

Hear Our Voices!

Developing Participatory Processes with Children with Intellectual Disabilities – Concepts, Tools and Good Practices



© Inclusion Europe



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

THE PARTNERS

- Inclusion Europe (BE) www.inclusion-europe.org
- Eurochild (BE) www.eurochild.org
- The Cedar Foundation, Bulgaria www.cedarfoundation.org/en/
- Quip, Czech Republic www.kvalitavpraxi.cz
- Down Syndrome Foundation, Madrid, Spain www.downmadrid.org/

And in collaboration with Lumos www.wearelumos.org

This publication was developed in the framework of Hear Our Voices - a European project aiming to promote children's rights and in particular the rights of children with intellectual disabilities. The project empowered and trained children with intellectual disabilities to directly participate in all issues that concern their lives, including situations of participatory activities in school settings, and in child-care services, with particular insight into the process of de-institutionalisation. The project outcomes and publications can be found on the project website: www.childrights4all.eu.

This publication has been produced with the financial support of the Fundamental Rights and Citizenship programme of the European Commission. The contents of this publication are the sole responsibility of the "Hear Our Voices!" project partners and can in no way be taken to reflect the views of the European Commission.

© Inclusion Europe, Brussels, 2014

Photo on the cover: © Inclusion Europe

Layout by Orangemetalic.be

ISBN: 2-87460-156-X

PREFACE BY GERISON LANSDOWN	4
INTRODUCTION	5
CHAPTER 1: PROMOTING PARTICIPATION FOR CHILDREN WITH INTELLECTUAL DISABILITIES	7
1. The Child's Right to Participate: Principles	7
a) The process must be transparent and informative	7
b) The process must be voluntary	7
c) The process must be respectful	8
d) The process must be relevant	8
e) The process must be child-friendly	9
f) The process must be inclusive	9
g) The process must be supported by training	10
h) The process must be safe and sensitive to risk	10
i) The process must be accountable	10
2. The Child's Right to Participate: participation in ALL settings	11
3. The Child's Right to Participate: Methods and Tools	12
A. Communication tools	13
B. Tools for interacting with children and getting their opinions	14
C. Promoting Self-Advocacy	15
D. Child-centred methods	16
CHAPTER 2: PROMOTING PARTICIPATION FOR CHILDREN WITH DISABILITIES - INSPIRING CASES	17
1. Health	17
2. Education and Work	17
3. Community and Leisure	18
4. Political and Social Issues	20
CONCLUSION	22
RESOURCES ON PARTICIPATION (selection)	23

Preface by Gerison Lansdown

Just think for a moment about the things that matter to you in life. And now imagine if decisions on these issues were made your behalf and without your involvement – where you live, who you meet, what and when you eat, what you wear, when you go out, what leisure activities you engage in, how to decorate your room, how your hair is cut, whether to go out or stay in. Loss of control over these choices would deny you dignity, undermine your self confidence, engender frustration, and impose passivity. Yet throughout history, this has been the reality for many millions of children. Traditionally, choices on all key issues affecting children have been made by adults on their behalf.

The Convention on the Rights of the Child (CRC) introduced a radical challenge to this assumption that adults can exercise control over all aspects of children's lives. Instead, it insisted that every child has the right to be listened to and have their views taken seriously. This recognition of the child as an active agent, entitled to be involved in matters of concern to them, presents a profound transformation in their status. And over the past 25 years, there have been enormous efforts in countries throughout Europe to explore how to give effect to this new approach to childhood. There is still a long way to go – transformations to such deep seated behaviours and power relations cannot be overturned easily. However, change is slowly taking place: in the family, in school, in institutions, in the wider community, and at the governmental level, spaces are being opened up for children to be far more involved in both individual decisions affecting their lives, as well as opportunities to influence public policy and the environment around them. Unfortunately, however, opportunities for children with learning disabilities to be heard are far less common. Prejudice and ignorance too often prevail, leading to false assumptions that they are unable to make informed choices or communicate opinions. As a result, children with learning disabilities tend to be silenced, their views ignored, their humanity denied.

