



# Listening Together

Examples of Child Participation in Action.



Protecting Children. Providing Solutions.



Turning Words Into Action



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# Introduction

The Turning Words into Action (TWIA) project took place over 21 months during 2011-2013 in Bulgaria, the Czech Republic and Serbia. Children and young people with intellectual disabilities, their parents, policy makers and health and educational professionals came together with a common objective: to bring the words of the World Health Organization (WHO) Europe's Better Health Better Lives (BHBL) Declaration to life in each of their countries.

## About this publication

Listening Together is intended to give a flavour of some of the methods used by the TWIA teams in Bulgaria, Serbia and the Czech Republic and some of the challenges involved in ensuring the meaningful participation of children and young adults with intellectual disabilities in all aspects of this project. It is not intended as an exhaustive manual to follow but to inspire all those who work with children with intellectual disabilities and the policy makers who work for them to integrate child participation into their work.

In annexe to this publication is a list of useful sources of further information about child participation. These were suggested by the project team and members of the project Steering Committee. This is one of a series of three publications which have been produced as part of this project. They are all available for download from the Lumos web site.

## Background

The BHBL Declaration built on the rights contained in the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD) by outlining what action each country must take to promote and protect the rights of children and young people with intellectual disabilities and deliver accessible services. To achieve this there must be a good understanding of what children and young people with intellectual disabilities need to ensure that their rights are realised.

Those with the responsibility for implementing human rights instruments and creating a more equal and accessible society need the experience of children and young people with intellectual disabilities to support their decision-making. It is the children and young people themselves who are most able to guide this process and their inclusion in shaping a better future for

themselves and others is essential. This was the guiding principle of the Turning Words into Action project.

The Turning Words into Action project involved policy makers and children with intellectual disabilities working in a new and participatory way. Together, they identified where policies and practices needed to be improved and suggested practical steps to improve the daily lives of children with intellectual disabilities.

## Children's Participation: the legal framework

The United Nations Convention on the Rights of the Child (CRC) is an international human rights treaty that grants all children and young people (aged 17 and under) a comprehensive set of rights.

In addition to the CRC, the UN Convention on Rights of Persons with Disabilities (CRPD) provides the international legislative framework for the rights of children with disabilities to fully participate in decisions taken about their own lives.

Article 12 of the CRC recognises the right of all children to participate in decisions that affect their lives. The CRPD preamble recognises, "the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices" while Article 3 lays out one of the general principles of the Convention, as, "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons."

In 2009, the UN Committee on the Rights of the Child issued a 'General Comment on Every Child's Right to be Heard.' The General Comment lays out in detail expectations on governments to take steps to protect, respect and fulfil children's right to be heard. Participation is a guiding principle of the UNCRC, meaning that not only is it a right in itself, but a principle that should inform every other right in the CRC.

The right to participation is also detailed in other human right treaties for specific groups, including disabled children and young women, and in regional treaties including the European Convention on Human Rights (ECHR).

Priority 7 of the WHO Europe Better Health Better Lives Declaration commits all the 53 European countries that signed it to, "Empower children and young people with intellectual disabilities to contribute to decision-making about their lives."

## About The Turning Words into Action Project

The project involved **two key activities**:

### 1. National Working Groups:

National working groups were formed in each of the three project countries. They were made up of policy makers from various levels of government, service providers, NGOs and children and young people with intellectual disabilities and their family members. The groups identified and agreed their starting point in each country. They looked at previous successes and failures, the number of children in residential care, barriers to community participation - including attitudinal, provision of services and legislative barriers and challenges. They then proposed concrete steps which should be taken to ensure the implementation of the Better Health Better Lives Declaration in their country. Working Group meetings were organised in such a way to ensure that children and young people with intellectual disabilities had meaningful opportunities to communicate their views, needs and wishes in a manner appropriate to their individual skills and communication styles.

### 2. Child Participation Activities:

Groups of children and young people with intellectual disabilities were formed, in cooperation with partner organisations, to enable them to express their views and advocate for change. The age criterion for participation was applied flexibly: For example Children and young people, in some cases young adults up to the age of 30, participated in the group activities. Young adults with intellectual disabilities, many of whom had grown up in institutions were included in the groups in response to their lack of opportunity and access to vocational training or education. The project represented an opportunity for them to learn more about their rights, support their younger peers and to express their need for employment, lifelong training and education opportunities based on their own personal experiences.

Through the groups, children and young people were empowered to become self-advocates and to participate at National Working Groups and Transnational Meetings. The young people each organised their own Child Choice event to raise awareness of their rights. Young adults with intellectual disabilities, many of whom who had grown up in institutions, were included in the groups in response to their lack of opportunity, access to education or vocational training and to give them an opportunity to learn more about their rights and express their need for on going training and support.

## Why is Child Participation Important?

This is what the children said:

*“We want to become stronger, and we want our voices to be heard out loud.”*

*“We need you to ask us what we want.”*

*“It is very important to ask me questions – How was it today? How is it going?”*

*“We learn how to listen to each other.”*

*“You can ask the mother or father, but you will get the best answer from the child.”*

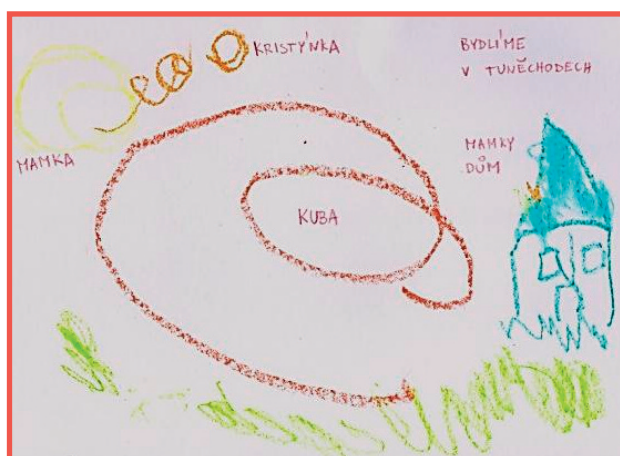
*“I think parents should ask us about our opinion, we know what is best for us. To be happy and satisfied we have to give our opinions about our life.”*

*“All of us have the right to continue studying, get a job and to be the same as everyone else. We are not second-class people, we are the same. We should have equal rights.”*

*“Any young person with disabilities has the right and need to have contact with so called ‘ordinary’ people. We are good for each other.”*

*“I really like this initiative because we kids, through talks, sharing, entertainment receive life lessons, and learn how to solve difficult things in our life.”*

Drawn messages from children with communication impairments:



This is what the adults<sup>1</sup> involved said:

*“It was a very new experience for us to try to give a space to young people with intellectual disabilities to speak. I was impressed by the strength of their voice.”*

Member of the National Working Group.

*“Thanks to these group activities, for the first time, after 10 years of being shy, my son has started to sing again, even in front of other people. He has much greater confidence and self-esteem now, in one word he feels excellent!”*

Parent.

*“I see a tremendous change in my son because of his participation in the group. He is willing to go there every time, and expects to draw with others.”*

Parent.

*“My daughter has had positive expectations from each group activity, waiting for another meeting and asking me when the next one will be. For many years, my husband and I have been facing huge barriers in supporting our daughter’s communication and socialisation with others. Thanks to this project we think our daughter’s communication has got a lot better”*

Parent.

## Child Participation in Practice

Despite the international Conventions, far too often well-meaning adults, including policy makers, service providers, parents and caregivers, make decisions on behalf of children with intellectual disabilities without consulting them about decisions which have a direct impact on their lives. In addition, parents’ priorities and wishes for their children are not always the same as the child’s priorities and wishes. While most children are able to express these feelings and views to their parents, these have to be actively sought and facilitated for children with intellectual and communication impairments.

<sup>1</sup> (Included staff from institutions, parents, professionals and policy makers.)

True and meaningful consultation with children in general remains rare and for children with disabilities, it is exceptional. When efforts are made to include children with disabilities in decision making processes, they are almost always directed at children with physical or sensory impairments, as it is felt that they are easier to include because of the communication and behavioural challenges associated with intellectual impairments. While these children are currently given little control over their own lives and decisions, even the most severely impaired are capable of doing so with the correct and necessary support. Children with intellectual disabilities and complex conditions such as Autism, Down syndrome or Cerebral Palsy are all but denied their right to participation, as outlined in Priority 7 of the Better Health Better Lives Declaration. Even in countries where disabled children are consulted with some frequency on decisions regarding their own lives and needs, involvement at higher strategic levels of planning and policy remains rare.

Where disadvantaged children are given the opportunity to act as advocates for themselves and for others in wider decision-making about policy and reform, the benefit is hugely positive on an individual level as well as on a wider community level.

