Participating in my life: Hear my Voice!

Inclusion Europe

REPORT OF A PROJECT LED BY INCLUSION EUROPE
Respect, solidarity and inclusion of persons with intellectual disabilities

THE "HEAR OUR VOICES!" PROJECT PARTNERS:

- Inclusion Europe: www.inclusion-europe.org
- Eurochild: www.eurochild.be
- The Cedar Foundation, Bulgaria: http://www.cedarfoundation.org/en/
- QUIP, Czech Republic: www.kvalitavpraxi.cz
- Down Madrid: http://www.downmadrid.org/

And in collaboration with Lumos: www.wearelumos.org

*“ Diana knows
quite well what she wants,
and when she really wants
something she will say the
respective word too.
- Milena ”*

Introduction

At schools, in child-care settings, and at home, we – families and professionals – tend to decide what is best for "our" children; this is even truer when the child has an intellectual disability. We are the ones who "know", the ones who decide and set the frameworks and the objectives. Traditionally, throughout this process, children often have no voice. The UN Conventions on the Rights of the Child and on the Rights of persons with disabilities have been carefully analysed by professionals, teachers, families and people dealing with children and young persons with disabilities. However, in the end, little attention has actually been paid to the right of children to participate.

Research conducted by Inclusion Europe, together with Eurochild and the Charles University, has shown that children with intellectual disabilities are even less likely to be involved than their non-disabled peers, in that they participate less frequently in many kinds of activities in general. Having friends, participating in social, cultural or sports activities, and participating in decisions which affect their lives are all healthy ways for children to become engaged in society, reflecting essential aspects of their social and personal development. However, participation in these activities – or uncovering opportunities to participate in these activities – does not always come easy for some children, especially when they have a disability.

Children can play a significant role as social change agents. Building children's ability to participate, taking into account their age, maturity and context, giving them the opportunity to be listened to, and to express their opinions on matters that affect them, all help them to mature, to gain self-confidence, and to experience essential feelings of self-determination as they undertake roles and responsibilities while continuing to respect adults. When children learn to communicate opinions, take responsibility and make decisions, they improve their skills and prepare for their adult life as equal and competent citizens. Again, these crucial benefits rarely reach children with intellectual disabilities.

Through the project "Hear Our Voices!", we intended to start bridging the gap between children with and without disabilities, by training and teaching children with intellectual disabilities to participate in various matters which affect them directly, so that they can begin to be masters of their own lives. We are guided by this principle that it is essential to empower them and provide them with the necessary support, skills and knowledge to participate in all areas of their life. They need to know how to enjoy the same rights as others, and they need to feel that their voices count.

This publication describes the work done in Bulgaria and in the Czech Republic with children living in small group home settings, and in large institutional settings. In it we aim to share promising practices from other countries, with parents and professionals who really want to make the right to participate a reality in their daily work. The publication looks at both individual and collective participation.

Because child participation is never a straightforward process, we have included our hesitations, lessons learned and challenges as well as successes and useful tools and methods we have used over the past year and a half of implementation.

We hope that the readers will find in this book both inspiration for change and concrete ideas, so that they may take concrete steps to ensure that all children with intellectual disabilities can participate more actively in their own lives.

DEVELOPING DECISION-MAKING AND PARTICIPATORY SKILLS IN MY LIVING ENVIRONMENT

The Cedar Foundation, a Bulgarian child rights organization working to eradicate the outdated institutional system of care, manages four small group homes (SGH) for children and youths with intellectual disabilities – two houses and two apartments – in Bulgaria. The houses are located in a residential area and are surrounded by a big yard, each hosting eight children. The apartments are located in different parts of the town. Four young ladies reside in one of the apartments, and in the other – two young men and two young women. A team of social therapists works in each SGH, providing 24-hour support to the children and youths in their day-to-day activities. Each team has a leader who is responsible for the daily operations of the home and who ensures that the highest standards of care and support to clients are maintained. Additionally, two social workers are actively involved in supporting the clients from all SGHs. They facilitate the services on a daily basis, keep the records, and liaise with all external specialists who assist the SGH clients. They also provide assistance to the teams whenever new work practices are introduced.

The overarching goal of the SGH is to provide an environment which is as close to the family setting as possible, giving children and youth the support they need to acquire the skills necessary to live a full and independent life. An integral part of this support includes nurturing their capacity to make decisions, and promoting their proactive involvement in the process of planning their own lives. These processes require significant time and persistence, in view of the fact that all of the SGH clients come from large institutional environments, in which they were deprived of the chance to develop decision-making and participatory skills.

I. "She started feeling she was important and part of something"- Milena

Diana is seventeen and has been living in the small group home setting for four years, together with another seven girls and boys. Since moving from the institution, she has been learning to pronounce some words, and is already able to ask for something to eat and to look for the persons who are closest to her. She loves to give a helping hand in the household, arranging the food supplies for the day, cleaning the table, and helping with the cooking. Diana has developed good personal and general hygiene habits and demonstrates substantial progress in her emotional development: she manages her own emotions, makes choices, and is responsible for her personal belongings.

The work with Diana under the **"Hear Our Voices!"** project was aimed specifically at laying the foundations of awareness and a sense of 'ownership' regarding her own life: That is, knowing that she is entitled to take part in decision making which directly affects her. We, as adults, are tasked with guiding her in this process, to provide to her the information needed, in an accessible form, and to encourage

Today Diana is a much more self-confident young lady who is able to say or show what she wants. She stands by her desires, yet handles the limitations set by the persons supporting her. She enjoys a new pink room, painted and decorated to her own taste.

In the beginning Diana did not participate, got easily distracted, and failed to show interest in individual work. Observations indicate that as results started to become visible – after having chosen herself the colour for the walls of her room and having seen this happen – she became more proactive in choosing subsequent changes for the room.

" Diana is seventeen and has been living in the small group home setting for four years, together with another seven girls and boys. "

her to make decisions which protect her safety and are in her best interests. An especially important aspect is to encourage her in the efforts she makes, regardless of their outcome.

One of the major objectives of our work was to show the SGH clients that they have the capacity to change their literal and immediate surroundings – they are able to decide if they want to redecorate their rooms, and how to change them. With Diana, we began by providing her with different pictures of rooms. We thought that upon seeing finished rooms, she might like one and tell us. We got twelve different examples of rooms for children and young people and uploaded them on the computer Diana and Milena[1] used to work on together. Milena had some prior talks with Diana in her room, explaining to her what was about to take place and prepping her for making the choice. Diana rejoiced, her face beaming, and clapped her hands.

> " We decided to have one file displaying all of the rooms at once. "
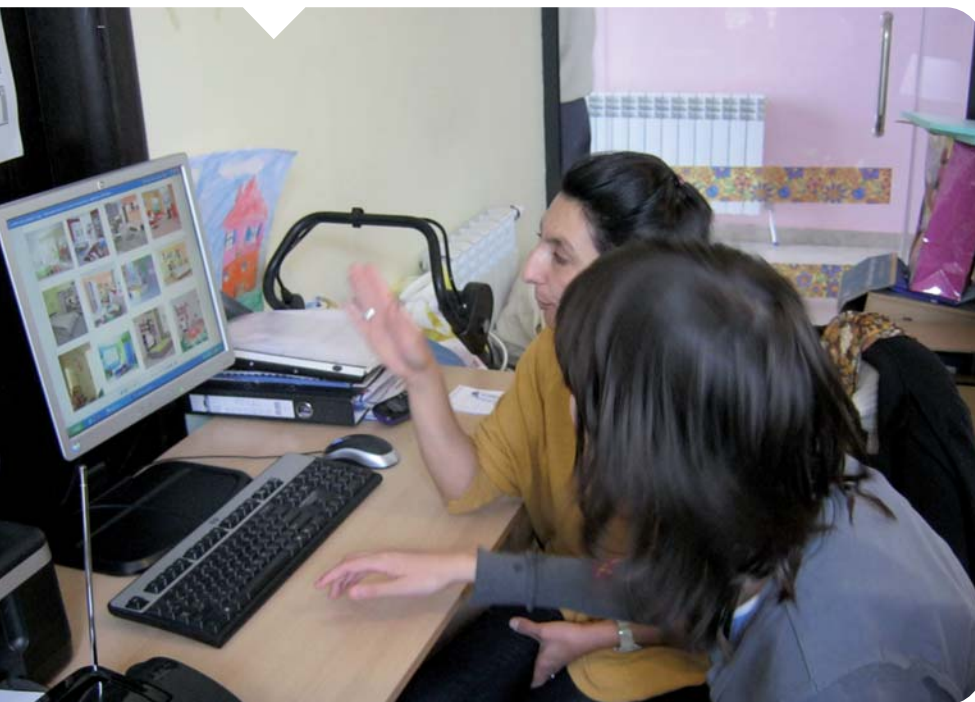
The next step was to run the pictures on a slideshow for Diana to see. After her first attempts, Milena suggested that we changed the way we showed the rooms. In her words, Diana initially came to like some of them, but at every restart of the slideshow she would express different opinions. Milena thought that the reason lied in that she could not have a look at all options at the same time and found it difficult to remember the previous picture and then to compare it with the one that followed to eventually make her choice.

[1] Milena is one of the staff people who work on a focused and personalised basis with Diana.

We decided to have one file displaying all of the rooms at once. Here again we failed to properly get Diana's attention. We concluded that the pictures of fully furnished and decorated rooms contained too much information and detail for Diana to fully grasp.

The work with Diana continued over a period of over three weeks. During this time, Milena and the social worker discussed the upcoming changes with Diana on a daily basis. Due to difficulties in Diana's concentration, such sessions rarely lasted longer than several minutes, but the staff took care to utilize every appropriate occasion to bring up the conversation. For example, whenever Diana entered the social worker's office, she would be prompted: 'So, you are here because you want to draw? Look, here we have the different colours of pencils. They are different as are the colours of the walls of your room.' Then Diana would be taken on a tour to see several different rooms, talking about their colours. When we utilized this method based on association with everyday life, we discovered that when we discussed something, Diana's attention was more focused and her interest would linger. This prompted us to undertake the process more slowly, addressing one change at a time, beginning with only the colour of the walls. After the walls were painted, we would move on to do some curtain shopping and then choose a bedcover.

We got samples of paints from the store and brought them to Diana. We wanted to have the samples next to the walls of her room, so that she would know that she was to choose the colour for them. We took Diana to her room, and Milena verbally reminded her of what had taken place over the previous few weeks. When Diana feels confident and relaxed, she easily smiles and readily shows others what she likes, taking the hand of the person next to her and pointing it to the desired object. This time she smiled, and whenever she heard the word 'wall,' she would touch the wall next to her bed. We produced the samples. She got filled with joy, started clapping her hands and laughing. Her behaviour indicated that she already knew what we wanted from her and she felt confident.