But the CRC does not limit the right to be heard to particular groups of children. On the contrary, it applies to every child capable of forming a view. Furthermore, the Convention on the Rights of Persons with Disabilities stresses not only that the right to be heard applies on an equal basis to children with disabilities, but that governments must provide appropriate assistance to ensure that they are enabled to speak out and be taken seriously. And the Committee on the Rights of the Child, the body set up to monitor governments' progress in promoting children's rights, has stressed that all children, however young, and whatever their ability, are able to form views. The challenge is to find ways of eliciting their views. Here, the Committee also emphasises that the onus for doing so rests with adults, not with children. Adults must take the time and effort to explore different ways for children to share their views – it might be in words, but could be through drawing, pointing to pictures or objects, facial expressions, body language, or play.

This report by Inclusion Europe and Eurochild describes work which does exactly that. Through investment of imagination, creativity, patience and love, and perhaps most importantly, through recognition of the children's fundamental right to be listened to, the Cedar Foundation in Bulgaria and QUIP in the Czech Republic demonstrate that it is possible to engage with children - children who have previously been locked inside themselves, and whose views have never previously been sought or heard. It provides powerful testimony as to the potential for children with learning disabilities, like all other children, to experience the joy and sense of empowerment that comes with making choices, being valued and being taken seriously. It is a report that radiates optimism and hope, and which is founded in fundamental respect for children with learning disabilities to be treated as equals and with dignity. The lessons it shares should be read by everyone working in this field.

Gerison Lansdown,
Chair, Child to Child

Introduction

For too long it has been commonly accepted that adults have the responsibility of deciding and planning children's futures according to the child's best interests. Often this has been done without children's involvement and participation due to their generally assumed lack of maturity to fully comprehend the subjects and voice their opinion.

Fulfilment of children's rights has focused mainly on the guarantee of implementation of their rights to education, health care, the right to play, the right and need to be protected from abuse, violence and negligence, and the right to be granted the promotion of their cognitive, emotional, social and physical development within the overall perspective of the individual. Despite the recognition of children as rights holders, the implementation gap remains and children are still seen as lacking the ability to contribute meaningfully to their communities.

Positively, the understanding of children's right to participate is increasing. This right is clearly stated in Article 12 of the United Nations Convention of the Rights of the Child (UNCRC), and reflected in other articles throughout the Convention, particularly¹:

- 1. States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.*
- 2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.*

Next to Article 12 UNCRC there are other related articles of importance for children's participation. These include Article 17 on the right to have access to information (including in a child-friendly manner) and the right to freedom of expression in Article 13. Article 23 CRC, which specially refers to children with disabilities, speaks about the right to

participation in the community. It is also important to recall that Article 12 is applicable to all other rights across the Convention.

To promote the participation of children, as individuals or as a group, involving them in decisions and giving their concerns due attention is not only crucial to the development of holistic processes and full implementation of the rights of the child, but also an obligation of evolved and democratic societies, imperative to achieving the goal of making the best decisions possible regarding children. Children are best placed to express their views on matters concerning them and to point out angles that adults do not necessarily think about, and which, as a consequence, might be neglected or forgotten. Like all children, children with disabilities are entitled to be heard, and likewise have specific needs, feelings and opinions. However, children with disabilities, and particularly children with an intellectual disability, face greater challenges to exercise their right to participate, both due to the long tradition of considering children and people with disabilities incapable of understanding the subjects related to their lives, and also because they might need to voice their opinions in different ways. In fact, conventional participatory processes may be difficult to apply due to particular impairments^{2,3}.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)⁴ is a landmark underpinning actions to promote and fulfil the rights of people with disabilities. Embedded in the spirit of the Convention, movements of self-determination and civil associations managed by people with disabilities are themselves milestones along the path of having the voices of people with disabilities heard and taken into account. Children with disabilities, sharing both the vulnerabilities of childhood and disability, need particular attention and care to make their ideas and feelings known and to open up the possibility that they can positively impact their own lives and those of their communities. This is the reason why Article 7 UNCRPD refers specifically to the need to take all measures in order to assure children with disabilities grow and develop in contexts of equality with other

¹ United Nations, 1989, Convention on the Rights of the Child, United Nations.