This is how project participants described some of the benefits of child participation:

***“These child participation activities are changing even our mind-set. At first I was shocked when I was asked what my child can do. It never occurred to me that I did not think what he could do; I only thought of things that he couldn’t do.”***

Parent.

***“We have children with intellectual disabilities in this room. The more [Child Participation] opportunities they get, the more adult their behaviour is. I would never have thought that they would get through the day without being tired. There were no outbursts of anger. Of course they are tired but they are rather adult in their behaviour. I saw one boy working with the earphones, he learned quite well, and could react when Czech is spoken. Children should be able to access these kinds of opportunities.”***

Steering Committee member, academic.

***“I think it’s very good that children were the main speakers today because they have so much to tell us, and that’s the way it should be. Children should be those who speak, and we should be listening. We should not be talking on behalf of children.”***

Policy Maker.



## Impact of participation on children and young people:

- Children learn about their rights.
- Their self-esteem and confidence can improve through new knowledge, new skills, stimulation and support.
- They get opportunities to learn and practice social skills, such as listening, negotiating and showing respect; and life skills such as solving problems, making decisions and analysing information.
- They become aware of different perspectives and democratic processes, including improving services through participation, consultation and compromising.
- They learn that they play an important part in their own lives, and in the life of their community. Participation activities offer a practical experience and opportunity to learn how to advocate for their own rights.

## Benefits to the community and society from child participation:

- Children involved are empowered to make change happen. This builds their individual confidence and self-esteem. It also allows them and others to develop important communication skills. Children learn to solve problems in a constructive and democratic way which therefore can help them contribute to how their communities develop.
- Children's participation raises public awareness of the needs of children and helps to build and improve services. Policies developed through consultative processes involving child participation are usually of a better quality and are more likely to respond to the needs of children.
- Children with intellectual disabilities are, of course, the only ones who can describe issues from their perspective. They are the experts in their lives; we cannot improve services for them without their involvement. Policy makers involved in participatory processes begin to see children as partners and agents of change, rather than just as 'beneficiaries' or recipients of services. The participation of children often induces policy makers to give greater priority to an issue and can therefore bring about more targeted and effective services in the future.

## What is child participation?

Engaging in meaningful participation is essential to children's growth and development into responsible adults and active citizens. Participation provides the opportunity to express a view, to influence and achieve change.

Hart defines participation as: “the process of sharing decisions which affect one’s life and the life of the community in which one lives. It is a means by which democracy is built and it is a standard against which democracies should be measured”.<sup>2</sup>

Children and young people have the right to participate in decisions that affect their lives, the lives of their community and the larger society in which they live.

### This is how the children defined child participation:

*“We had a chance to tell the adults our opinion, they heard our voices.”*

*“I sang in front of everyone, which I had never done before.”*

*“Give us a chance to share our dreams, hopes and problems.”*

*“Meetings with new and old friends.”*

*“I had a chance to talk about my dreams, getting a job, friendship, doctors and what is good or bad for me.”*

*“I rode a bicycle with my friend and after that we discussed children’s rights!”*

*“We learnt not to argue in a bad way, and how to work together.”*

*“It helped me to become useful for myself and also for others. I got brave, more confident, and I started to feel that people are listening to what I have to say. I became a thoughtful and more independent person who is able to analyse things. The project opened a door to for us to achieve more in our lives.”*

<sup>2</sup> Hart, Roger A., Children’s Participation: From tokenism to citizenship, Innocenti essays, no. 4, UNICEF International Child Development Centre, 1992, p. 5.

## Points to consider when working with Child Participation:

Child participation is not simply an activity, but a way of working with children and young people with intellectual disabilities. It is a journey as well as a destination.

It is important to try to involve every child in group activities and to develop and plan activities in partnership with them. It is essential to find out what a group enjoys doing, what their strengths are and how to use those strengths in designing and building activities. It is also important to consider the barriers that children may face when engaging in group activities.

Child participation is based on children's knowledge, information and past, present and potential experiences. They are more likely to participate as long as they are comfortable and encouraged to be enthusiastic. They need accessible information and support from trained and prepared adults. Involvement should be by choice with the freedom to opt out. The methodology should include local traditions and practices that will support the development of new skills and experiences for the children involved.

There is no one clear approach or strategy on how to organise Child Participation. However there are some core guiding principles which the project team found useful:

- **The process is just as important as its outcomes.**
- **Participation is a human right that all children and young people are entitled to. All children have the potential to participate in decisions that affect their lives.**
- **Adults need to adjust their behaviour, language and practice in their relationships with children.**
- **The activities should create a safe space for children to express themselves and where they can grow in confidence to take action.**
- **Short- and long-term goals and plans to influence policy makers should be developed.**

There are a number of risks and challenges to be considered in developing child participation activities:

- **Children need to understand the purpose of their participation.**
- **Participation cannot be genuine unless children understand the consequences and impact of their opinions.**

- **Children are vulnerable to manipulation and exploitation. It is the responsibility of the adults involved to ensure they are not putting words into children's mouths.**
- **Without appropriate support involving children in developing policy to reform services may raise unrealistic expectations about timescales for change. Adults involved must ensure that children have a realistic understanding of what their involvement might achieve in the immediate, short and long term.**
- **Child participation activities are often short-term. Often children are asked to participate in a specific event or action, and there is little or no follow-up. This can result in disappointment and frustration on the part of the children or at worst, a sense that they have been exploited.**

The following examples from the Turning Words into Action Project illustrate the approach taken to try to address some of these challenges.

#### **Example 1: Preparing children who live in institutions**

The TWIA project aimed to provide participation opportunities for children with intellectual disabilities in institutions, as well as those living with their families in the community. Children in institutions are used to a rigid system and many children had not been used to having a choice or making their own decisions based on their personal preference. This meant that the children needed some individual time at the beginning of the process, to assess their individual needs, to understand preferred communication methods and to be given time and opportunities to learn to make choices. They also needed to have the chance to listen and to express their own thoughts rather than trying to guess what was 'the right answer' that adults were looking for.

#### **Example 2: Getting started and helping children understand the process**

In Bulgaria the project team sought to include 15 children from a wide range of backgrounds: those with intellectual disabilities from both residential institutions and from families, their siblings, children from mainstream schools and young activists. The team then set about engaging parents, professionals, institutions and staff and enlisting their support for child participation principles and values. Once a programme of activities had been developed, the team created a stimulating environment in which the children could participate, have fun and accept this new experience as part of their routine.

Potential child participants were visited at locations in which it was felt they could comfortably be introduced to the concept of participation; they were then invited to join the group. A colourful, personalised invitation booklet was prepared for each child, presenting some basic idea of what the child might experience in the group. This approach was designed to help build a sense in each participant that they owned the group and that their participation in it was valued. It was hoped that this approach would contribute to build the self-esteem and confidence of the participants.

Once the children were comfortable working in groups, sessions became focused on empowering children to feel confident to express positive and negative feelings and views on the Better Health Better Lives Declaration, and what it means for them and their lives. Activities were designed to help children to accept themselves and to be proud as individuals with potential and abilities to be discovered and supported. Some representatives of the groups were given opportunities to participate at national meetings with policy makers and contributed their views to plans aiming to improve lives of children and young people with intellectual disabilities.

### **Example 3: Preparing the adults**

It was equally important to prepare the adults who were going to be involved in supporting the children and young adults. Therefore in a parallel process, during the project period, the 3 Local Coordinators employed for this project organised approximately 15 meetings and training sessions for family members, personnel working in residential institutions, members of the National Working Groups and NGOs to raise their awareness on the rights of children with intellectual disabilities and the basic principles of Child Participation. At these meetings parents and carers discussed children's abilities and their capacity to contribute to decisions about their own lives and the need to overcome the many negative stereotypes of disability with which they are often confronted.

Parents and carers were actively involved all the time sometimes together with the children but many times in parallel. They discussed the same issues based on BHBL Declaration, supported children to participate when they were together, or expressed their views on personal issues about their local and national environment for raising children with Intellectual Disabilities. The ratio of adult supporters to children was generally 2:1.

The challenge of having adults so closely involved in the actual exercises and who are usually considered as "gatekeepers" for those with intellectual disabilities is well documented as they

are often in a role of speaking for the child or adult for whom they care.

However as a consequence of their involvement in the project, parents became mobilised, interested and engaged. Involving adults as supporters helped them to see beyond disability and recognise ability and at the same time ensure empowerment of children of the children and young people that they were supporting.