Diana loves pink. She would often choose her clothes in many different shades of pink. Therefore, it came as no surprise that she

picked two shades of pink for the walls of her room.

When the time came to have the walls of the room painted, we proposed to Diana to take part. She would not go anywhere near her room. We made several attempts to talk her into helping, but eventually decided that we had to respect her wish. When her room was ready, Diana could not wait to go in and immediately demonstrated how pleased she was. She rejoiced, clapped her hands, sat on the bed and started jumping.

The next step of our work related to the make-over of the room was to take Diana shopping for some curtains. In order to prepare her, we took her to the window to show her that the old curtains had holes and faded colours. Upon asking whether she felt like doing some shopping, Diana got excited, but when we passed by the big grocery where we would usually buy food, she was surprised. We explained to her once again that we were not going to shop for food, but for curtains instead. Upon going into the shop, it was necessary to have Diana spend some time there; we had to explain to her what the different rolls of fabrics piled there were for until she finally relaxed. She started pulling at pink fabrics only. The shop assistant took out all the fabrics she wanted to see. We chose some appropriate fabrics with the right thickness and set them aside. Diana stood and watched with great interest. We unfolded the fabrics and invited her to step forward and

DIANA:

Step 1: Choosing what her whole room would look like, using set of finished rooms.

Confusion, lack of interest, inability to manage large amounts of information.

Step 2: Breakdown of the process: Changing individual items in her room.

1. Paint Samples
2. Curtain samples
3. Bedcover samples

Starting feeling confident and happy with the decisions taken.

We promise:

- To provide Diana with secure and calm surroundings in which she is not pressed for time, there are not too many people around, and we are not driven for quick results.
- To simplify the tasks given her as much as possible, so that she is able to grasp everything and feel confident in her participation.
- To provide information in small steps, with no excess details.

Diana promises:

- To continue working with us.
- To take part in the activities we offer her.
- To keep showing us what the best approach to her is.

choose. After a slight hesitation, she took hold of one and turned to leave the shop with it. It was crystal clear that she wanted to take home this fabric.

The choice of bedcover and sheets was made much faster. We believe that this was because Diana comes into direct contact with bedcovering on a daily basis, and she was much more familiar with them compared to curtains. Upon entering the store, she liked the pink set the most.

What Diana thought us was that whatever work plans we might devise, she had her own pace, took her own time, and when we really began to observe her reactions, there was much she could show us. She is able to understand just as anyone else; we just needed to find the way to demonstrate to her the things we talk about. We realised that when the picture is free from excess details, when the process was simplified and when the guidelines were clear, then Diana managed the task perfectly. We also realised that relaxed surroundings made Diana feel confident; when the tasks we gave her were not too complicated she would make efforts to crack them, she was happy and confident in her actions. And the positive evaluation and the clearly demonstrated joy on our part were the stepping stones we used in every further stage of our work with her.

II. "I choose what I want to eat!"

If we serve something he wanted for dinner, he is so happy, clapping his hands and expressing his joy. If the food was not something he wanted, he again would make it clear that he has noticed this.
- Dessislava[2]

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[2] Dessislava is one of the staff people who work on a focused and personalised basis with Ivan.

Ivan is a fourteen-year-old boy, smiling, mischievous, and full of energy. He loves to play with his best friend in his house, to listen to music and to sing. He has a difficult time sitting still for very long. He loves children's songs, and usually when he speaks, his words run as a melody. He is very good at expressing what he wants and where he wants to go through signs and vocalisation. He knows the names of the children and the staff at his home. He is able to help with the housework – to make pizza dough, to put the dishes in their places, to set and clean the table. He enjoys being active and a part of everything that happens around him.

The aim of the second stage of our pilot project was to implement a comprehensive system wherein clients may help choose the meal options in the service. Typically, the menu is prepared one week ahead, supplies are bought, and food is cooked on-site. All of this happens with the participation of our clients, according to their ability and willingness. In view of the specific organisational arrangements, we wanted to have a system which would promote maximum involvement on the part of children in decision-making and be as close as possible to the family environment. Therefore we designed menus containing all the dishes that our clients ate and cooked. We took pictures of each dish ready in the pot, or in the serving plate, and put together folders.

Initially the intention was to have all the children, Ivan included, sit and participate in the designing of the menu for the upcoming week and have them decide what they wanted to eat. As with the work with Diana, we here too had a strict plan in the beginning: a few days of preparation with pictures, followed by attempts to involve Ivan and the other clients actively in the designing of the menu. At every meal we had the team member on duty sit by Ivan's side, open the menu and show the picture of the served dish. They were to demonstrate to him that the dish in the plate was the same as the dish in the picture. Ivan would not always respond with interest; rather, he acted annoyed that we would not let him eat his meal in peace.

The next stage, according to the plan – participation in the designing of the menu for the following week – was to have the member of staff on duty sit with all of the children and use the photos of dishes from the folder to give them the opportunity to choose what they would like to have the following week. Of course, there were different opinions, but we felt that one week was enough to have the wish of each child satisfied. After beginning the process, however, we saw that if we placed five pictures before Ivan, he would fail to select any, but if we placed only one picture and asked him whether he would like to have the dish, he would readily agree and be happy. We assumed that one possible reason was because there was no good connection in place between the choosing of the picture and the receiving of the real dish, and that there was no way to establish such a connection if Ivan opted for his favourite soup on Monday morning and got it for dinner Friday night. In other words, the time-span between the act of choosing and the result was too long.

There is much more to the applied method of choosing food than the mere selection of food – it helps nurture discipline, a habit of observing rules, and, last but not least, especially for Ivan, a sense of being a master of what happens to himself.

because if one day he had the chocolate wafer, he would have to choose from the crackers and the fruit on the following day, and eventually have the fruit on the third day. The second situation was more difficult to handle because he would get angry with not being allowed to have all three. Here we worked not only on making choices, but also on observing rules. We staged alternative situations requiring patience to get something or choosing only one item from a selection of two – be those activities, games or places for going for a walk.

In view of his wilful character, Ivan needed time to come to abide by the rules. However there is already great progress, and he does not get as angry as before if he fails to get right away what he wants. There is much more to the applied method of choosing food than the mere selection of food – it helps nurture discipline, a habit of observing rules, and, last but not least, especially for Ivan, a sense of being a master of what happens to himself.

Together with the work related to the choice of afternoon snack, we continued to build the link between the pictures and the food, yet Ivan continued to ignore the photos, expecting instead that we would make the selection. Therefore, we decided to keep the practice of having a menu for the week, shopping in advance, but letting the children decide on the immediate meal to be served on any particular day. Every day after lunch we place on the table pictures of the options for dinner. Each child, Ivan included, has the opportunity to say/indicate what they would like for dinner, the dish with the majority of votes 'winning' and the picture of this dish being posted on the refrigerator for everyone to see.

There is a lot of hard work ahead of us to develop the concept of 'voting' on menu

IVAN:

Step 1: Choosing menu for the following week.
Folder with pictures of dishes.

No solid connection between the choice and obtaining of the result.

Step 2: Choosing immediate afternoon snack.
Real food and pictures.

Nurturing discipline and good association-based link between an item and the image thereof.

Step 3: Voting on dinner for the same day from available options.
Pictures of the options for dinner.

Real choice and coming to realise the consequences of the choice.

Therefore we made two adjustments in our approach. First, we decided to have the staff member on duty show the picture of the served dish in a way which did not interfere with the meal itself, i.e. upon serving of the dish, they were instructed to show the picture beforehand and to verbally identify it. The other change we decided to try was to begin by having our clients decide what to have for their afternoon snack. Since afternoon snacks are ready-to-eat and do not require prior cooking, it was much easier to show to Ivan the real items, rather than pictures, and give him immediately what he has chosen. Here, we faced yet another difficulty but we knew it would simply take time to help Ivan get accustomed to the rules. Whenever we placed a chocolate wafer, fruit, and crackers, he would very seldom opt for the fruit, or he would want to have two things at a time. We did not worry much about the first situation,

He would always make it clear with his behaviour that he is aware of being part of making the dinner and not just eating what he is served. - Dessislava

options, as well as in applying the same method to selecting lunches. Thus, step by step, our clients will be able to design a full menu for the following day, perhaps eventually for the following week. And together with the power to choose one's own food they are coming to realise that their opinion matters with respect to issues much more important to their personal lives. Because the choice of meals affects all the children who cohabitate with each other, the issue of human interactions comes into play as well: Questions such as 'How to be tolerant to the choice of others?', 'How to negotiate in order to get what I want', 'How to learn to be patient' come up spontaneously, and through the experience and emotions attendant upon them, are slowly being addressed.

We promise to provide to Ivan:

- A relaxed environment with few distractions.
- Leaner information: Few details in connection with available options.
- Quick obtaining of the result of the decision taken.
- Continued work on what it means to vote for something in a group..

Ivan promises:

- To continue having fun with us.
- To surprise us with the progress he makes every day.
- To stand by his position.

III. "We decide!" or How to build a Client Council?

One of the houses is home to seven children and one young person, each with their own unique personality, skills, and desires. After repeatedly asking ourselves the question of how to engage children at a higher level of decision-making, we developed the idea of establishing a Client Council to represent clients, to protect their interests, and to serve as a conduit for proposing changes in the arrangements of life in the house. We realised that it would be easiest for us to organise the establishment and the operations of such a Council. It is easy to fall into the trap of thinking that we, as adults, and moreover – as professionals, tend to know what is best for our clients, that we can say who would be on that council, set the rules and steer the meetings. However, after discussing many ideas within the team and with outside consultants[3], we chose a slightly different path, committing ourselves instead to begin with trying to truly understand the group, and to help our clients experience what it means to be part of a larger collective and to be responsible for others. This path was certainly longer than we originally anticipated, with more unknowns than we hoped for, but we are confident that it has been the right approach.

In order to start nurturing these concepts in the clients, we developed and began engaging them in a daily activity called Circle Time. Circle Time consists of morning and afternoon sessions where all the residents from the house

get together and discuss upcoming events and daily tasks and – at the end of the day – share the way they feel.

Circle Time works as such: Every morning the social worker gathers the clients in the sitting room, where they discuss different aspects of their day, displayed visually on the whiteboard. They begin by going through the staff members on duty, the day of the week, the weather, all the while the children taking turns placing the pictures corresponding to the topics discussed. This is an easy way for everyone to be able to participate. Next, the day's activities are discussed. There are individual discussions with every child – the mandatory activities for the day are enumerated, such as going to school, to the Day Centre, or the Centre for Social Rehabilitation and Integration, followed by a listing of any elective activities. Children are free to choose whether or not to take part in various activities, such as taking care of our small pets, working in the greenhouse, gardening, or taking walks.