² SPRU, 2004, Participation of Disabled Children and Young People in Decision-Making within Social Services Departments, Quality Protects Research Initiative – A survey of current and recent activities in Social Services in England, The University of York.

³ UNICEF, 2007, Promoting the Rights of Children with Disabilities, Innocenti Research Centre, UNICEF.

⁴ United Nations, 2006, Convention on the Rights of Persons with Disabilities, United Nations.

⁵ Latimier C. & Šiška J., 2011, *Children's rights for all! Implementation of the UN Convention on the Rights of the Child for children with intellectual disabilities*, Brussels, Inclusion Europe, p. 28.

children and express their views and opinions freely in matters regarding them, and that they all must be given support and assistance necessary to fully accomplish the exercise of that right.

It is therefore central to promote every child's right to be heard, to pay due attention to their opinions and develop practices of active citizenship that include them in decisions impacting their lives. Yet, too often there is a reluctance to recognize the competence of children with intellectual disabilities to contribute to decision-making processes. Changing such views so as to encourage child participation in discussion and decision-making concerning their lives is critical and challenging⁵.

This publication aims at providing an incentive for the development of inclusive practices by clarifying and discussing, from the perspective of children with intellectual disabilities, the concepts of participation and the right to be heard.

Chapter One discusses the principles of the right to participate, Chapter Two presents methods and tools for participation and how to present examples of good practices. Finally, Chapter Three describes some inspiring cases of participatory processes involving children with disabilities, including intellectual disabilities.



PROMOTING PARTICIPATION FOR CHILDREN WITH INTELLECTUAL DISABILITIES

1. The Child's Right to Participate: Principles

The concept of participation encompasses the involvement of children in inclusive processes of decision-making with a direct or indirect impact on their daily lives, whether in institutional or organizational settings, at school or at home. This requires continuous exchange of information between children and other actors in order to facilitate everyday participation and to develop programmes, policies, measures and strategies in all contexts relevant to children's lives. The UNCRC Committee General Comment N°.12 - The right of the Child to be heard⁶, describes the basic requirements for the effective and meaningful implementation of the right of the child to be heard. In the following section, we aim to illustrate how these requirements can look in practice for children with intellectual disabilities:

a) The process must be transparent and informative

At home or in school settings, participation should be an integral part of the daily lives of every child. When involving a child in a participatory process in institutional settings, it is mandatory to inform him/her about all the relevant aspects of the process. *"Those responsible for hearing the child have to ensure that the child is informed about her or his right to express her or his opinion in all matters affecting the child (...) and about the impact that his or her expressed views will have on the outcome."*⁷ Children must be clear about the subject they are going to give an opinion on and about their right to speak freely and form an independent point of view. It is also fundamental to inform them about the real impact their participation is intended to have on the outcome. The details of this process should be communicated clearly to children and children must give their consent to take part. Anonymity should be guaranteed and explained when necessary.

For children with intellectual disabilities, adequate communication is the fundamental basis for equal participation. It means that accessible communication and information should be in place for them:

- *using age appropriate and easy-to-read language as well as texts or adapted formats, supported or replaced by visual tools or audio and tactile aids if necessary,*
- *using different communication methods, including alternative communication systems (like pictograms)*

With regard to consent and anonymity, children can be involved in choosing the name that will be used for his/her story, and you can show a concrete product or result, such as a draft document with his or her picture, work, or quote for his/her consent.

b) The process must be voluntary

Children must also be informed that they are not compelled to participate; it is a matter of personal choice to either be involved or not. They must also understand that they can cease their participation at any moment of the process and this does not affect their right to express an opinion at any other time or in any other context.