### **Asking the experts: Tips from children about participation activities:**

***“Make it Fun.”***

***“Make it Interesting.”***

***“Give us chances to make new friends.”***

***“Help us learn about our rights.”***

***“Help us learn to listen to each other.”***

***“Use pictures, games and easy words.”***

***“Give chances to tell adults about our opinion.”***

***“Make us heard.”***

***“Give us chances to talk and share about our dreams, hopes and challenges with each other.”***

***“Do something together.”***

***“Learn new things.”***

***“Create rules that make everyone in the group welcomed and happy.”***

***“Create a wonderful atmosphere.”***

***“Help us grow and become more.”***

***“Keep your promises.”***

## Learning Points from the Process:

Below is a selection of some of the lessons learned by the project team in delivering child participation activities as part of this project. More detail about the project and its results can be found in the *Turning Words into Action* and *Our Words our Action* publications which can be found on the Lumos web site.

### Impact on family well-being.

Particularly in Bulgaria the involvement and engagement of families was found to be greater than expected with anecdotal evidence of positive benefits on the well-being of family members. For example, some family members said that they found that the participation activities had an impact on their thoughts and feelings and that they felt more positive about the future for their children more ambitious about their potential. Although child participation is a primary aim of the project, the BHBL Declaration emphasised how the health and well-being of children with intellectual disabilities is dependent on that of their family (for those who live with families or in family-like settings). Family members can be powerful advocates and allies and may have wider influence within their own communities than politicians or policy-makers. In countries where institutional care is widely used, such family members could act as role models and help to shape positive attitudes towards family and community-based alternatives. Families who have been engaged in this project may therefore be key to the sustainability of activities and initiatives after the project is complete.

**Learning point: Future work should also consider a separate strand of activity specifically working with family members to address how family attitudes, beliefs and resources can be strengthened within countries.**

### Involvement of mentors and role-models.

A professional adult self-advocate with intellectual disability from the UK was actively involved in the steering committee meetings of the project and the transnational workshops. By speaking out with confidence, he acted as a positive role model for young people from participating project countries. The older young people who worked with him returned back to their child participation groups inspired to mentor those younger or less confident than themselves. At an early steering committee meeting, a parent of a child with an intellectual disability also shared her experience and knowledge on supporting her child's participation without imposing her own views on her child and respecting her child's human rights and dignity. This was helpful to the other parents

involved who before the project, had little experience of supporting their children to advocate for themselves.

**Learning point: In order to achieve sustainable outcomes from child participation and continuity of action, it is important to learn from the experiences of others and enable supporters to best empower the children and young people involved.**

### **Child participation activities as part of a project.**

When child participation activities are part of an externally funded project, it is important that there is a shared understanding and clarity of the underlying principles and aims of that project. This is especially important in a transnational project such as Turning Words into Action, where different countries may have a different interpretation of the concept of child participation. In addition, it is important that the project cycle is flexible enough to ensure that the child participation activities can evolve at the appropriate speed for the children involved. A notable feature of Turning Words into Action was that from an early stage, the young people involved expressed strong concerns that the child participation activities should continue after the end of the project. This prompted Lumos and its local and national partners to commit to maintaining the child participation groups after the project.

**Learning point: Time should be taken to allow the children (and adults) involved to fully understand the purpose of the project and give space for the children's concerns or questions to be answered. Concepts which are well understood in one country, might cause confusion in others. For example picture tools developed in one country showing cultural diversity might confuse a child in another country where such images are rarely used. Every effort should be made to ensure the sustainability of the child participation activities if this is what the children involved wish. Key relationships, partnerships and collaborations across statutory and non-governmental organisations, professionals, self-advocacy and family groups should be built up to achieve this goal.**

### **Lack of awareness or skills in professional groups e.g. doctors, social workers.**

Children and young people and their families all raised the lack of training, awareness and skills in health and social care professionals as a significant barrier to implementation of the



BHBL Declaration. They voiced concerns about not only a failure to be able to meet the health needs of children and young people with intellectual disabilities but also in terms of their power and influence over the direction of their own care or treatment. ( e.g. determining that institutional care is not the most appropriate or expedient intervention.)

**Learning point: While training and awareness-raising of these groups might be seen as peripheral to the child participation activities, vital issues such as these may present a barrier and impede the potential impact of child participation activities. Therefore specific actions and initiatives may need to be taken alongside the main project work.**

**Poor status of professionals working with people with Intellectual Disabilities.** This is again a potential barrier to ensuring optimal health and wellbeing for children and young people with intellectual disabilities. The absence of specialist skills and provision focussed on the needs of this group can mean that professionals may find themselves with little incentive or motivation to be able to do things differently if their work is seen as have little value and low status.

**Learning point: Staff need to feel valued and given positive encouragement to become and remain involved in child participation activities.**

## Child participation in action

Project teams from three countries shared their examples of sessions and activities that have contributed to the success of this initiative. Here is a selection of the activities which they found effective. More detailed session plans can be found in the appendix. Further tools can be found in the resources section in annexe to this report.

### Providing Choices

Offering children choices encourages their independence and learning. When we offer children choices, we allow them to practise skills of autonomy and responsibility, while we look after their health and safety by monitoring the options.

Making choices is part of problem solving. When given choices, children stretch their minds and create new and unique combinations of ideas and materials. This contributes to their cognitive development and self-esteem.

Choices offered to young children must be legitimate and meaningful to them and not too overwhelming. When there are too many options, even adults have difficulty choosing. Therefore younger children manage better with fewer options.

Children in institutions, who are used to decisions being made for them, may easily feel overwhelmed by a situation in which they are suddenly expected to choose for themselves. They need time, support and practice as well as patience to help them learn this skill.

These are examples of activities that were used with children and young people participating in the project.

### Activity 1. Art sessions.

For our art sessions we used various materials which are tactile and have different textures so they are interesting for children to explore – shiny paper, bubble wrap, silky materials, ribbons, wool, string, glitter etc. We played with soft toys and encouraged finger painting. These are good for developing fine motor skills, cognitive skills and self-expression. Using materials like pictures from old magazines, photos and stickers was also identified as a creative and helpful way to exchange views and share experiences. It was obvious that children were exploring

some of these materials for the first time. We expanded the choices available by doing cooperative activities, such as playing musical instruments, singing and playing games with a small parachute, which were very popular. We had a lot of fun.

## Activity 2. Our jobs.

A lot of participants in the Czech group were over 18 years old. The question of having a job was very important for them. Some of them already work in sheltered workshops or help in the institution, by doing cleaning jobs or helping in the kitchen. A lot of them attend a practical vocational school, or a transitional programme between school and a job.

They have a lot of aspirations about their jobs and future life. We had a couple of sessions where we discussed these issues. During the session they tried to choose an occupation for themselves and explain their choice, either by describing or drawing it. This was followed by discussions on how they could get a job, what their strengths are and where they might need support.



## Activity 3. Life outside an institution.

Some of the young people involved in the project live in institutions. These children usually take part in free-time activities within the building, but rarely have the opportunity to go out. Young people and children often have fears about going out into the city, and therefore spend all of their free time in the institution. As part of this project, we held sessions where they were encouraged to think and imagine what the world outside of the institution might be like, and what activities they could do. As a result we organised many trips out: exploring the surroundings, travelling by bus and train, going to the zoo, visiting a puppet museum, going to an amusement park, having a bonfire and cooking sausages, and many other activities. These events were not just about having fun, but also about providing more choices and learning new things.

## Activity 4. Agree or disagree.

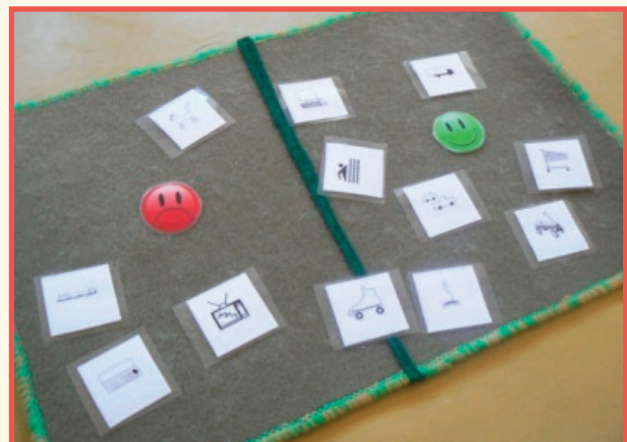
This exercise works very well for children with low self-confidence and for children with communication difficulties. We prepared a list of different statements that were relevant to the participating children. Then we placed three signs around the room: “agree”, “disagree”, and “do not know”. Depending on the age and ability of the group, sometimes it’s helpful to use emoticons, e.g. a smiley face, unhappy face and unsure face. One person reads a statement from the list and lets the players move around and express their attitude to the statement by standing near their choice. This exercise can be also used for filling in questionnaires for surveys or feedback.