At the end of the day, the children gather again and discuss how their day has been. We focus on encouraging children to evaluate their own experience themselves; some of them express this verbally, while others use the drawings of a happy, sad or angry little face. If someone is not happy, we try to understand what the reason is and search for a solution together, as a group. For example, once one

Children already participate actively in the activity – 'actively' meaning a different thing for each of them. For some this means that instead of doing everything and saying what will happen with each one, they patiently wait for their turn and follow rules to respect the desires of others. For others, this means that whereas before they would isolate themselves at the other end of the room, totally indifferent to the surrounding world, now they either come over and sit with the others or at least watch what happens, and when their turn to choose an activity comes, they gladly do so. We are aware that this is far from having a full-fledged Board of Clients, yet if all our clients fail to realise the importance of their participation as equals, or if they fail to grasp, at least subconsciously, that they are part of a group in which there are some rules, then the engagement of anyone in the Board would fall short of being effective and useful.

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[3] The Cedar Foundation would like to thank Aneta Teneva from the Lumos Foundation Bulgaria for her advice and expertise on these matters especially.

When we started, the children who were already quite active continued as so, while the ones who typically were not willing to participate in group activities continued to stay out. After about three months, a change began to take place – the more active children began more consciously to observe the rules, while all the rest began participating in their own way by sitting on a chair next to the white board, by handing over a picture, smiling, shyly tilting their head or uttering words the moderator used.

" *The children of one of the Small Group Homes, participating in the Circle time in the morning.* **"**

of the boys was unhappy with not being able to feed the animals, although this had been his choice for the day, but the labour therapist had mistakenly recorded a different activity instead. We asked him what needed to be done in his opinion and he said that when someone chose a picture, the social worker should tell the other members of staff what everyone chose to do for the day. We asked all the children whether they agreed to this and they said 'Yes.' To help every child understand the arrangement, in the following mornings, whenever someone chose something, we always remind them that we would advise the relevant staff member responsible for the respective activity. In a few days' time, even the children who do not express themselves verbally started to clap their hands and to point at the picture of the respective staff person. We interpreted that as a sign that they understood the procedure.

" *When someone wants something and I cannot understand what this is, they would take me to the board and show me a picture of what they expect to happen to them.*
- Elena [4] **"**

In the course of the work, we concluded that in order to ensure sustainability of established relations between the clients and the Circle Time leader, he or she needed to be always one and the same person. Replacements needed to take place only by exception. The time spent with certain clients leads to building of bonds, to nurturing of habits and rituals in communication and interaction, in turn making everyone feel relaxed and confident.

Not all clients expressed interest toward group activities, and we hesitated to persist at the risk of having the client 'close up.' Overtime, by allowing them to progress at their own pace, the clients who stood aside began slowly coming closer and following with interest what was happening. Other clients got quickly accustomed to the 'pictures' (as they came to dub them) and were unwilling to give up and part with roles which they had already assumed. Thus we ended up with two distinct challenges – how to pique the interest of half of the children and to engage them with more than a glance, and how to 'temper' the overexcitement of the other half of the children, so that everyone could step in.

[4] Elena is the staff Team leader at this SGH.

Children celebrating 1st of June

We decided to try allocating tasks: 'Today you will remove all of the pictures we will not need. You (turning to another child) will tell us the date and the day of the week today,' and so on. Thus, again we realised that with the help of straightforward rules and simple tasks, everyone felt confident with respect to their skills, no one felt embarrassed, no one interfered with others' expressing themselves, and everything ran more smoothly. 'Shy' children got the chance to speak up, to look at a given picture, to dance with the social worker if they wanted to, before they posted the picture on the board. And they could do this without being pressed by the energetic nature of others. Meanwhile the 'active' children learned to wait their turn, to respect the chance of others to express themselves as well as the wishes of others with whom they shared a home.

Once we achieved this balance, it was time for the next step, making a collective decision. International Children's Day was around the corner, and this was a wonderful opportunity to have the children organise a fun activity, which they could experience and enjoy very soon after discussing it.

In order to show them different options for how we could celebrate the holiday, we produced pictures of past festivities with various activities. We felt that the festive occasions they had experienced in the past should have left an emotional impression in the minds of our clients. Our hope was that the photographs would prompt our clients to remember their experience and they would select the activities that made them happiest. Over almost two weeks, every morning we talked about the upcoming holiday – we described what the pictures portrayed and discussed the options of having each home

Children working on the participation agreement

celebrate on its own or get together for the festivity instead. In the end, they unanimously decided to get together outdoors, to have contests, games, and dances. Some even wanted special music, while others said they wanted balloons, indicating their activeness in the decision-making: they chose the decoration, the dances, and the music.

On the day of the holiday everyone was very excited and many expressed recognition if we did something that they had previously seen in a photograph.

After using the Children's Day festivities to prepare the children for more serious group work, it was time to develop group rules that would be binding for all and were meant to make the collective effort easier. Several days prior to starting work, we had a discussion to the effect that we as a group had to abide by certain rules and keep certain promises with respect to each other, so that no one was unhappy, and that soon we would need to draw these rules. The children were told that when the time came, everyone would have the task of expressing what the most important thing of all was, in their opinion. After the morning sessions, we brought in a flipchart in the sitting room, along with some pencils and colour markers. We tried to focus the attention of the children on the activity with the help of questions such as: 'What it is that we do together every morning?', 'What needs to happen so that we work well?', and everyone who spoke said that we needed to be all there. We asked the children to draw this and they drew eight little people. There were children that did not manage to draw a little person, but they nevertheless did some drawing. Those who would not draw at least stood nearby, not far from the rest.

THE CHILDREN FROM THE SMALL GROUP HOME:

Step 1: Building together a working group, with awareness of the other person, nurturing tolerance and skills for taking collective decisions.

Circle Time.

Building a group that works together.

Step 2: Making a collective decision.

Pictures of past festivities.

Decision made and implemented.

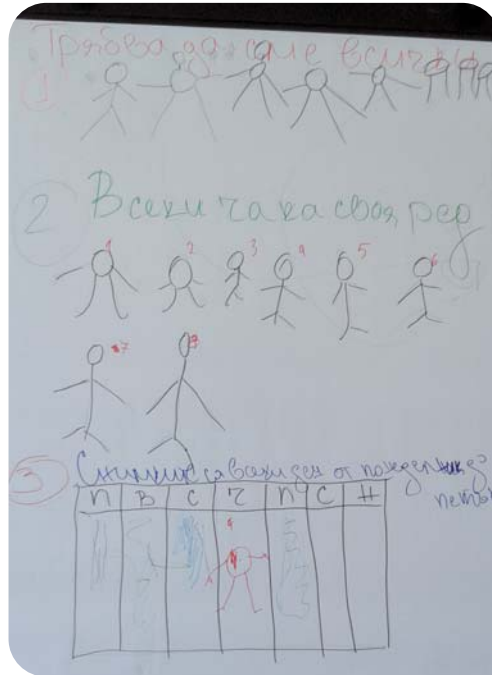**Step 3:** Preparing a set of rules of their own.

Flipchart and drawing.

Developed set of rules for Circle Time.

The participation agreement

The following rule was that the "pictures" had to be done every working day morning. On the board itself, along with the name of the day of the week, a table with seven columns was placed, the relevant day being highlighted in a different colour. The children said that this was the way they wanted to use to display the new rule.

Our work continues – in connection with building a link between the choices made and the responsibility assumed, with setting of rules to regulate the interactions among the clients, and, last but not least, with recognising and supporting every attempt on their part at empowerment and gaining control over their everyday lives.

After several days of repeating this rule so that it reached everyone, we began the preparations for the next rule, again using the flipchart. We asked guiding questions, so that we did not have just one or two children coming up with the rules, but instead engaging as many children in the process as possible. The suggestion for the next rule was that everyone waited for their turn. The children drew eight little persons and assigned numbers to them.

Children taking part in the Circle time: at the beginning only few of them participated

IV. Instruments used

1. **"I change my environment!"**

1.1 *"I decide how my room will look!"*

A) **A set of pictures of finished** children's rooms – different colours of walls, decoration, and furniture.

Why did we select this instrument? We chose this way of providing information and working with children because we assumed that once they saw finished children's rooms, it would be easier for them to understand what exactly we offered to them and they would have an idea of the things they liked. We selected twelve images of children's rooms and uploaded them on several computers so that we could work with several children simultaneously.

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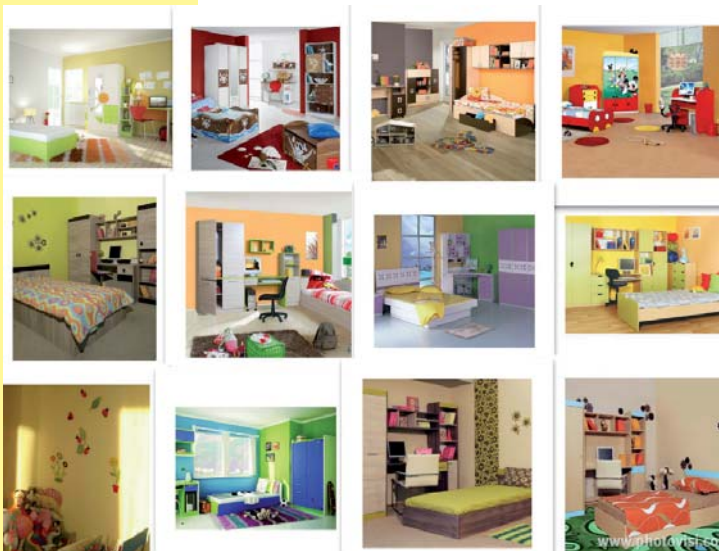
[5] Bilyana is a Key Social worker and mediator of Circle Time.

What were our expectations? Our expectations were that the children would understand what we were offering, and would select a favourite photo to guide us in how to change their room.

What happened? It turned out that the information we provided was too much and tended to confuse our clients. One picture following the other did not allow the children to have a proper look at both and make comparisons. We changed the approach, creating one file in which all the images were displayed, but the result once again was not good. The children clearly indicated that our ideas were not working for them and we would need to work harder to get their attention.

B) **Samples of paints** – the ready-made samples available in shops. We limited the number of colours to twenty-four. In addition to taking account of the need to select colours appropriate for rooms of children and youths, we also knew that if we provided an excessive number of options, children would not feel confident and would not make their choice.

Samples of paints

Why did we select this instrument? Once the children showed to us that they needed fewer details, we decided to employ the same method one resorts to when choosing the colour of walls – with the help of samples available in shops.

