regular job

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[29] Description was prepared according to article written by Milena Johnova & Dana Korinkova, Implementation of Article 12 of the Convention on the Rights or Persons with Disabilities, The role of social workers, May 2015.

outside of sheltered employment. Elena also received advice from her therapist in her sheltered living, a lawyer and social workers (one of them was from QUIP) and decided that her application for legal capacity restoration will be complemented with her support plan relating to her mental health and her finances.

After Elena identified what is important to her, what are the main people in her life that she trusts, and after the opinions of these people about what is important to Elena have been heard, it became possible to talk openly about the risks connected to her mental health and about the financial issues that might be a consequence of her decision to restore legal capacity.

In the field of mental health these important areas where discussed, and the support persons where identified:

What kind of help Elena needs	What is necessary to do and who shall do it:
To recognize the episode onset at the beginning so that it can be stopped without hospitalisation	It is necessary to stay in regular contact with Elena – to see her and to note how she is doing. Elena will continue to be in regular touch with her family, mainly her parents. Within the community, in which Elena lives, she is in daily contact with the N. family. Elena agreed with her parents and N. family that they would monitor her situation.
To be conscious of warning symptoms showing the episode arrival.	It is necessary that people close to Elena warn her when they notice warning symptoms. Elena agreed with other people from the community with whom she is in daily contact and with her family that they will alert her of warning symptoms.
To contact the psychiatrist when the episode is coming.	The psychiatrist can help Elena to master the situation without hospitalisation. Elena agreed with her parents and the N. family to offer her their help visiting the psychiatrist, i.e. to accompany her. In case Elena is losing objective evaluation of her situation, she would need one of the above mentioned persons to call the psychiatrist. For this purpose Elena presented her psychiatrist to N. family. Parents are also in touch with the psychiatrist.
In the field of mental health these important areas where spoken about, and the support persons where identified:	
To get advice in banking operations	Mother will help, when help is needed
In case Elena, due to the possible new episodes, concludes unfavourable contracts, she needs the help to negotiate the cancellation of contract with companies or the return of money back.	After the restoration of her capacity Elena shall authorise her mother and one spouse from N. family, to apply the invalidity of legal action of Elena that would cause damages to her, if she, due to her current health situation, is not able to solve the invalidity on her own. This could be done by giving them full powers or via an anticipatory declaration.

8   Peer support in supported decision-making

Personal Ombudsman (Sweden)

Peer support has proven itself as very helpful and effective in supported decision-making also. For instance, Sweden has established a nation-wide system of Personal Ombudsman (PO) since 2000. The PO provides support in decision-making for people with psycho-social disabilities.[30] The PO can assist supported people in taking control of their own situation; it can identify care needs, draw the action plans and ensure that the supported person receives the necessary help.[31]

One well-functioning PO service is provided by an NGO – PO Skåne, which was founded by a user-led organization – the Swedish National Association for Social and Mental Health, and by a family organization – the Swedish Schizophrenia Fellowship Association. The organization is totally managed by people with psycho-social disabilities. The PO focuses on supporting those with psycho-social disabilities who are most hard to reach – they can be homeless or can live isolated. The PO works only with the consent of the person he/she supports. It might take several years to build a trust relationship to be able to address essential matters.

The PO should be able to support the person in all kind of matters. According to previous experience of running PO service, the first priorities of the supported person are usually not housing or occupation, but existential matters (e.g. why should I live? why has my life became the life of a psychiatric patient? do I have any hope for a change?), sexuality and problems with relatives. A PO

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[30] Centre for Disability Law and Policy, National University of Ireland, A study on the Equal Recognition before the law. Contribution towards the Council of Europe Strategy on the Rights of Persons with Disabilities, Council of Europe, March 2017, p.66, https://rm.coe.int/168070d7f5.
[31] Ibid, p.66

must be able to spend a lot of time talking with the person he/she supports also about these types of issues[32].

The publication "A New Profession is Born" – Personligt ombud, PO" emphasizes that the task of the PO is to help the supported person to express his/her needs and therefore it is important that the PO and the supported person have a good relationship and they trust each other.[33]

9 Conclusions

The good and promising practices collected in this guide are just a start, as supported decision-making in most countries is still a relatively new mechanism.

We are aware that there are significant areas of life where we still need to make the supported decision-making model better available to all people with disabilities: e.g. genuine and effective support is needed in decisions regarding medical treatment and use of medication, in decisions regarding forming a family and having sexual relationships, parenthood etc.