## Activity 5. Yes or no.

This exercise helps participants become more confident in expressing their views. The group is divided into two. They then stand or sit in two rows facing each other. One side just says “yes” and the second side just says “no”. During our session we created a kind of very impressive dialogue, where participants reacted to each other emotionally; sometimes aggressively, sometimes quietly and calmly.

## Activity 6. Communication pad.

This is a great tool for children that understand pictograms, pictures or photos. It is a useful tool to learn what a child prefers, e.g. offering a choice of two options to, determine popular and unpopular things, foods, subjects, people etc. Children can choose yes or no by using smiley faces. It’s very easy to make – we used a piece of carpet and made pictures or pictograms with adhesive Velcro on the back. (This is sometimes referred to as a Picture Exchange Communication System or PECS.)



**Case Study: supporting communication with peers.**

Sasha had limited language skills. He communicated through PECS. While this form of communication worked very well in his interaction with an adult practitioner, he could not easily interact with his peers, which was effecting his confidence in himself. During an icebreaker session a Local Coordinator created a guessing game with PECS which raised the interest of other children in this form of communication. Sasha was made an expert, smiling and nodding when other children were right in this new guessing game. Sasha became popular and his self esteem was restored. Other children learnt about the needs and strengths of Sasha, and most importantly how to be more inclusive.

**Activity 7. Child-choice events.**

All Child Participation groups in three countries were given an opportunity to plan and organise an event of their own choice. Children were given a budget, support and resources to design, plan and carry out a fun event, which was highly visible to the general public, which demonstrated their inclusion in community life and highlighted the BHBL Declaration's priorities. Local coordinators facilitated the decision-making for this activity and the use of the budget, as part of the child participation working group sessions throughout the project. These child-choice events were widely publicised through local media. The events were a great success in all project countries, and served as a great opportunity to disseminate positive messages of children and young people challenging discriminatory attitudes in their countries. (They are further described in the publication, 'Our Words. Our Actions' which can be found on the Lumos web site.)

**Observing and listening**

Observation and listening are vital in organising participation activities. This includes using all senses and emotions, and is not limited to speech.

Observation can be key in collecting children's views, particularly for children with severe communication impairments. Children show how they feel by the way they do things, as well as by what they do. Children also communicate through their voices, postures, gestures, mannerisms, and facial expressions. If a child has complex disabilities it is always good to start by asking a child to show you their 'Yes', 'No' and 'Don't know' signs. It's possible to learn the child's communication system, even if it is unfamiliar at first.

Another key principle is to establish a listening culture where everyone's view is taken into account using many ways of listening, including different activities, observations, using puppets, art and drama and taking into consideration the children's ages, abilities and consent.

These are some examples of activities used by the project team to promote observation and listening skills.

### Activity 8. I like...

All the participants stand in a big circle. The leader starts by saying: "I am John and I like drawing." While he is saying the sentence, he mimes the activity. When the player has taken his or her turn, the rest of the group repeats, "This is John and he likes drawing". Everybody mimes the activity. This keeps going round the circle.

### Activity 9. Rhythm machine.

All the participants sit in a circle. A volunteer starts by standing in the middle of the circle and making a movement and a sound. The task for other players is to connect with another movement and sound to the previous player, to create a 'working machine' with sound and motion. By the end everyone is involved in one machine. This is a great training for cooperation and increases perception of each other.

### Activity 10. Rights and needs.

The group were given cards with pictures of different rights and needs. The group discussed what they meant and what the difference is between a right and a need. Participants were asked to divide the cards into two groups, and then to choose the five rights and five needs which they thought were the most important for them.



## Reflecting and feeding back

Reflecting or thinking about what has been observed and recorded is an essential part of any child participation activity. It includes a responsibility to act on the views of children as appropriate, and to make sure that they receive feedback.

Group child participation activities may start by simply telling children about their human rights or the principles contained in the BHBL Declaration. They can start by exploring stigma and prejudices that create barriers in the community. Another way of supporting and involving children can be by discussing their concerns, hopes, dreams, or any other topic that children feel like sharing

These are some examples of activities used by the project team to promote reflection and enable feedback.

### Activity 11. New home in the community - reading session.

To make our sessions useful, we focused on the process of deinstitutionalisation, which was relevant to the actual situation of the children. We talked about living their dreams, by discussing the places where they would like to live, with whom, and whether they could imagine such a place. We provided some outputs from our reading session, where we used Books Beyond Words to inspire young people to think about moving to a new place and get some idea of what it would entail.

Books Beyond Words ([www.booksbeyondwords.co.uk](http://www.booksbeyondwords.co.uk)) can be a great tool that helps people with intellectual disabilities to explore and understand new concepts and challenges in life. These books tell stories in pictures and make learning and communication easier, more enjoyable and effective.



## A story about Adam

A leader or facilitator sits in a circle with young people, holding a book so that everyone can see it well.

**Facilitator:** “We are going to talk about a young man called Adam. He is living in a big institution with several people and some friends. Now I will let you to continue the story by looking at pictures. What is happening there? Someone came to visit him.”

**Tereza:** “Parents.”

**Míša:** “Grandma and grandpa.”

**Facilitator:** “They are showing him something, showing a house.”

**Tereza:** “That he will be living there on his own.”

**Facilitator:** “You think he is showing them he will be living on his own, now a woman has come to visit him.”

**Eliška:** “A social worker, right?”

**Facilitator:** “Well, it might be a social worker. What is she showing him?”

**Eliška:** “Showing him that he may live on his own.”

**Facilitator:** “So he might live on his own in a flat or a house.”

**Facilitator:** “What is Adam doing now?”

**Jakub:** “Congratulating.”

**Tereza:** “Saying hello.”

**Petra:** “Saying goodbye.”

**Facilitator:** “He is saying hello to somebody, who?”

**Tereza:** “Saying hello to people.”

**Facilitator:** “He is saying hello to a woman. Let’s look at another picture.”

**Eliška:** “Well, here he is going inside, going to have a look at the flat probably.”

**Facilitator:** “He is going there to look at the house or the flat. Who has he met there?”

**Eliška:** “Family.”

**Petra:** “Or his friends. He has met some friends there.”



**Facilitator:** “So he went inside and met friends there. And here what is he doing?”

**Petra:** “He is reading newspapers.”

**Miša:** “He is holding a map.”

**Eliška:** “He is reading something.”

etc.

The story was very relevant and easy to understand, especially for young people who live in institutions, as many of them have had similar experiences. For young people with an intellectual disability from a family background, it was more difficult to understand some characters (a director of institution, a social worker). Therefore it was mainly the young people from institutions who took part in this free narration. For many of them, the idea of living on their own was introduced and after the narration of the story they were able to say specifically whether they would prefer to live on their own or with somebody else, and what they would take with them to the new place.

## Activity 12. Peeling oranges.

We brought some oranges into the room, and used enough to share one with each participant. Firstly we looked at them as a group and discussed whether they are all the same. We let participants think about the characteristics of the oranges, and asked them to put them down on paper. Then we distributed one orange to each participant and asked them to peel it. We discussed again the similarities and differences. We tried to show that all oranges are ‘the same’ at first sight, but after a careful look they are actually very different, just as people are.

## Activity 13. Evaluation of the session.

During the sessions we did not just use our own observation and assessment, we also used feedback from participants. Here are some of our evaluation methods:

- Individual satisfaction of participants during each session: everybody expresses his or her feelings about the event, before and after the meeting on a large poster.
- Group satisfaction is another way of sharing feelings and attitude to the event, by using a magic ball or another game.

- Parents' feedback notes or talks during or after the meetings.
- Informal individual communication during snack time or before the end of the sessions.
- Feedback from team members, helpers and guests.
- Written notes from specialists who participated in sessions.
- Questionnaires filled in after the training.
- Informal meetings with parents and colleagues.

## Activity 14. Agreeing and establishing values and principles of the group.

The picture below shows the key ingredients that we chose to build our child participation activities on in Bulgaria. We wrote the values on stones to symbolise stepping stones for success. These were the starting point for all our work.

### “Our values”

- Provide individual choices.
- Create a friendly and safe environment
- Ensure mutual respect
- Use accessible and relevant information
- Establish a dialogue and culture of listening.
- Aim for usefulness for all involved.



## Building self-esteem and confidence

A child's self-esteem and confidence is usually influenced by how much he or she feels wanted, appreciated and loved. A child's view of him or herself is often built from what parents, carers and those nearby say to them. It is built from his or her sense of achievement, and how the child relates to others.

Children's self-esteem can grow through participation activities, if they are built around promoting self worth, responsibility, autonomy, self-awareness, emotional competencies, developing

new skills, membership and belonging.

Their confidence can be boosted by showing **appreciation** for their participation, contribution, opinions, ideas etc. Thanking a child when he or she does something good can have a very positive impact.