What were our expectations? Our assumptions were that the more secure environment and the fewer details of information provided would work better.

What happened? After repetitive individual work, our clients chose the colours for walls.

When everything was ready and the children took part in the cleaning up and arranging the rooms, their reactions showed us the children were happy with the makeover.

C) **Samples of curtains and bedspreads** – the individual work and the choice itself took place in a specialised shop. This showed that with some preparatory work and relevant support our clients could shop like everyone else.

Why did we select this instrument? Once we saw how the children managed with the choice of colours and that the real instruments used by everyone else worked well, we decided that the children could make the choice of curtains in a real-life environment.

What were our expectations? We were somewhat concerned with the fact that we were to visit a shop that was unfamiliar to the clients. Yet the logical next step was to go to a less secure and controlled environment.

What happened? Only several of our clients decided that they wanted new curtains, once consultations with staff took place. When we got in the shop, the girls were a bit nervous and they needed a few minutes to find their bearings and relax. Once this happened, we started the preparatory work for the choice itself. We selected the appropriate fabrics. The moment the girls realised what we were offering them, they got excited and started looking at the different options.

1.2 "I choose my meals!"

A) **The menu** is a folder with photos of the dishes our clients eat. Clients also take part in the shopping and in the cooking.

Why did we select this instrument? Using pictures of familiar dishes would facilitate the association between the image and the real object.

What were our expectations? Here we definitely expected that the adaptation period would be shorter and we would soon have our clients choose the whole menu for the week.

What happened? It turned out that the challenge was less related to making a choice than it was related to the time period between making the choice and seeing the result, i.e. the association between 'I want potatoes!' on

The menu

Saturday, and the actual enjoying of potatoes on the following Wednesday evening: this method did not work. We decided to focus on linking the real meal with its picture and at the same time providing the chance for choosing the afternoon snack (with immediate results). We also moved to providing clients with the immediate choice of what to cook for dinner (with seven or eight options prepared in advance) every evening. If there is no unanimity, the meal getting the majority of votes 'wins.' The picture of the selected dish is posted on the fridge. For now the children seem happy with this arrangement, and we hope that in the near future they will be able to choose the menu for one whole day, and, as a next step, for one whole week.

2. "We decide!"

2.1 Circle time or "the pictures"

The objective of this activity is to have clients realise the opportunity to think and work together and to teach them to make collective decisions, with the hope that in the future this collective understanding will lead to the development of a Client Representative Council.

A) The Circle Time Board
Why did we select this instrument? Our clients are inevitably part of a group; therefore we decided that one of the crucial steps toward having a working Client Council is to nurture in the children the sense of belonging to a group and to teach them how to make collective decisions and implement them together. The method employed in practice for the achievement of this objective is Circle Time – sessions during which every morning and afternoon all the children from the home get together and discuss upcoming events and daily tasks, and at the end of the day share their feelings and experiences.

What were our expectations? We expected to have the clients consciously take into account the presence and desires of the other members of the group; to provide them with a secure environment in which to share concerns or complaints; to look for a solution together, and, finally to grasp on an emotional level what being a part of a group,

The Circle Time Board

participating in collective decisions, and entrusting somebody with representing others is about.

What happened? A better connection between the social workers steering this activity and clients was built. Children became more attentive to the needs of others and stopped being angry when they needed to wait for their turn to come. We have still a lot of work to do, but our plan is to have Circle Time as the instrument for introducing all these changes in the service and in the lives of our clients. So far they respond very well and have already internalised this activity as an integral part of their daily routine. One of the important steps is to prepare an agreement for participation in which the children make visual expressions of some simple rules and which they symbolically sign in witness of their commitment to follow these rules.

2.2 "We decide how to celebrate"

Making a decision how to celebrate International Children's Day

Why did we select this instrument? This is an important holiday for our clients and they are accustomed to having a celebration every year. We decided that the first collective decision could be based on how to celebrate this day. We produced pictures of past festivities displaying different activities – dances, games, contests.

What were our expectations? We hoped that these pictures would trigger recollection of the experience of past celebrations, and this would make the children select the activities that made them happiest.

What happened? After several days' work, our clients decided what kind of celebration to have. They decided that they wanted to be all together, to have contests, and then dance. Moreover, preferences that were not previously displayed came up – concerning the type of music and decorations.

CONCLUSIONS

What did we try?
At the beginning of the pilot project we thought we knew what to expect. We had an action plan and a strict schedule. In the course of the work we stuck to the plan yet

with few results. It did not take long for us to realise that if we wanted to bring about change in the participation of our clients, in their attitude towards the surrounding world, and above all, in their perception and awareness that they had the power to change their environment, we needed to change ourselves. We switched approaches, we tried to put ourselves in their shoes, to employ visual symbols with which they were already familiar, in a way that would make them feel confident in their own skills. Results were soon to follow – tasks were not frightening anymore, they welcomed us with eagerness to work, and were proud showing what belonged to them, what they did, and what they changed.

What were the lessons we learned?
One of the primary lessons we learned was that one of the major motivating agents for children is fun and amusement. Another important aspect is to set tasks that are easy to fulfil and are as free from excess details as possible. Among the instruments which we were most successfully used in our work are the photographs used to visualize what we're discussing. Also highly important became the need to create the association between the current task and everyday life, using every possible opportunity to connect the choice with their everyday experiences. Thanks to the participation agreements which we prepared together with the children, it became clear that when they are involved in the whole process of making a decision, through to seeing it come to fruition, they are far more committed. Only through full participation can children who have never before held any responsibility for their own lives and what happens to them, learn that they also have the right to receive appropriate information and to be heard. The stories which we tell in this publication are examples of exactly that – how to involve a child with the idea that something can be different, how he can get involved in the processes of decision-making, even for something very small, and how, in the end, this small thing can become the foundation for a much larger change – a change which can lead to a whole new way of looking at his role in his own life.

What pleases us about the work completed?
Looking back, it is clear that the plan we so meticulously made turned out to be but a brief sketch of the road we followed. We are

satisfied with the fact that we managed to alter our attitudes – we took the children as they were. They also accepted us and unfailingly showed us the right way and kept leading us along it. We are pleased that there is a change in everyone, albeit to a different degree. Some would loudly voice their opinion, insisting that it be taken into account; others would smile and by a glance indicate the dish, object, or activity they favoured.

What are our concerns?

Each success comes with the risk of complacency, and our concern is that we may become less vigilant and wary, less resourceful and open towards our clients. It is so easy to say to yourself: 'Good job, I did what I had to.' The truth is that our work is on-going and that what lies ahead is no less important than the work already accomplished.

What lies ahead?

- To continue the work related to the establishment of a Client Council.

- To prepare a program for sustainability of child participation by means of planning activities and modifications to the service that will take place solely with the engagement of our clients.

- To cascade our experience to our co-workers in the other non-residential social services our clients use, so that the opinion of our clients is properly taken into account across the board and their skills to stand up for their rights are further developed.

- To disseminate our experience as broadly as possible, for maximum outreach, since child participation can happen at all levels of the functioning of society.

" I love to play! "

## PERSON-CENTRED PLANNING AS A TOOL FOR PARTICIPATION IN DECISION-MAKING

Quip provides support to people with disabilities through independent coordination and training. We provide these services in order to help people with disabilities (regardless of age) to be included into mainstream society and to live independent lives, in accordance with their own values and preferences.

Within this mission framework, Quip also works directly with two boys with disabilities who were placed in institutional care from birth. The aim of Quip's efforts with these young people is to open the way for family care, with maximum involvement of both boys in the decision-making process.

I. Mathias' story

Mathias is a 13 year old boy with multiple disabilities (physical and intellectual disability, as well as serious visual impairment). He has lived in an institution his entire life. Currently he is placed with a group of approximately 50 adults with intellectual difficulties. He has no family; the municipality was appointed to be his guardian.

When we started to work with Mathias, nobody knew him except for the staff of the institution, a social worker from the child protection authorities and an education specialist, who provided Mathias with four hours of individual teaching per week organized within the institution. Mathias had no peers and no experiences in regular, mainstream life. There was no communication system which could be used for understanding what Mathias wants or dislikes, or which facilitated us in what we wanted to say to him. Mathias had never experienced an opportunity to participate in decisions which concern him.
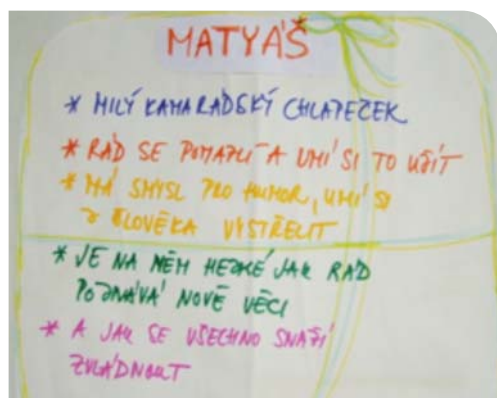
We have included Mathias' story because in it we can show how to involve a child who cannot communicate verbally or through any other formalized system, in decision-making – even regarding such important decisions, such as changing schools.

Matyáš
Milý kamarádský chlapeček
Má mysl pro humor,
umí si z člověka hezky vystřelit
Krásně se mazlí

Co má rád
Má rád společnost
Má rád vodu – je spokojený ve vaně i bazénku
U jídla rád sedí na svém vozíku a jí samostatně svou lžící
Nejraději jí jogurty, piškoty, oplatky, bábovku a medvídky
Má rád hudbu a rámus vařečkou na hrnce
Rád se pohybuje samostatně lezením
Rád se houpe v houpačce a miluje pobyt venku v zimě v létě
Rád jezdí autem a pozoruje dopravní ruch

Co potřebuje ve škole
Individuální pomoc při výuce i dalších činnostech (toaleta, oblékání, pohyb)
Vyškoleného asistenta (pomoc dítěti s postižením a techniky AAK)
Do školy by měl zpočátku chodit cca 15 hodin týdně
Bezbariérové prostředí (výtah/schodolez/rampu)
Místnost pro výměnu inkontinenčních pomůcek a odpočinek (lehátko)
Ve třídě speciální lavici a prostor pro odpočinek vybavený kobercem

We started with "gifts and strengths", in order to find out what other people like and admire about Mathias. We knew that this could help us to present him in a positive perspective. We wanted to replace the abundance of negative descriptions about Mathias (from doctors, psychologists, special aid teachers and other specialists) with positive information about him, for which people could accept and love him.

As Mathias did not use words and there was no other system of communication, our work was based on interviews with the staff of the institution and his teacher, as well as on observation. We found a lot of very positive evaluation, for example, "Mathias is nice friendly boy", "He has a sense of humour and is able to joke around with people", "He likes to learn new things", and "He really tries hard to handle everything".