If you know about practices that could be considered good or promising in these or any other areas of life, that match the criteria stated at the beginning of this guide, please send the descriptions to the authors of the guide at: zelda@zelda.org.lv

10 Useful Resources

10.1 General information on supported decision making

Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014), Article 12 (Equal recognition before the law), Geneva: United Nations, 2014, http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/1&Lang=en

Inclusion International, Independent but not alone: A Global Report on the Right to Decide, 2014, http://inclusion-international.org/wp-content/uploads/2014/06/Independent-But-Not-Alone_-final.pdf

Mental Disability Advocacy Centre, Supported Decision making: an Alternative to Guardianship – http://mdac.info/sites/mdac.info/files/English_Supported_Decision-making_An_Alternative_to_Guardianship.pdf

Guide of promising practices on legal capacity and access to justice – http://www.easpd.eu/en/content/ajupid-european-project-collection-promising-practices-access-justice-persons-disabilities

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[32] Description of PO-Skåne support service is prepared according to information provided by Maths Jesperson, available on PO- Skåne website – http://po-skane.org/in-foreign-languages/.
[33] Socialstyrelsen, A New Profession is Born – Personlight ombud, PO, 2008, https://www.personligtombud.se/publikationer/pdf/A%20New%20Proffession%20is%20Born.pdf, p.16

World Health Organization, "Realising supported decision making and advance planning: WHO QualityRights training to act, unite and empower for mental health (pilot version)", 2017 – http://apps.who.int/iris/bitstream/10665/254808/1/WHO-MSD-MHP-17.8-eng.pdf

Choices. A platform on supported decision making – http://www.right-to-decide.eu/

10.2 Examples of pilot projects of supported decision-making

Australia:
1) South Australia Supported decision-making project – http://www.opa.sa.gov.au/resources/supported_decision_making

2) ADACAS Advocacy – Supported decision-making project – http://www.adacas.org.au/media/1083/spectrums-of-support-final-20130911.pdf

Website "Support my decisions" – http://www.support-my-decision.org.au/

Bulgaria:
Bulgarian Center for Not-for-Profit Law (BCNL) "Supported Decision-Making or how people with intellectual disabilities or mental health problems can live independent lives" (2014) – http://inclusion-international.org/wp-content/uploads/2014/01/PodkrepEN.pdf

Israel:
Supported decision-making service model, implemented by Bizchut, the Israeli Human Rights Center for People with Disabilities – http://bizchut.org.il/he/wp-content/uploads/2017/06/Support-system-Model-Bizchut.pdf

Czech Republic:
Pilot project "Black and White", implemented by QUIP – http://www.kvalitavpraxi.cz/projekty/probihajici-projekty/cerna-a-bila/ (in Czech) http://www.right-to-decide.eu/2014/10/black-and-white/ (in English)

Latvia:
1) Pilot Project for Introduction of Supported Decision-Making in Latvia, implemented in period of 2014-2016 by RC ZELDA – http://zelda.org.lv/en/zelda/pilot-project-of-supported-decision-making

2) Project "Development of the description, organization and financing procedure for the support person service, implementation of the support person service pilot project and evaluation of the results of the pilot project", ongoing (July 2017 – December 2020), implemented by RC ZELDA – http://zelda.org.lv/en/news/rc-zelda-commences-work-on-the-development-and-implementation-of-the-support-person-service-2619

3) Videos

Michael Bach (Canada) – Video "Speaking differently at Disability and Decision Making" – https://www.opensocietyfoundations.org/voices/looking-differently-disability-and-decision-making

Helen Sanderson Associates – Video "Decision Making Agreement" – http://helensandersonassociates.co.uk/person-centred-practice/person-centred-thinking-tools/decision-making-agreement/

The UC Davis MIND Institute (Medical Investigation of Neurodevelopmental Disorders) – Video on supported decision making – https://www.youtube.com/watch?v=i0jd-J9Lozs

From YouTube channel of Kirsten Sanchirico, Person Centred Thinking Trainer – Informed Decision Making Training video – https://www.youtube.com/watch?v=k2WKPMG9kNc

Bizchut, the Israeli Human Rights Center for People with Disabilities – Videos on Article 12 – http://bizchut.org.il/en/551

4) Circles of Friends/Circles of Support:

Resources (books, DVDs on circles of friends) – http://www.inclusion.com/circlesoffriends.html

Circles Network. Circles of Support – http://www.circlesnetwork.org.uk/index.asp?slevel=0z114z115&parent_id=115

Community Living BC, A guide for Self-Advocates Support Network – http://www.communitylivingbc.ca/wp-content/uploads/Support-Networks-A-Guide-for-Self-Advocates.pdf