Esteem is boosted with **encouragement**. Encouraging decision-making can help to build a feeling of confidence and independence.

Children's self-esteem becomes higher if they are treated seriously and with respect. Explain everything to the child and treat him or her as an intelligent individual able to understand and reach conclusions. A child who is belittled, patronised or put down will suffer from a lack of confidence. Mutual respect will foster trust and confidence.

Furthermore, to empower children to participate in decisions that affect their lives, it is important that they are provided with support to develop their skills. This includes training about their right to be involved in decision-making and having their voices heard.

These are some examples of activities used by the project team to build the self confidence and self-esteem of the children and young people.

#### **Case Study: Providing choices to build self-esteem.**

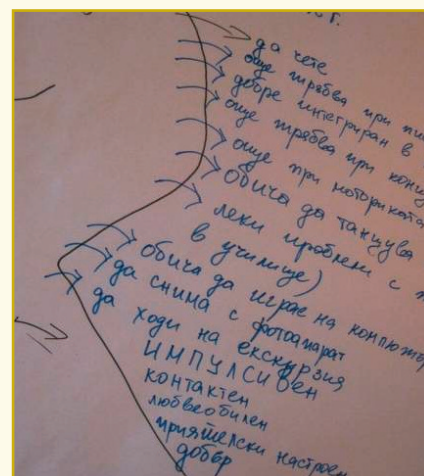
Tanya had Down's syndrome and had been lacking in interest to engage in group activities. She was only happy to join in singing children's songs. As a result she was not accessing the range of other activities available. The more she refused to try new activities the more her confidence was being affected. The Local Coordinator decided to encourage her to play an active part in the planning of sessions, so she was given a role to choose which song to sing during fun break exercises. Tanya gradually started taking part in choosing other activities too, including a friend to perform an activity with.

## Activity 15. I can speak up for myself.

This topic was the main idea of most of our sessions. We wanted to let young people speak up for themselves. We tried to discuss ordinary, day-to-day situations, cases and problems that they struggle with. We discussed medical care and doctors. We asked about making decisions, and whether they are really responsible for their statements. We also asked what they would like to achieve, and what their dreams and wishes are. The children were able to express their own wishes very easily. They want to have a job, money and friends. They usually think about the world from their own perspective and it was very difficult for them to imagine the views or wishes of other people with disabilities for example.

## Activity 16. “My child can...” - Focusing on strengths.

During one of the sessions, parents of children in Bulgaria were asked to share with others what their children can do. Surprisingly this turned out to be a challenging exercise for some of them. Some parents admitted that while dealing with their children’s disability and everyday difficulties, they completely forgot how many things their children could do. Changing the focus of discussions from weaknesses into strengths, this session became an empowering reflection.



## Activity 17. If I were ...

This game is about association and abstract thinking, which can be quite difficult for people with intellectual disabilities, but after a couple of training sessions, it can work well.

The leader can start: “If I were a **dumpling**, I would be boiled in hot water, but because I am **a car** I...” The lecturer sends the idea to the next player. The next player starts the sentence with: “If I were **a car**, I would drive very fast, but because I am **a chair** I...” We keep going around the circle.

## Activity 18. Fairy tale space - imagination.

The players move around the room. We ask them to imagine they are in different spaces and situations, with all the participants miming together, e.g:

- “You are in the forest, you are picking mushrooms and berries, crawling through the bushes...
- Now, we are on the street like tourists, in the big city, we have cameras, looking into shops...
- It is raining and we are trying to run as fast as we can, to find somewhere to go out of the rain...
- We are on the beach, the sun is shining, we can swim, sunbathe...”

We can create whatever situation we need to think about to get some feedback about the project activities, or to remind the children of their best experiences or situations. For example you could ask them to imagine their first meeting with the group, another memorable meeting or a child choice event etc.

## Providing accessible information

Asking children to make decisions before they truly understand the issue being discussed misses a vital ingredient of successful child participation and risks tokenism. Children should have access to information, not just because they are in a child participation process, but because they have the same rights as everybody else. It is important to plan and allow time for making information accessible, and enough time for discussing the issues and exploring options.

One of the tools that proved to be particularly successful in supporting children and young people to communicate and participate in activities was the use of Communication Passports. They enabled the development of individual communication programmes for children with communication difficulties.

An agreement with a leading human rights organisation, CHANGE, allowed children involved in the project to meet and learn from adults with intellectual disabilities. As part of the steering committee meetings, a designated CHANGE staff member, who also had an intellectual disability, worked directly with the young self-advocates to develop models of genuine participation so that they could easily share their views with policy makers. Adult self-advocates can act as

role models, and increase the children's and young people's confidence to advocate for themselves and for others in their own way.

These are some examples of activities used by the project team to provide information in an accessible way.

### **Activity 19. Making a TWIA National Working Group Meeting accessible for children with intellectual disabilities.**

Here are some tips on how to make sure that meetings with others work well:

#### ***Everybody is involved***

- Everyone understands what is being discussed.
- Everyone has a chance to say what they want.
- We work in small groups as well as in one large group.
- We respect everybody's opinion.

#### ***It should be comprehensible for everyone***

- We use simple words.
- We agree on using red and green cards for young people with disabilities. ( When a child does not understand or wants to stop they show the red card. The green card means that the child is happy to continue and understands.)
- We provide enough time for expressing opinions.
- We provide enough time for everyone to understand what is being discussed.
- We always agree on key outputs of the discussion.

#### ***We try to hold the participants' attention and interest***

- Breaks.
- Games.
- Active approach.
- At the end of the meeting everyone knows what is going to happen next time.

## Activity 20. What does the BHBL Declaration mean for me?

We spent a lot of time trying to analyse the promises of the Better Health Better Lives Declaration. These were sessions involving art, music, visual materials like cards and toys, games, trips and excursions outside the institutions. Young people were provided with an easy-read version of the declaration, to assist better understanding. By sharing their experiences and listening to each other, the declaration became a tool to advocate for their rights. (A sample session plan around one of the priorities of the BHBL Declaration has been included in the appendix of this publication.)

## Activity 21. Communication passport.

We started to work on creating communication passports with some children to help them to reflect more about themselves, to get to know themselves better and to help staff in institutions in their communication with children. There is a huge staff turnover in big institutions and these passports can be helpful to get to know the child better and more easily than by studying the official documentation. The child can show staff the pictures and simple statements to let them know about him or herself.

(This content below is for illustration.)

### About me...

My name is Maria

I am 9 years old

I live in a big home with other children

I go to school in our home

### People around me...

I have a close friend Aneta who visits me

I like one "aunt"

Petra teaches me to use a communication book with pictures

### I like...

Sausages and pasta

Hugs

Jumping in a pool with balls

Swimming and bathing

### I don't like...

Charlotte (bread and butter pudding)

Noise and yelling

When somebody makes me do something I don't want to do

Wearing glasses

### What I am good at...

Puzzles and bricks

Putting on slippers and shoes with Velcro fastening

Eating with a spoon and drinking from a mug

### What I need to help with...

Buttoning and unbuttoning trousers

Zippering up

I manage to say what I want

### How I communicate...

I have my communication book with pictures

When I am scared, I cry, resist and sometimes bite

When I have a nice time with you, I stroke you on your back

When I feel like a hug, I take your hand and I stroke myself with it

### Case study: Language and Communication.

Dima had delayed speech and language skills. His parents would try to communicate with him and ask him what he had done at the Day Care Centre but sometimes would find it very difficult to understand his response. This would leave Dima being frustrated with himself. The Local Coordinator took pictures of Dima engaging in different activities and created a folder for him to share with his parents at the end of sessions. Using it his parents were able to initiate the conversation and help Dima talk about what he had done that day. Then his parents started sharing pictures of Dima doing things at home which helped him to join other children in this session with more confidence and joy.

## Having fun

Meaningful participation takes a lot of time. It takes time to build skills, trust and confidence. It takes time to discuss information, to reflect and develop opinions on it, to develop accessible versions of adult documents and to plan and contribute to action plans. This kind of participation can become a chore unless there is time for fun. Playing games can make learning fun so



children enjoy sessions and want to be there. Fun team activities help their social and cognitive development, leading to a greater confidence and capacity for self-expression. The best thing about children's play is that they learn a great deal while enjoying themselves. Play can develop language skills, thinking skills, small and large muscle skills and creative skills.

These are examples some of the games and activities that were played with children and young people. They come from websites, books and personal experience of local coordinators. ( Further examples can be found from the many resources included in the annexe to this report.)

### **Activity 22. Adjective with names.**

This is a simple activity used to get know each other. Everybody thinks about his/her name, and adds an adjective that characterises them.