It was also clear to us that Mathias is an abandoned boy who lives without love, individual attention or opportunities for development. It was therefore necessary to work on a change as soon as possible.

"gifts and strengths"

Step 1:
GIFTS AND STRENGTHS

Outcome:

We were able to present Mathias as the nice friendly boy he is, to potential peers, teachers, supporters and possible foster parents. We felt that this would increase his chances of being accepted into society and of discovering a normal life.

Step 2:
PATH

Outcome:

We had a strong vision for Mathias, and clear steps on how to increase Mathias' chance to find a foster family.

There was a clear task to work on in developing a communication system, which could increase our ability to involve Mathias in decision making processes.

We visited all regular schools and one special school in the town using the one-page profile as a basic instrument for introducing Mathias.

We organized a meeting to discuss Mathias' future with representatives of the institution and child protection authorities. We used the "PATH" planning format. As there was no communication system with Mathias at the beginning of our work, we did not involve Mathias directly in the decision making process. We began instead with Mathias' gifts and strengths, using our previous work. Then we agreed on possible dreams for Mathias: growing up in a family and having friends among peers. We subsequently set up two objectives for Mathias: to find a foster family for Mathias and to find a school where Mathias will be accepted – by both peers and teachers.

There was a very big disparity between Mathias' dreams and his present situation. The most serious problems included the lack of a system for communication, no opportunity for contacts with peers, very little individual attention, and his anonymity – very few people knew he existed. The group set up a few basic steps: 1) Ensure that Mathias will be included into the list of children suitable for foster care, 2) Find a mainstream school in the town,

3) Develop a communication system, and 4) Prepare a one-page profile for finding the school and prospective foster family.

We had set ourselves the task of finding a mainstream school where Mathias could establish contact with peers. For this, we needed to present Mathias to prospective schools in a positive way. But we had only a folder containing expert reports, full of appalling diagnoses and labels. We could imagine how principals and teachers from mainstream schools would be afraid to accept such a pupil. The ideal solution was

to prepare a one-page profile, containing a pleasant photograph of Mathias, a list of supports and adjustments which Mathias will need to be able to attend the school, and a list of Mathias' favourite activities, places and things.

Mathias was involved in this process indirectly – through information which was gathered from staff of the institution about what was important to him.

We visited all mainstream schools and one special school in the town using the one-page profile as a basic instrument for introducing Mathias. The head of a small school, when she saw the picture, decided immediately to accept him in the school.

Mathias communicates with his behaviour. He does not use words, and he has a visual impairment. His potential to communicate depends on the extent to which people around him know him. But staff of the institution routinely interpreted Mathias' behaviour as misbehaviour. School staff did not understand many of his behaviour, and thus could not adequately respond to it.

We began to apply "communication charts". There were two important issues at hand: Beginning to understand his behaviours, and responding adequately and consistently to

respective types of behaviour. All support workers filled in the chart with four columns regarding different types of behaviour in specific situations. Then the workers together agreed on the meaning of respective behaviours and adequate responses. One common, agreed chart was (and continues to be) developed.

Support workers could now recognize situations which regularly caused discomfort to Mathias. Based on observations, we recognized situations of discomfort as they were manifested by shouting and self-harming which could last almost two hours. In the past, people around him thought that "he was being very naughty". This happened when Mathias was returning from school to the institution. As we began to understand Mathias, we could address the situation and together we found ways to help Mathias manage more easily his return from the school to the institution.

The next step in our work was to create for Mathias a system of communication which will strengthen his ability to express himself and to be understood, as well as to provide a means for both sides to initiate communication.

We decided to use communication objects. We had to take into account two important issues which affected the selection criteria:

Step 3:
ONE PAGE PROFILE

Outcome:

A short, concise and positive description of what is important to Mathias, what kind of support he needs and what are his gifts. This was the preliminary material for setting up support in the mainstream school, which Mathias was to start attending the following school year.

Step 4:
COMMUNICATION CHARTS

Outcome:

Thanks to the communication charts, Mathias´ manifestations of behaviour started to be interpreted as a form of communication, i.e. he was clearly expressing what he does not like.

| WHAT IS HAPPENING	MATHIAS IS DOING:	MATHIAS SAYS:	WE ARE DOING:
Anytime	He is sitting in a wheelchair and arches backwards	He wants to get out of the wheel chair	Help him climb to the place where he can lie down or crawl
We offer him an object	Pushes the object aside	I do not want it	We offer other objects he likes, we let him choose one of two
Anytime When choosing one option out of two	He is reaching for an object	I want it	We hand it to him
Anytime	He is reaching for a person	I want to be caressed	We embrace Mathias and caress him
Anytime	He is smacking his lips loudly and flailing his hands	I am in a bad mood	We take Mathias by his hand and we stroke alternately his face, and our own

Step 5:

COMMUNICATION
OBJECTS

Outcome:

We developed the foundations for increasing the opportunities for Mathias to make the choice between more than two activities as the following scheme shows.
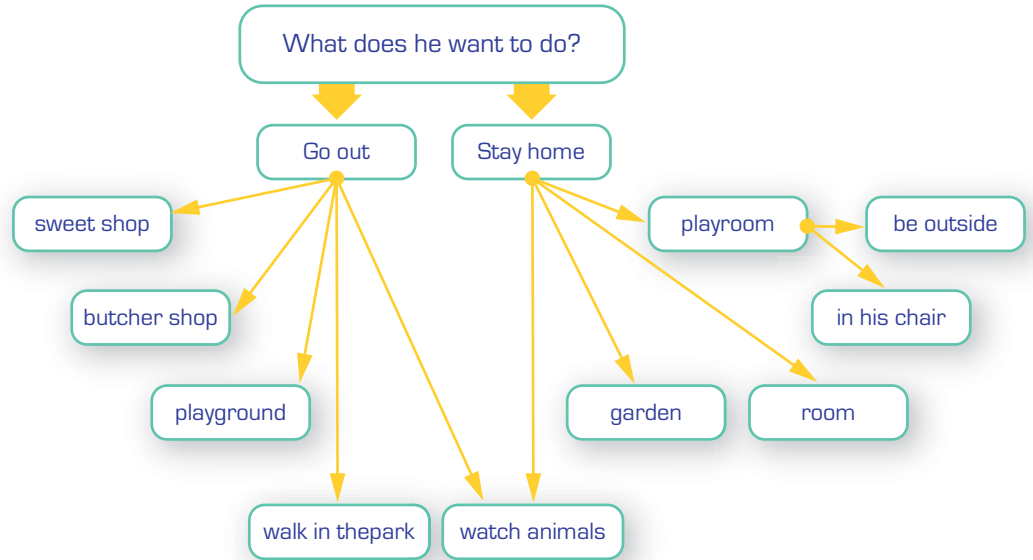
Step 6:

SORTING OUT
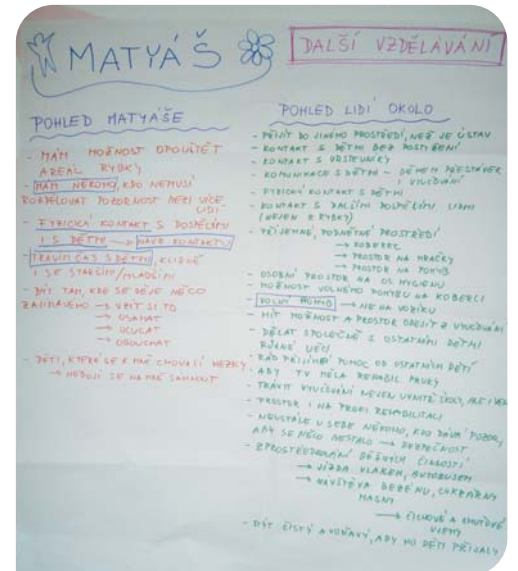IMPORTANT TO
THE CHILD AND
FOR THE CHILD

Outcome:

The final decision regarding Mathias' school placement was made by his guardian (public authorities). But for making this decision, information was taken into the account such as what Mathias loves in the school, which children, activities, etc.

1) We had to know what Mathias likes and what attracts his attention – sounds, light reflections, structure of a material, etc.

2) As Mathias learns about objects around him by putting them in his mouth, we had to ensure that objects were safe.

Several months later, based on exploring and testing, Mathias´ school assistant found a most suitable aid – small bottles of hard plastic which could be filled with different materials and make different sounds when being shaken. Several plastic bottles were filled with different materials and Mathias differentiates between them by listening to them. Each bottle represented a specific activity: Water means bathing, larger pebbles means staying outside, rice means music lessons, green peas mean exercising and physiotherapy.

We are starting at this moment to always use the appropriate aid before engaging Mathias in the activity, so that he can establish a link between the activity and the aid. Then it will be possible for Mathias to select out of two options and thus let us know about his preferences and decisions.

One year later, another important decision needed to be made: whether Mathias would stay in the same school for another school year, or whether he should continue in a different school with his schoolmates, who would be graduating out of the elementary school after grade five. The director of the institution requested to place Mathias in a special school.

*"What is important to" and
"What is important for"
Mathias regarding the school.*

To decide this with Mathias' involvement, we gathered information about what was important to Mathias at the given moment. We interviewed the staff and other people and we observed Mathias at school and in the institution. Following this, a planning meeting was organised which included other people in Mathias' life, not just professionals. At that time, there was a particular woman who was fond of Mathias and would frequently invite him over to visit her family, so she was involved.

The colleague who was responsible for gathering information was established as the voice of Mathias. She listed what she learned

about what was important to Mathias. Then, other people who loved Mathias and cared for him also listed what was important for Mathias. So we had two lists: "What is important to" and "What is important for" Mathias regarding the school.

We decided to start with a systematic recording of Mathias' involvement in decision-making which affects him. There are quite a lot of people who support Mathias, especially in the institution. We wanted all people to know exactly how Mathias had to be involved.

We decided to use a specific "Decision making agreement" form, which consists of three columns, where we listed various different situations.

This structured way of thinking gave the support team a clearer view of the best approach in different decision making situations, and who should be involved in the respective decision. At the same time, it is a way of recording and sharing agreed-upon procedures.

There were three options: Remaining in the same school, continuing with peers to another mainstream school, or enrolling in a special school. **It was decided that he would remain in his current school**.

EVALUATION OF THE WORK IN QUOTATIONS

The guardian: "I am very glad that I was able to peek under the hood of how to work with a child who cannot communicate verbally.

Using the tools you develop, you can find a lot of information, which replace the missing verbal language. It is then possible to decide how to take into account the child's wishes."