### **Activity 23. Singing competition.**

We create two groups. One group starts to sing any song. The other group is listens for one of the words, and thinks of another song that includes this word. If they can think of a new song, they start to sing it. This continues with the two groups.

### **Activity 24. Sending claps.**

The group stands in a circle, and one person starts by clapping. We try to send the clap around the circle as quickly as possible.

### **Activity 25. Signs.**

All the children are given a sheet of paper, so they can draw a sign that represents them. They draw a coat of arms or a logo, and divide it into four parts. They can then choose four activities or items about themselves and draw or write them into the four gaps.

## Activity 26. Changing seats.

The group sits in a circle on chairs. There are fewer chairs than players. One person stands inside the circle and says, for example, "Change seats if you like the colour blue." The players who like blue stand up and have to find a new seat. The person inside the circle tries to get onto a seat. If the player in the middle is successful, a new player stays inside the circle and comes up with a new sentence: "Change seats those who like/have/are/know etc." This is a simple and fun way for children to find out something new about each other.

## Activity 27. Cooperation.

The group is divided into pairs. Each pair stands face to face. The pairs agree three movements or actions, and gives each one a number. One person is the leader, who says numbers one, two or three, in any order. The players jointly do the corresponding action.

For example:

- 1 - clap hands
- 2 - say the letter B
- 3 - touch knees

## Activity 28. Hearing memory game.

We distribute small boxes (plastic) with different things inside (rice, sand, peanut, coins, water, lentils, nails, screws, small stones, piece of paper,...). When you shake it, the box makes a sound. The participants look for a partner with a matching sound in the box. It is very popular game in our group. It is very helpful to differentiate sounds and for concentration. It can also be used if you need to make pairs in a creative way.

## Activity 29. Vampire Nosferatu.

This is a very fun way to get to know each other's names. Everyone stands in a circle. Before they start, each of the participants says their name. One participant is inside the circle, that child is the "vampire". The vampire chooses one person as a "victim" and slowly moves in their direction with arms stretched out. The "victim" needs to catch somebody's eye and wink at that

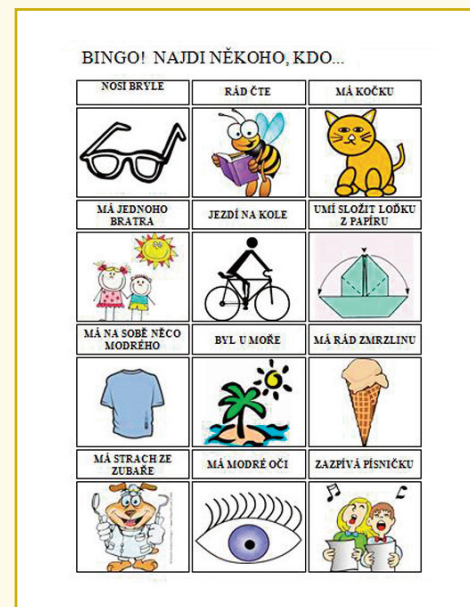
person to be saved. If the person gets the message, he or she must say the victim's name to save them. If the victim is successful the vampire has to take another turn. If not, the victim switches with the Vampire. This is a very entertaining and popular game.

### Activity 30. Kevin.

This game is very good for creating a relaxing atmosphere and assists concentration. Everyone stands in a circle, facing out. The leader counts to three. The group then shouts loudly. Everybody from the group turns round (facing in). They look down at their feet and silently choose one person from the circle. When the facilitator says start, everybody looks at their chosen person. If two people are looking at each other, the pair both shout out and leave the game. The game continues as long as there are players left in.

### Activity 31. Bingo.

Each participant gets a sheet of paper with different pictures including activities, colours, animals, food, hobbies and so on. The players find as many people as possible who do the activities, or like the food or agree with the things they have on their chart.



## Conclusion

The Turning Words into Action Project took place over 21 months during 2011-2013. It aimed to bring the laudable policy and practice commitments in the World Health Organization Europe's ***Better Health Better Lives Declaration*** to life. It did this through policy-makers and children with intellectual disabilities working together to identify where policies and practices needed to be improved and to suggest what practical steps should be taken now to improve the daily lives of children with intellectual disabilities. The views of children, young people and their parents were central to this process so participation activities were developed to enable this to happen.

Everybody involved in the project agreed that the equal involvement of the children in the actual design of these activities was key. This very experience of co-producing activities built their confidence in the process and also ensured that the views expressed were genuinely those that they most wanted to share. In turn this ensured that the views expressed highlighted what policies and practices most urgently needed to change to meet their needs.

Because the activities were developed together with the children and young people, the pace was adapted to their needs and capacities and built up over time in a sustainable way. Many activities focused on building opportunities for the children to express their thoughts about their daily lives, their dreams and their worries. Initially these opinions were largely about their individual concerns. Over time, a sense of group identity was built up and they began to express their opinions and wishes for all children and young people with intellectual disabilities, in their countries and around the world.

Enough time was given to prepare the children and young people before every meeting where they might be sharing their views with others and those meetings were organised according to the environment and structure most appropriate to the needs of the children not the conventions of the "adult world". Indeed for such a process to be effective, the commitment of everybody involved to work together on changing their way of working was key.

For the participation of all children in decisions that concern them to become sustainable and embedded in societies, a friendly environment, an inclusive culture and firm political commitment are essential. Such a culture change takes time. It requires understanding and commitment at all levels to exploring new ways of working together with children, starting from carers, families, professionals and policy makers.

The Turning Words into Action project aimed to demonstrate a new way of working together with children with intellectual disabilities as partners so that better policies, better practices and ultimately better lives for the many children and young people with intellectual disabilities whose views have for so long gone unheard.

Advice that was given to us by one of the young self-advocates is that not everything requires money; we could start by changing our attitudes. This all starts by “Listening Together.”



# Appendix: Example Session Plans

## Sample Timetable of Activities

The following is an example of a timetable of child participation sessions taken from one of the Turning Words into Action project countries. It is intended to illustrate how over time the theme of the sessions can develop and how the concept of human rights as contained in an international agreement such as the WHO Europe BHBL Declaration can be introduced. To illustrate how the activity sessions can be organised, detailed plans are included for themes 1, 3 and 6.

	Theme	Method	Resources
1.	My new friends. Let's meet and introduce each other.  Create together a safe, friendly atmosphere for all.	Games, fun activities, alternative space, personal space with photos, drawings, rest area, parents' corner.	Flipchart paper, crayons, markers, PECS, photos, colour paper, tape, personal photos, pictures for 'my corner' in the room;
2.	Let's get to know each other better!	Games for playing different scenarios exploring who we are. I am...; My family is..., my house, my school, my town.	Flipchart paper, old magazines, PECS, crayons, markers, colour paper, tape, finger puppets, art and craft materials.
3.	Value of different ways of communication. Understanding each other is important; find out different ways of communication, express your emotions, opinions, wishes, and dreams	Games, drawings, pictures, photos, life situations, puppet theater, example of positive communication;	Flipchart paper, old magazines, PECS, markers, colour paper, tape, easy read agenda, art and craft materials;

<b>4.</b>	Making simple choices every day.	Interactive games and activities in the park / garden.	Outdoor clothing, outdoor games, snacks and drinks.
<b>5.</b>	<b>BHBL Declaration. Priority 1.</b> Keep all children and young people safe.	Games, storytelling, discussion.	Flipchart paper, photos and pictures about keeping children safe.
<b>6.</b>	<b>Priority 2.</b> Support children to grow up with families.	Games, group exercises, discussion.	Flipchart paper, photos, pictures with relevant theme, art and craft materials.
<b>7.</b>	<b>Priority 3.</b> No child should live in an institution.	Games, group exercises, discussion.	Flipchart paper, photos, pictures with relevant theme, art and craft materials.
<b>8.</b>	<b>Priority 4.</b> Find out what each individual child needs.	Games, group exercises / storytelling, discussion.	Flipchart paper, photos, pictures with relevant theme, art and craft materials.
<b>9.</b>	<b>Priority 5.</b> Children and young people with intellectual disabilities need good health care.	Games, group exercises, storytelling, discussion.	Flipchart paper, photos, pictures with relevant theme, art and craft materials.
<b>10.</b>	<b>Priority 6.</b> Make sure families have help to care for children with intellectual disabilities.	Games, group exercises / storytelling, discussion.	Flipchart paper, photos, pictures with relevant theme, art and craft materials.