EVALUATION OF THE WORK WITH MATHIAS

What worked well:

- Finding a way for Mathias to participate in decision concerning his life.

- Connecting people who support Mathias in different surroundings (social services provider, school, and host family) in sharing communication systems and integrating them.

- Taking into consideration things which are important to Mathias in deciding about his further education.

- Letting Mathias' voice be heard via an intermediary – a person who presents the views of another person who does not use words.

- Finding a system which supports Mathias in participating in decision making, instead of making decisions for him.

- Finding alternative, tailor-made communication elements for Mathias.

What did not work well:

- Making all persons who support Mathias in the institution utilise a communication system which allows Mathias to understand what is being said. Often they make decisions for him.

Step 7:
DECISION MAKING AGREEMENT

Outcome:

This tool also directly helps children increase choice and control of their lives.

Decision making agreements support the child's involvement in the decision making process, due to the increased attention paid by support staff to the child's voice.

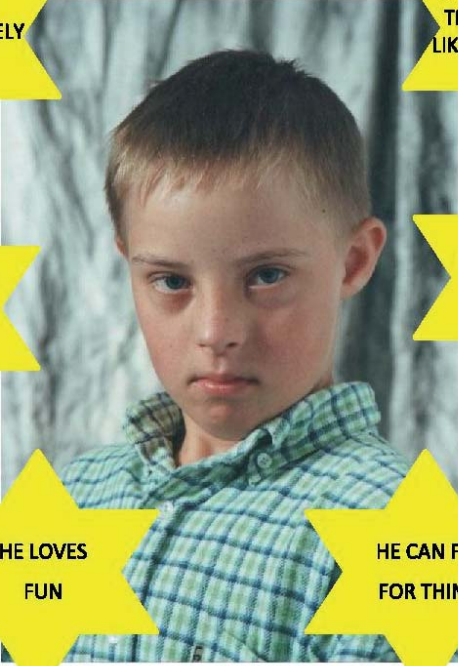| IMPORTANT DECISIONS IN MY LIFE	HOW I MUST BE INVOLVED	WHO MAKES THE FINAL DECISION
Take a bath in the swimming pool.	We give Mathias two plastic bottles –one containing water (meaning I want to take a bath) and one with rice (meaning I do not want to go into the water, I want to play). The bottles are laid before Mathias at the same distance. Mathias chooses one of the bottles to choose the activity he wants to do.	Mathias.
Next decision regarding we to attend school.	The views of Mathias are mapped by systematic observation of his behaviour and interviews with support persons in advance of the decision. Mathias is involved through an advocate, who mediates Mathias' voice based on the preliminary mapping.	Guardian.

CHEERFUL, FRIENDLY, LOVELY BOY

WHEN TRYING NEW THINGS WHICH HE LIKES, HE HAS A REAL STAMINA

TALENTED FOR SPORTS AND MUSIC

HE LIKES HELPING PEOPLE

HE LOVES FUN

HE CAN FALL FOR THINGS

Mark's relationships map.

Step 1:
RELATIONSHIPS MAP

Outcome:

We got a clear picture of the persons in Mark's life.

We could see who would be useful to ask for further information and for being involved in planning and providing support for Mark.

Step 2:
SORTING IMPORTANT TO AND FOR

Outcome:

We got a picture of all different activities, places, persons which are important to Mark, and also what is important for Mark from the point of view of people who love him.

It was very easy to find out what works and what does not work in Mark's life. The majority of things were not working out for Mark.

II.   Mark's story

Mark is an eleven year old boy who lives in a residential home together with about 75 adults with disabilities. He has lived in institutional care since his birth, moving between several different residential facilities. He has no real contact with his biological family. He doesn't know his parents personally, despite the fact that he is placed in the institution on a signed agreement between the institution and his father.

Mark attends a special school in the town. After he gets home from school at noon, he spends the rest of the day among adults with

What is important for Mark and for the people around him

nearly no possibility of being involved in activities fit for children. In fact, he has very limited contact with peers at all.

Mark keeps regular contact with the family of a former social worker from the institution. He calls her "mom". They spend most of their weekends together. Mark goes for holidays and trips with them and he is unconditionally accepted by all members of the whole family – parents, siblings, their partners, grandparents, friends of parents.

We started our work with Mark by mapping important people in his life in four spheres: family, friends, paid services and school.

We used a form from a workbook for Person Centred Planning. Mark was specifying persons and places, while we made the figures of people.

Most importantly during this activity, we discovered that there is a woman whom Mark calls "mam", who loves him and whose family also accepts Mark, as a host family.

The biological parents were not on the map, even though they exist.

We began to ask Mark what was important to him – what he likes and dislikes to do in the institution, at school, in the family and places where he spends time. We were interested in learning how and with whom he likes to spend his leisure time.

We tried to find out his wishes with the help of a "magic wand" and a set of pictures. First, we identified a real situation, and then we explored what he would like it to be. Questions were adapted to be more interesting for Mark: If you went to a magic island, whom would you bring with you? If you could change something now, what

Mark's PATH

would it be? What present would you like to receive? You meet a magic knight in a mysterious castle. He can fulfil three wishes - what would they be? What do you want to do on holidays and where? You can tell this teddy bear absolutely everything. What will you tell him?

We also used different forms from workbooks for learning what is important to Mark.

We also developed a short list of what Mark dislikes: Shouting, being on my own, and being beaten with a wooden spoon.

Based on the findings which showed deep differences between Mark's real life and the life he wishes to have, we decided to hold a planning meeting. The goal was to bring more of what he loves into Mark's life, through the planning of his future. Together with Mark, we chose who would be invited: Mum, sister (Mum's daughter), a key staff worker and another direct care worker from the institution.

We decided to use PATH as we had a clear idea about Mark's dreams and we needed to plan the steps for fulfilling the dream.

The meeting took almost two and half hours. Mark was present all the time and he was very active. He loved using the magic wand, which helped him stimulate creative thinking in all participants. We set up a list of goals: Mark will attend a hobby circle, will have at least one permanent friend, will have his own room, and will go for a trip at least once a month. He will start to learn cycling, line skating and skiing, he will read and write, he will get a motorcycle lift and finally he will live in a family.

When we were sure that Mark was interested in becoming a member of the camping club, we started our preparation.

We decided to prepare Mark's one-page profile for becoming a member of the club. We included in the profile Mark's photo and three parts of text focused on Mark's gifts and strengths, supports which he needs for attending such a club, and information on what is important to him.

We involved Mark directly in the preparation of his profile. We asked him about what he likes and dislikes. We discussed the support which he will need in regular meetings and trips with other children and so on. We also used information collected through discussions with people who take care of Mark.

Mark's decision-making

Step 3:
PATH

Outcome:

We created clear goals, which were set up with Mark's direct involvement.

We have formulated a key objective: Mark will live in a family environment. In relation to this, the facilitator turned for help to the local child protection authorities.

Step 4:
DECISION MAKING AGREEMENT

Outcome:

Mark decided clearly that he wants to attend the club.

Other children are informed about how Mark needs to be supported (e.g. with reading).

We discovered effective types of support in decision making about daily activities.

IMPORTANT DECISIONS IN MY LIFE	HOW I MUST BE INVOLVED	WHO MAKES THE FINAL DECISION
What to do in my leisure time.	Show me a few possibilities visually: Put pictures of activities on the sheet of the paper, talk about respective activities, ask me questions to be sure I understand, and then give me the chance to point my finger at my choice.	Mark

Mark's other important wish was to have friends and do typical child's activities – play games, go for trips, play a musical instrument, spend time in nature, ride a bicycle, skate on inline skates, and ski.

To address this wish we found a hobby club (the camping club mentioned above), attended by about 20 children who meet once a week, play games, go for trips, organize explorations using bicycles, inline skates or skis. We needed to be sure that Mark would like to become a member of the club.

We knew that Mark frequently answered questions of choice by reacting to the last mentioned option which is offered to him. For example, if we ask him, "Do you prefer to go to the zoo, or to the cinema?" he will answer "cinema", although we know that he doesn't like the cinema, while he could spend all his time in the zoo.

Therefore we visualized the information on large sheets of paper and information connected with decision making was drawn and complemented with prepared pictures. When introducing all activities of the club we asked him various questions to see that he really understood the information. This type of support was useful: Mark was with us all the time, he was actively asking about things and it was clear that he was enjoying himself.

In the end Mark repeated his choice saying YES and he pointed his finger at the sheet describing activities he could do with the club.

We used this experience in preparing a decision making agreement, which is available for all support persons in Mark's life.

Step 5:
ONE PAGE PROFILE

Outcome:

We had information for meeting with the leader of the club, which was portrayed in a positive manner and where all important issues were included in accordance with Mark's will. Mark was accepted to be a member of the club and started to attend.

Marek

Co mám rád:

- o Sport
- o Sladkosti
- o Hraní na hudební nástroje
- o Lidi, na kterých mi záleží – máma, ségra, Pája
- o Pochvalu
- o Děti
- o Pomáhám všem okolo
- o Učím se novým věcem

Co nemám rád:

- o Nerad končím činnost, která mě baví
- o Jsem smutný, když odcházejí lidé, které mám rád
- o Když jsem sám

- ♥ Snaživý
- ♥ Milý
- ♥ Usměvavý
- ♥ Má hudební sluch
- ♥ Vše zkusí

Jak mi dobře pomůžete?

- o Do všeho se často vrhám po hlavě. Potřebuji zpomalovat. Stačí, když mi to řeknete. Třeba – ještě počkej.....teď už můžeš.
- o Některé věci dělám pomaleji. Buď se mnou prosím trpělivý.
- o Rád dělám věci až do konce tak, jako ostatní. Když třeba nějakou soutěž nestihnu, všichni už mají hotovo, budu moc rád, když ji také budu moci dokončit.
- o Potřebuji občas vyčistit brýle. Sám si o to ale neřeknu.
- o Potřebuji vědět, za kým mohu přijít, když si s něčím nebudu vědět rady.
- o Někdy se stane, že něčemu nerozumím a nezeptám se. Ověřuj si to prosím tím, že se mě zeptáš, nebo mi to ukážeš (co mám dělat).
- o Věcem více rozumím, když mi je ukážeš, než když mi je pouze řekneš.

EVALUATION OF THE WORK IN QUOTATIONS

Host family mum: "If I hadn't seen it, I would not have believed that Mark can be focused for such a long time. He liked it very much, he enjoyed being in the spotlight and he liked that everybody was here for him at any moment. He didn't have to share a close person with anyone else."

Host family sister: "When I saw Mark waving the magic wand, I really had a feeling that anything was possible... I was not thinking about reasons why things couldn't be done, but I was thinking about ways how to proceed so that things went well".

EVALUATION OF THE WORK WITH MARK

What worked well:

- Finding a way to pass information to Mark so that he can understand.

- Transferring these ways of communication to people who are close to him (his mum, his sister, key social worker) and upon whom Mark depends (they work with the information further on).

- Letting Mark decide how he wants to spend his leisure time on Thursday, and acting in accordance with his decision.

What did not work well:

- Including all persons who support Mark (staff of the institution, school teacher and teacher's assistant) in the system of transferring understandable information to Mark. Often they make decisions for him.

III. Group story

One of the topics of this project was the participation of children in decision making at the level of public administration. International studies show that the right to participate in decision making is one of the most frequently denied rights to children with intellectual disability.

Therefore, we approached the local authority Prague 14 and began to work with them on involving children with intellectual disabilities in municipal policy through specific activities, e.g. Pupils' Council and Children's Forum.

First, we began attending meetings of the Pupils´ Council, which meets regularly every first Tuesday of the month. The Council discusses various matters which are of concern to children, and prepares interesting events to which other children are invited, where they systematically collect the participants' opinions. The Council representatives acquire certain skills through "playing" at municipal policy. Such play is organized by the local authorities at the beginning of every term of office. The term of office for the Pupils' Council is one school year.

One meeting of the Pupils' Council focused on the life of a child with intellectual disabilities. First, each member of the Council reflected on their own interests, likes and dislikes and recorded all of their observations on paper. Second, we began to introduce children with intellectual disabilities into the group, using one page profiles which clearly indicate what the child likes and what support he/she needs. The pupils came to the conclusion that in fact there is no difference and that they do not understand why people make such a fuss about inclusion. The pupils voted to adopt several agreed steps and they unanimously decided to include two more children in their Council. Together we agreed that the Children's Forum would be the first joint event. The next meeting of the local government focused on this topic only. In light of welcoming new members of the local government we prepared together with the Pupils' Council (20 children aged 12 - 17) texts which could be easily understood by everybody. One of the topics for the Children's Forum was leisure and sports. We needed to collect the opinions of participants concerning opportunities for spending leisure time and playing sports - whether the local authority provides space and places where young people can engage in activities which they really like.

WHAT TURNED OUT WELL?

Meeting with the mayor who clearly supported the idea.

Meeting with 3 people who support these children's activities in Prague 14. One person was very positive about our proposal ("it's a natural thing"), two other persons also positively approved, saying "let's try it".

Meeting with Pupils' Council with a clear result - we don't understand why these children did not join us a long time ago.

Together with councillors, preparing materials that would be easily understood by everybody.

Finding two families who supported their children to become members of the Pupils' Council.

Arranging participation of Petr and Dasa during the next term of office.

WHAT FAILED

Find a family that would support their child to participate in Children's Forum.

In the case of Petr and Dasa we agreed with one of the organizers, selected by the team to be a contact person for us at the Pupils' Council, to shoot a documentary that could be later used by other councils. However, on the day, the other members of the team didn't know about the shooting, which caused a discord in planned actions.

"To be different does not mean not to be a good friend. …To be different is normal and he who does not consider it normal is not normal." (Member of the Pupils' Council).

We approached nine families in Prague 14 with the help of social services operating in the district. We offered their child with intellectual disabilities to participate in Children's Forum. However they all gave us an unexpected negative answer: they did not wish to send their child to an event which was organized for all children (children with and without disability). They did not want to expose their child to ridicule. Thus we saw a paradox. Children themselves were ready to accept individuals with intellectual disabilities. Barriers exist namely in our heads, that is in the heads of adults. The event took place, and although there had been preparations for involving young people with intellectual disabilities, none of them participated.

It was the third year of joint meeting of about one hundred pupils and students to discuss problems of the district in various spheres of life (culture, sports and leisure, greenery, public space, system of education, transport, criminality and security).

The event was an example of good practice of engaging children and young people in municipal politics. This was an opportunity for children to influence future development and quality of life in their district.

"Some of you probably do not know that Prague 14 organizes events at which at least some of the adults pretend to be interested in what young persons of our age think. I guess I now offended most of my peers, but seriously - we are children of mother Earth and our parents". (Jakub Resutík, 16 years old, Member of the Pupils´ Council of Prague 14).

We also acted individually and in May we found two families who supported their children in the decision to participate in the meeting of the Pupils´ Council. The meeting took place in June 2014. Given that this was the last meeting before the summer holidays, the content of the meeting was to evaluate the past year and to prepare an event which was presented by the deputy mayor of Prague 14. She offered to the children to attend a meeting with Members of the Parliament which she had arranged. 8 children wished to attend, including Petr, who participated for the first time. Both young persons, Petr 15 years and Dasa 16 years, liked the meeting very much and they concluded that they would join the Pupils´ Council in September.

After the meeting, we spoke with Dasa's mother, who came to pick her up and bring her home. She told us that she had not

believed in it (and that she had been one of those mothers who was offered the same thing by social service which her daughter visits), but as Dasa insisted, she finally supported her. When we asked her why she did not support Dasa, when her voice had been heard for the first time, she explained that she had had a bad experience. Several times she visited DDM (the Centre for children and youth), which helps organize the Pupils' Council) to have her daughter enrolled in the flute course. She was rejected with an explanation that DDM is not able to provide services for children with intellectual disabilities, as their staff are not trained. Therefore she enrolled Dasa in a specialised institution which only children with intellectual disabilities attend.

A key change in the thinking of the whole DDM was that a children's voice was respected by the staff. The voice was clearly saying: We do not understand why these children should be someplace else than we are. We want them here.

IV. Resources

This part of our publication includes a summary of tools which help involve children in the decision making process. We give a short description of each tool and also refer to Internet links where other sources can be accessed.

We based our work on Person Centred Planning. Techniques and tools resulting from this concept create – if correctly applied – a space for identifying and respecting the opinion of a person that is provided assistance and support. At the same time, the health, safety and acceptance of a person by their community is adequately taken into consideration. Specific cases of the application of tools listed below can be found in the previous chapters.

Person Centred Planning (PCP) is a specific approach to planning support and assistance which a person with disability or some other disadvantage needs in everyday life or in taking steps that lead to major changes in their life. It takes into account things that are important to them and thus extends opportunities for their self-determination. It is not limited to services provided by professional service only. Also the skills and gifts of a person, their family and friends,

wealth of the local community, common public services are included among resources.

We used the following tools in the "Hear Our Voices!" project to strengthen the voice of children with intellectual disabilities.

One page profile

One page profile is a brief outline of major findings about the person. It needs to be developed for a purpose so that its preparation does not become mere formality. A One page profile is usually developed as a result of the first meeting with the child to summarize key findings important for further care and support. Other reasons for developing a one page profile can include the child's enrolment in school, changing service provider or looking for a foster family.

Usually one page profile is composed of three parts:

1) What do people who know the child and who love him/her, like and admire about the child?

2) What is important to the child - what does he/she like to do, where and with whom does he/she like to go?

3) How can we provide the best support to the child?

It also includes his/her photo and possibly objects that tell something about his/her personality.

One page profile should give as many details as possible to enable maximum practical use (e.g. *she likes doughnuts and honey cake instead of she likes sweet meals; he needs his backpack perfectly buckled, his belt tightly fastened, he hates to have things on his table moved instead of he likes his order*). The section on support should contain a description of support/assistance, not a list of limitations (e.g. *he needs advice on where to note the meetings in his diary and remind every morning, what he is supposed to do instead of he has problems with time*).

If we want to involve a young person in decision making, we should know what is important to them. Often children need help when expressing their ideas and when making themselves

understood. The One page profile is a good tool which helps us understand the preferences of a young person and the ways to best help them.

To develop a One page profile it is good to use data collected by such tools as Gifts and Strengths, Relationship Circle/Map, sorting the important to/for, Staff Matching etc.

For further information about One Page Profile go to:

http://www.helensandersonassociates.co.uk/media/38428/onepageprofilesinschools.pdf

http://www.helensandersonassociates.co.uk/media/38450/oppinschlguide.pdf

http://onepageprofiles.wordpress.com/

http://www.google.cz/url?sa=t&rct=j&q=&esrc=s&source=web&cd=15&ved=0CJYBEBYwDg&url=http%3A%2F%2Flibrary.teachingtimes.com%2Farticles%2Fwhyeverychildneedsaonepageprofile&ei=gUGGU6b9K_u_T7Aa88IH4Cg&usg=AFQjCNEG9Ew4JDuYFiM7pEchO_RggIFfPA&sig2=NFhMOjHCXuq85gLIItSKyA&bvm=bv.67720277,d.ZGU

http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-thinking/one-page-profiles.aspx

Gifts and Strengths

Mapping of a person's strengths - gifts and talents - has at least three purposes in person centred planning. First, it compensates for numerous negative descriptions - medical, psychological, psychiatric and other diagnoses which are often used with a disabled person; they often stigmatize and represent a barrier for positive perception of a person. Second, gifts and talents can be practically used for building social bonds and relations, for finding one's place in school or at work, as well as for inclusion in common life of society. And lastly:

Finding out what the young person is good at increases the probability that we help them plan activities they are interested in and they will like. This is especially important with young people with severe disabilities who are not capable of articulating verbally

their likings. It is based on the assumption that one usually wishes to do things, at which he/she is already good.

To make thinking about gifts and talents easier, we can use a simple illustration which reminds us that gifts and talents are not only in one's head, but they can be found in the arms, heart, roots (family history, faith etc.).

To get an idea about someone's strengths, we ask members of the staff, family members, friends and other residents, etc. We can also organise an "art" workshop, where we draw a contour of the person on a large sheet of paper and then draw his/her talents to it.

For more information go to:

http://www.nes.scot.nhs.uk/media/435128/13875-nes-mental_health-module4.pdf (page. 100).

Relationships map/circle

A Relationship map is a graphic description of who the young person is in contact with, and how close the relationships are. The shorter the distance between people on the paper, the closer the relationship. The map helps discover who is important for the child, out of family members, schoolmates, friends and staff, including teachers and other paid persons.

The map can be divided into four sectors, each of them representing relationships with different groups of people: family, friends, professionals, and schoolmates and house mates. This graphic description of relationships also clearly shows who is missing in the child's life, which relationships should be reinforced, who has not been used in providing support (and should be involved), and who should be invited to help develop the plan or be invited to a planning meeting.

When developing a map, the young person should be given the opportunity to give their idea about relationships. The child can draw the map himself/herself; he/she can place photos of people around his/her portrait, etc. In the case that the child cannot be involved directly, we need to read information from their behaviour or use other alternative methods.