11.	<p><b>Priority 7.</b> Involve children and young people and their families in making choices.</p>	Games, group exercises / storytelling, discussion.	Flipchart paper, photos, pictures with relevant theme, art and craft materials.
12.	<p><b>Priority 8.</b> Train staff.</p>	Games, group exercises / storytelling, discussion.	Flipchart paper, photos, pictures with relevant theme, art and craft materials.
13.	<p><b>Priority 9.</b> Make sure services for children with intellectual disabilities and their families are good.</p> <p><b>Priority 10.</b> Pay money to make sure every child gets good health care.</p>	Games, group exercises / storytelling, discussion.	Flipchart paper, photos, pictures with relevant theme, art and craft materials.
14.	Let's choose our next theme together!	<p>Create a bank / jar of ideas to choose as a group our favourite next theme;</p> <p>Discussions and debates.</p>	Flipchart paper, old magazines, markers, art materials.
15.	Planning an event of children's own choice.	Games, discussions, planning.	Flipchart paper, old magazines, markers, etc.



## Sample Session Plans

### Theme 1 – My new friends. Let's meet and introduce each other.

<b>Overview</b>	This session allows children and young people to introduce themselves to each other and start making new friends.
<b>Key Aim</b>	To create a friendly environment so the children can get to know each other in a comfortable and fun atmosphere. To help children to build their self-esteem and confidence.
<b>Key messages</b>	We are all unique with different tastes, interests and abilities. We are different but equal. Each of us is an expert in various areas.
<b>Materials</b>	A4 sheets of paper for each participant, old magazines, coloured pens or pencils, scissors for children to share, tape or glue for children to share. alternative communication tools like PECS <sup>3</sup> , emoticons, traffic light cards, materials for ice breaker exercises.
<b>Facilitator notes</b>	To empower children and young people to think about themselves and things that makes them happy. To celebrate a diversity of tastes, interests and personalities.
<b>Activity</b>	Children and young people draw, decorate or make collages for their own badges that show their name, favourite animal, favourite colours and other things that make them happy. If carers or parents participate at the session they can write up things that they love or like about a child that they are supporting.
<b>Facilitator notes</b>	Explore and recognise our different abilities and skills. Focus on individual strengths and celebrate them. (Some children initially may need the support of their carers.)
<b>Activity</b>	Children are encouraged to show, mime or express in different ways what they think they are good at. This can vary from obvious abilities like jumping, singing to dreaming, being kind, loving, etc. Other children are encouraged to guess them.
<b>Facilitator notes</b>	Understand that although we are all different and have different interests and abilities, we also have a lot in common. Explore and see what common interests we share in the group.
<b>Activity</b>	Three emoticons are put in three different corners of the group. One shows a smiley face – indicating an 'Agree' sign, one unhappy face – indicating a 'Disagree' sign and one neutral face indicating a 'Not sure' sign. Facilitator reads out simple statements. After each statement children and young people choose to stand under the sign that corresponds to their view.  Some examples of statements: I like music; I like playing football; I love cats; I like painting; I like my school; I like meeting new people; I like stories; I like making friends.
<b>Activity</b>	<b>Closing activity. – 15 min.</b> Snacks, drinks and games. Saying goodbye.

<sup>3</sup> PECS = Picture Exchange Information System – see activity 6

### Theme 3 – Value of different ways of communication.

<b>Overview</b>	This session explores different ways of communication.
<b>Key Aim</b>	To explore, discover, acknowledge and value communication other than speech and language. To help children to build their self-esteem and confidence.
<b>Key messages</b>	We all communicate in different ways. Every form of communication is important and valued. Communication is not only about transferring of messages. It is also about sharing feelings, showing empathy and just listening. It is important to make everyone welcomed.
<b>Materials</b>	A4 sheets of paper for each participant, old magazines, coloured pens or pencils, scissors for children to share, tape or glue for children to share. alternative communication tools like PECS , emoticons, traffic light cards, materials for ice breaker exercises.
<b>Facilitator notes</b>	To explore body language. To raise our awareness on how we use our body to express ourselves.
<b>Activity</b>	The facilitator asks volunteers to show how they use their body to express themselves. She/he reads out different feelings, like joy, anger, etc. and asks children to show how they would express it. While they are showing it an adult volunteer or an assistant makes a list of them, if possible with graphic pictures on a flipchart.
<b>Facilitator notes</b>	Keep exploring other ways of communication, including PECS <sup>4</sup> and other symbols to find out how children in this group like to express themselves.
<b>Activity</b>	The facilitator shows different themed pictures, for example a mother giving a goodnight kiss to her child, children playing snowballs, somebody bullying a child etc. and after each picture the facilitator asks volunteers to show their opinion about the picture by means other than a speech or language. Other children guess what it means.
<b>Facilitator notes</b>	Find out what we find helpful in communication with and between the children and what creates barriers.
<b>Activity</b>	The group of children is split into two small groups where they brainstorm and make a list of things that they like or find helpful while expressing themselves and things that they find difficult. Some children are confident and better at expressing themselves via acting and should be given such choice.
<b>Activity</b>	<b>Closing activity. – 15 min.</b> Snacks, drinks and games. Saying goodbye.

<sup>4</sup> PECS = Picture Exchange Information System – see activity 6

## Theme 6 – Support children to grow up in families. (Linked to BHBL Priority 2.)

<b>Overview</b>	This topic introduces children to the concept of a value in growing up in a family as opposed to an institution.
<b>Key Aim</b>	To explore priority number 2 of the WHO Europe BHBL Declaration, the concept of a family and to empower children to express their views on living with a family. To help children to build their self-esteem.
<b>Key messages</b>	All children should be supported to grow up in families. They should live with their own parents whenever possible. If this is not possible then they should live in loving homes, with people who understand them, with their brothers and sisters.
<b>Materials</b>	Pictures of families for colouring, a range of family pictures expressing different moods and scenarios, old magazines, play dough or plasticine, alternative communication tools like PECS , emoticons, traffic light cards, materials for ice breaker exercises, coloured pens or pencils, scissors for children to share, tape or glue for children to share.
<b>Facilitator notes</b>	Children and young people express and share their expectations from the session via a method they most like or prefer. They are given a choice to do so via: drawing, writing, making a collage, or choosing appropriate pictures or PECS. <sup>5</sup> These are all displayed on a 'Our hopes from the session' board.
<b>Activity</b>	Opening ice breaker exercise ' I am here because I want to...or because I like to...'
<b>Facilitator notes</b>	Introduction to the topic. Explore: What do we mean by a family? What kinds of families do we know? What kinds of families do we like? Why?
<b>Activity</b>	<p>Children are given an opportunity to choose to engage in an activity of their choice. Each activity has a reference to the concept of a family.</p> <ul style="list-style-type: none"> <li>• Colouring pictures of families.</li> <li>• Making a joint collage on 'Family life' out of magazines.</li> <li>• Making a family of animals out of plasticine or play-dough.</li> <li>• Finding pictures of families they like from a pile of various pictures.</li> </ul> <p>Feedback from children and discussion.</p>
<b>Facilitator notes</b>	Children and young people assess the session by sticking a relevant emoticon or traffic light card on the 'Our hopes from the session' board next to their earlier expressed expectation cards.
<b>Activity</b>	<p>Three emoticons are put in three different corners of the group. One shows a smiley face – indicating an 'Agree' sign, one unhappy face – indicating a 'Disagree' sign and one neutral face indicating a 'Not sure' sign. Facilitator reads out simple statements. After each statement children and young people choose to stand under the sign that corresponds to their view.</p> <p>Some examples of statements: I like music; I like playing football; I love cats; I like painting; I like my school; I like meeting new people; I like stories; I like making friends.</p>
<b>Activity</b>	<b>Closing activity. – 15 min.</b> Snacks, drinks and games. Saying goodbye.

<sup>5</sup> PECS = Picture Exchange Information System – see activity 6

# Annexe:

## Bibliography and Resources on Child Participation

During the course of the project, the project teams found the following resources helpful. It is not intended to be an exhaustive list of resources on child participation but to give a taste of some of the expertise which exists across the world in this field.

- 1. The following publications focus on person centred planning, helping individuals identify their own strengths and aspirations and then shaping opportunities and support to encourage their personal development. To the author's knowledge they are not available online.**

Aitchison, J, Community Care Development Centre, Deciding Together: *Working with people with learning disabilities to plan services and support*, Institute for Applied Health and Social Policy. 2001.

Aitchison, J. and Perez, W. *Deciding Together: Getting Control of My Life*, IAHSF, King's College London, 2001.

Mount, B. & Zwernik, K. *It's Never Too Early, It's Never Too Late*, Metropolitan Council of Minnesota, 1989.

Pete Ritchie et al *People, Plans and Practicalities* SHS, 2003.

Sanderson, H. et al *People, Plans and Possibilities*, SHS, 1997.

O'Brien, J. et al *Action For Inclusion: How to improve schools by welcoming children with special needs into regular classrooms* Inclusion Press, 1989.