Relationships mapping can inform us on many things: with whom the young person wants to spend the most time, whose presence they are not interested in, who is missing in their relationships, etc. Respecting these findings strengthens the participation of children in decision making.

Mark's relationships map.

For further information go to:

http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-thinking/person-centred-thinking-tools/relationship-circle.aspx

http://trainingpack.personcentredplanning.eu/attachments/article/90/pct%20relationship%20circle.pdf

http://www.gadoe.org/Curriculum-Instruction-and-Assessment/Special-Education-Services/Documents/Quad.RelationshipMap.pdf

https://www.realopportunities.org.uk/media/64285/relationship_circles.pdf

4+1 questions

This simple tool gives a structured way for everyone to gather collective learning and to make this visible to everyone. It asks the following questions: What have you tried? What have you learned? What are you pleased about? What are you concerned about? The answers to the first four questions lead us to the 'plus 1' question: Based on what we know, what should we do next?

We can use 4+1 questions during meetings as the basic input for deciding on the next steps. We can post sheets of flip chart paper on the wall, each with a different question, while the facilitator asks people (including the child) to write on them. A child might need help from somebody else to be involved actively.

4+1 questions can help us listen better to the child, if we include him in the process personally or if the appointed representative (in the case where the child cannot directly communicate) expresses the view of the child thanks to previous work with other tools, such as the Communication chart, Sorting important to and for, etc.

For further information go to:

http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-thinking/person-centred-thinking-tools/4-plus-1-questions.aspx

Sorting Important to and for

It is necessary to establish a balance between what is important to (what one likes and dislikes) and what is important for a young person. It is important that the care provided to a young person enables them to engage in favourite activities with favourite people at favourite places. At the same time, the young person needs to be kept healthy and safe; their positive mental and physical development needs to be ensured, as well as the opportunity to be raised in the family. In this case it is not about deciding "either - or".

In children whose capability to phrase and express their ideas is reduced due to an intellectual disability, attention needs to be paid to mapping of what is important to them and differentiate it from what is important for

What have you tried?

What are you pleased about?

What have you learned?

What are you concerned about?

Based on what we know, what should we do next?

them. This is how we can enable children with disabilities to participate in decision making. A scale diagram IMPORTANT TO AND IMPORTANT FOR can be of great help.

When planning support, we focus on addressing items on the right side (important for), but we need also to take into consideration items on the left side (important to). Taking into account favourite activities, toys etc. can have an essential impact on the child's motivation to participate in activities which are not very popular with them but which are important for their development.

Descriptions on the right side are meant to represent things which should be avoided when raising a child, and things which should be ensured (it cannot only be a list of medical or psychological diagnoses). The left side includes only the opinion of the child (important to).

Visualisation (drawings, pictures, photos etc.) or various playful and imaginative techniques - using for example the magic wand, or a teddy bear in which the child can confide a secret - help us gather information from the child (and also from adults).

Observations and interviews with people who know the child well in various situations can be used to identify what is important to children who do not use words, do not understand what is being said, and for whom there is no functioning two-way communication system.

Both sides of the diagram are developed depending on the provision of opportunities for the child to explore the world, and depending on how people around the child get to know him/her. If we know very little about what the child likes at the beginning, this should be a signal for us to engage in activities that will offer new opportunities. For example, nine-year-old Mathias was transported to the consultation about alternative communication in a car, at which point it was discovered that he loved riding in a car and he liked city traffic (as any other typical young boy).

For further information go to:

http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-thinking/person-centred-thinking-tools/sorting-important-tofor.aspx

http://trainingpack.personcentredplanning.eu/index.php/en/person-centred-thinking-tools/important-to-for

PATH

PATH means **P**lanning **A**lternative **T**omorrows with **H**ope. PATH consists of 7 steps visualized in specific format which is used to facilitate a planning process. The basis of PATH is a template which reflects the process of discussion among people who are supposed to help a focus person plan a practical journey leading toward a future that makes sense to them.

The objective of PATH is to identify clear steps that lead to a desirable change for the better. PATH starts with dreams of the focus person and continues then with what the group considers it should be the first steps towards achieving positive changes.

7 steps of PATH:

1. Dreams
2. Goals
3. Now
4. People to enroll
5. Ways to build strength
6. First steps
7. Next actions

PATH is a great tool for setting out dreams, positive and possible goals of a child or a young person. The process results in a pictured time-lined action plan to achieve the goals.

The discussion is ideally moderated by a facilitator who guides the group and a person who records the discussion in a template.

IMPORTANT DECISIONS IN MY LIFE	HOW I MUST BE INVOLVED	WHO MAKES THE FINAL DECISION
Description of the decision.	Description of the direct involvement and needed support.	Name of the person, who make the final decision.

For further information go to:

http://www.inclusion.com/artcommonsense tools.html

http://www.inclusion.com/path.html

Decision making agreement

This tool also directly helps children increase choice and control in their lives. It is a simple form which consists from three columns.

Such a structured method of thinking gives the support team a clearer view of the best approaches and who should be involved in respective decisions. At the same time it is a way of recording agreed-upon procedures, and means of communicating these procedures to others.

> *Decision making agreement increases the child's involvement in the decision making process due to an increased level of attention which support staff pays to the child's voice.*

For further information go to:

http://www.helensandersonassociates.co.uk/ media/75056/decisionmakingwithexamples.pdf

http://www.helensandersonassociates.co.uk/ reading-room/how/person-centred-thinking/ person-centred-thinking-tools/decision- making-agreement.aspx

Communication charts

Communication charts is an effective way of capturing what people are telling us through their behaviour, as well as a means of informing others what to do, should the person communicate with the specific behaviour. This tool help us especially when people do not communicate with words or other formalized communication systems (like sign language, pictures etc.) or when behaviours are a clearer method of communication than words.

Communication is a bilateral process; due to this we need two types of charts: 1) How we understand what the person is telling us and 2) How we will communicate with the person what we would like them to do.

1. Chart of how the person communicates

The chart of how the person communicates can have two forms for two different situations. First, when we do not know what a specific behaviour means, we can try to explore the meaning in specific circumstances. The second approach addresses a situation where the meaning is known and we need to capture this knowledge for all support persons (serving like a dictionary).

2. How we tell the person what we would like them to do

This chart helps all support persons know what to say and what to do to make a person understand them.

> *Communication charts give to children who communicate mainly through behaviours the possibility to express themselves and to be understood. This is central to them having adequate choice and control over their lives.*

For further information go to:

http://www.helensandersonassociates.co.uk/ reading-room/how/person-centred-thinking/ person-centred-thinking-tools/communication- chart.aspx

http://learningcommunity.us/documents/
Chapter4_PersonCentredThinkingTool_4_Com
munication.pdf

Objects communication

These are small objects or parts of objects which represent things, activities, or persons. Objects can be used to give individuals an idea of what is about to happen, e.g. a small shoe can mean going out, a spoon can symbolize food, etc.

This type of tool is used for enhancing understanding and expression especially for children who have severe intellectual disabilities. Visuals and objects are often easier to understand for some children than spoken words.

The selection of objects must conform to a specific person, and conform to the environment in which it is being utilized. There is no complete series of these objects. Objects are selected according to the needs and capabilities of the person.

For further information go to:

http://www.icommunicatetherapy.com/
child-speech-language/children-special-needs-
learning-difficulties/using-visuals-aids-objects-
reference-enhance-communication/

CONCLUSIONS

What worked well:

- Using various Person Centred Planning tools.

- Connecting the work of the department of child protection, the institution, the school and after school activities, and the host family.

- Interconnecting communication tools and person planning tools.

- Including children with intellectual disability in Pupils´ Council.

What pleases us about the work completed?

- The people who are personally interested in the children worked with us and use the outcomes of the planning.

- In both cases we managed to link up professionals and non-professionals and involve them cooperatively.

- We managed to get the voices of the children heard by those who make decisions, and the children's views were taken into consideration.

- We managed to find a system for persons who support the children which helps them participate in everyday decision making.

- We developed a functioning communication system which is used to help the children participate in decision making.

- We managed to exercise the inclusion of children in the community.

- Children without disability showed a great interest in including children with disability in the Pupils' Council.

- The local authorities were willing to help.

What are we worried about?

- Uncertainty in the departments of child protection in relation to one of the children's biological family, which needs to be taken into account.

- It is evident that the existing system provides for departments of child protection to use diverse approaches; however if there is no will to support a new approach, it is a big barrier.

- There is a certain percentage of children with intellectual disability about whom we have very little information; some of them cannot be approached at all because the department of child protection does not want to address the issue, or does not perceive a child as being at-risk.

- The negative attitude of parents of children with disability regarding the opportunity to involve their child in the Pupils´ Council.

What have we learned?

- It is worthwhile not to be content only with communication aids offered on the market, but also to rely on one's own creativity and activity.

- It is useful to enter into contracts with parties (e.g. service providers) to enforce an approach which will ensure that the child will be taken seriously.

- Everything needs time because at all levels, there is always a risk that things will stop moving forward.

What are the next steps?

- Finding a way to incorporate this approach in the work of departments of child protection and institutions.

- Showing that children with intellectual disability have their own opinions and that they should be taken into consideration in decision making.

- Searching for a way to make children with intellectual disability contribute to the work of the Pupils´ Council.

INCLUSION EUROPE

Inclusion Europe is the European network of associations representing people with intellectual disabilities and their families in 36 European countries. Since 1988, Inclusion Europe seeks policy mainstreaming, equal opportunities and full participation of people with intellectual disabilities in all aspects of society. www.inclusion-europe.org.

EUROCHILD

Eurochild is a network of organisations and individuals working in and across Europe to promote the rights and well-being of children and young people. Eurochild's work is underpinned by the United Nations Convention on the Rights of the Child. www.eurochild.org.

CEDAR FOUNDATION, BULGARIA

The Cedar Foundation is a Bulgarian not-for-profit organisation registered in 2005 which focuses on de-institutionalisation: the process of closing down big specialized institutions for children and young adults with physical and intellectual difficulty and replacing them with family-type community services. http://www.cedarfoundation.org/en/.

QUIP, CZECH REPUBLIC

The civic association Quip was founded in 2003 to support the development of quality and good practice in social services, promote education in this area and encourage awareness and rights of social service users, especially of people with intellectual disabilities and complex needs. http://www.kvalitavpraxi.cz/en/.

FUNDACIÓN SINDROME DE DOWN, MADRID, SPAIN

Down Madrid is a non-profit organisation, whose mission is the pursuit of individual autonomy of persons with Down syndrome or other intellectual disabilities and their full social inclusion. www.downmadrid.org.

In collaboration with Lumos: www.wearelumos.org. Lumos works to support the 8 million children in institutions worldwide to regain their right to a family life and to end the institutionalisation of children.