Institute for Applied Health and Social Policy, *Speaking Up For Health in Valuing Health For All*, King's College London, 2003.

- 2. The following resources are available on line**

WHO, Better health, better lives. Empower children and young people with intellectual disabilities, 2010. The paper provides background information and proposes pragmatic steps for giving effect to Priority no. 7 of European Better Health Better Lives Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families:

[http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0003/126570/e94430.pdf](http://www.euro.who.int/__data/assets/pdf_file/0003/126570/e94430.pdf)

Circles Network, Inclusion Matters: an introduction to person centred approaches, available at:  
[http://www.circlesnetwork.org.uk/upload/file/impact-report-3-12-10-final-final\\_lores.pdf](http://www.circlesnetwork.org.uk/upload/file/impact-report-3-12-10-final-final_lores.pdf)

Books Beyond Words: Books Beyond Words tell stories in pictures to help people with learning and communication difficulties explore and understand their own experiences.

<http://www.booksbeyondwords.co.uk/>

COFACE, The Family Dimension of the United Nations Convention on the Rights of Persons with Disabilities, 2012. The UN Convention on the Rights of Persons with Disabilities explicitly acknowledges the critical role played by families for the promotion of human rights and the inclusion of persons with disabilities in society. Available at:

<http://www.coface-eu.org/en/Publications/The-Family-Dimension-of-the-UNCRPD/>

Hart, R., Children's Participation – from Tokenism to Citizenship, UNICEF, 1992. Roger Hart's work is widely seen as a key to defining and understanding children's participation, available at:

[http://www.unicef-irc.org/publications/pdf/childrens\\_participation.pdf](http://www.unicef-irc.org/publications/pdf/childrens_participation.pdf)

Inter-Parliamentary Union & UNICEF, A Handbook of Child Participation in Parliament, 2011. This handbook addresses some of the key ways in which parliamentarians can guarantee that children's voices, concerns and interests find expression in and enjoy meaningful attention from parliaments. Available at:

<http://www.ipu.org/PDF/publications/child-parl-e.pdf>

Mount, B. & Zwernik, K., Making Futures Happen - A Manual for Facilitators of Personal Futures Planning. Available at:

<http://www.mnddc.state.mn.us/learning/document/GT124.PDF>

Murray, P. & Sanderson, H., *Developing Person Centred Approaches In Schools*, HSA Press, 2007. Available at:

<http://www.hsapress.co.uk/PCASchools/pdf/1273319685.pdf>

*New Path to Inclusion* this is project focuses on the transfer of the evidence based and innovative concept of "Person Centred Planning" (PCP) and Practice from the United Kingdom, to be adapted and conceptualized into new vocational education qualification formats for the rest of Europe. Available at:

<http://www.personcentredplanning.eu/>

Scown, S. & Sanderson, H., *Making It Personal; A provider's journey from tradition to transformation* Dimensions, HSA Press, 2010. Available at:

[www.dimensions-uk.org/EasySiteWeb/GatewayLink.aspx?allid=246](http://www.dimensions-uk.org/EasySiteWeb/GatewayLink.aspx?allid=246)

Scown, S. & Sanderson, H., *Making It Personal For Everyone: From block contracts towards individual service funds* Dimensions and HSA Press, 2011. Available at:

[www.dimensions-uk.org/EasySiteWeb/GatewayLink.aspx?allid=2787](http://www.dimensions-uk.org/EasySiteWeb/GatewayLink.aspx?allid=2787)

Save the Children, *Speaking Out, Being Heard Experiences of child participation and accountability to children from around the world*, 2010. Available at:

<http://resourcecentre.savethechildren.se/content/library/documents/speaking-out-being-heard-experiences-child-participation-and-accountabilit>

Save the Children, *See Me, Hear Me - A guide to using the UN Convention on the Rights of Persons with Disabilities to promote the rights of children*, 2009. Available at:

[http://www.crin.org/docs/See\\_me\\_hear\\_final.pdf](http://www.crin.org/docs/See_me_hear_final.pdf)

*Blissymbolics.*

Bliss is a symbol system first introduced as an alternative means of communication for children with physical impairments more than 20 years ago. Bliss was designed to be an international language. Available at: [www.symbols.net/blissre.htm](http://www.symbols.net/blissre.htm)

*Chailey Communication System*

This is a comprehensive communication system designed to incorporate a range of alternative systems e.g. pictures, photographs, Rebus, Makaton and other. The system grows with the child. Available at: [www.sussexcommunity.nhs.uk/index.cfm?request=b1004181](http://www.sussexcommunity.nhs.uk/index.cfm?request=b1004181)

CHANGE produces helpful resources and books on a series of issues including how to make information accessible, making transition work, child abuse and a series of 6 booklets on sex and relationships. [www.change-people.co.uk](http://www.change-people.co.uk)

*Children and Young People Now Manifesto* for children and young people. Available at:

<http://offlinehbpl.hbpl.co.uk/NewsAttachments/PYC/Full%20Manifesto1.pdf>

*Diversability* - Including Young People (with and without disabilities) within Youth work provision - Northern Ireland; has some useful insights. Available at:

<http://ycni.org/downloads/publications/DiverseAbility.pdf>

*Every Child's Rights to be heard* - a resource guide on the UN Committee on the rights of the child general comment no.12. Available at:

<http://www.savethechildren.org.uk/resources/online-library/every-childs-right-be-heard>

*After School – What's Possible?* A collection of DVD materials for young people and their families and it shows how citizenship skills can be built through after school activities. Available at:

<http://www.hsapress.co.uk/publications/dvd's.aspx>

Helen Sanderson Associates is a UK agency which develops materials for influencing policy and practice. See: [www.helensandersonassociates.co.uk](http://www.helensandersonassociates.co.uk)

*Include Me Too* for disabled children. This includes a charter of rights and you can listen to it as well as read it. Available at:

[http://www.includemetoo.com/index.php?option=com\\_content&view=article&id=56&Itemid=59](http://www.includemetoo.com/index.php?option=com_content&view=article&id=56&Itemid=59)

*Inclusion Press* has useful guides to inclusive education based on individualised approaches. See: [www.inclusion.com](http://www.inclusion.com)

*Participation Works*. This is a partnership of seven UK children and young people's agencies that enable organisations to effectively involve children and young people in the development, delivery and evaluation of services that affect their lives, available at:

<http://www.participationworks.org.uk/>

*Raise your Potential* – this toolkit from National Children's Bureau in the UK is a free resource aimed at workers or project leaders, for them to adapt and use when looking to train or support young people in facilitation research and media, available at:

[http://www.ncb.org.uk/media/444181/raise\\_your\\_potential\\_web.pdf](http://www.ncb.org.uk/media/444181/raise_your_potential_web.pdf)

The UK Council for Disabled Children has a number of publications relevant to child participation:

- *Diversity Matters*  
<http://councilfordisabledchildren.org.uk/resources/cdcs-resources/diversity-matters>
- *How to involve children and young people with communication impairments in decision-making*  
<http://councilfordisabledchildren.org.uk/resources/cdcs-resources/how-to-involve-children-and-young-people-with-communication-impairments-in-decision-making>

- *Including Me: Managing complex health needs in schools and early years settings*  
<http://councilfordisabledchildren.org.uk/resources/cdcs-resources/how-to-involve-children-and-young-people-with-communication-impairments-in-decision-making>
- *Inclusion Policy*  
<http://councilfordisabledchildren.org.uk/resources/cdcs-resources/inclusion-policy>
- *Making Ourselves Heard*  
<http://councilfordisabledchildren.org.uk/resources/cdcs-resources/making-our-selves-heard-exploring-disabled-childrens-participation>
- *Top Tips For Participation*  
<http://councilfordisabledchildren.org.uk/resources/cdcs-resources/top-tips-for-participation>
- *Transition guide. To help professionals working with disabled children as they prepare for transition into the community.*  
<http://councilfordisabledchildren.org.uk/resources/cdcs-resources/transition-guide>

*The Whole Shabang!* Resources for schools and families on using theatre and arts as a means of participation available at: <http://www.shabang.org.uk>

*Voice of the North* – the project brings together key partners working for and with young people in the North of England. The young people working on the project produced a youth-friendly version and an accompanying video version, available at:

<http://www.youtube.com/user/TheVOICEOFTHENORTH#p/a/u/0/OLYHXOizLb0>



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- Turning Words into Action: A Guide to Influencing National Policies through the Active Participation of Children and Young People with Intellectual Disabilities
- Our Words. Our Actions: An easy read publication sharing the views and opinions of the young people involved in the project.
- Various films made with and by the children and young people who participated in the project.

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To protect their identity, children's names in the publication have been changed.

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