Children who have no previous experience of participation will learn and develop the necessary skills if adequate support is provided to them. It may require time and several attempts to find the right support for children with intellectual disabilities to enable them to participate. The fact that a child may not show interest or actively participate at the beginning, but is present during participation, may lead to his or her participation at a later stage.

If a child cannot express or indicate whether he/she wants to participate, the decision should be based on the best possible understanding of his or her will. It is possible to observe the child's attitude: Who the child likes, with whom he/she likes to spend time, what he/she likes to do, etc. For example, Mathias, a young boy with intellectual disabilities, did not express the fact that he wanted to get involved in deciding whether he

⁶ United Nations, 2009, General Comment N°. 12 - The right of the Child to be heard, Committee on the Rights of the Child, United Nations.

⁷ Op. cit. § 41, 2004, Participation of Disabled Children and Young People in Decision-Making within Social Services Departments, 2006, Convention on the Rights of Persons with Disabilities, United Nations.

⁸ See, Inclusion Europe, Participating in my life: Hear My Voice! Available in the tools at www.childrights4all.eu

would stay in the same school next year, but the decision to involve him in this decision was based on observations and interviews with people who do know him well⁸.

c) The process must be respectful

The whole process must be conducted with respect for the children's points of view, interests and specific needs.

For children with intellectual disabilities, it is important to make sure facilitators are aware of their support needs in terms of communication, orientation/mobility, personal support or social interaction. Family members, support staff or other persons close to the child can help to identify his/her needs.

While some general accessibility principles should be in place for all children, additional support needs should be individualized and should be shared with the relevant persons in charge.

A simple table describing support needs can be used (see the table below):

d) The process must be relevant

Children should be called to participate in decision-making on issues that are truly relevant to them. These issues must impact their lives directly and their opinions must be based on their knowledge and their life experience of the subject.

It is important to ask children with intellectual disabilities to participate in issues that are concretely known to them. It is also important that they understand the effect of decision-making by seeing the results of their choices and the influence of their decisions.

For example, they may start choosing their leisure time activities or be involved in choosing the food that will be served or the clothes they want to wear. By proceeding with elements of their lives that are concrete, children with intellectual disabilities will grasp the importance and the impact of participation. It is important not to ask children about how they would want something they have no experience of (e.g., if they have never been in hospital, they will hardly be able to formulate an opinion about what is good or what should be changed with regard to hospitalization).

AREAS OF SUPPORT NEED

DESCRIPTION OF THE SUPPORT NEED

HOW TO SUPPORT ME?

Conceptual skills (language and literacy; money, time, and number concepts; and self-direction).

Social skills (interpersonal skills, social responsibility, self-esteem, gullibility, naïveté or wariness, social problem solving, and the ability to follow rules/obey laws and to avoid being victimized).

Practical skills - activities of daily living (personal care, occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone).

e) The process must be child-friendly

Methods and environments must be adequate to the children's ages and abilities.

A child-friendly environment has to be created in order to make children feel comfortable and secure to express their opinion. It is important that children feel they are participating in an informal conversation rather than an examination, and that confidentiality requirements, when applicable, are fulfilled.

For some children it is better to find a neutral place or a quiet, familiar place where they may be more open to talk. They may also appreciate being in a different setting and might feel they are special. However, for other children an unknown place could be a source of stress and they may not feel comfortable in an unknown setting.

For children with intellectual disabilities it is important:

- *To think about a setting they know and like, friendly places: Formal meeting places, such as a Parliament or a council room, could be distressing environments for anybody, but will be even more so for children with intellectual disabilities. While it may be necessary that they participate also in formal settings, alternative, friendly places where children can feel they have fun are much more adequate for certain participatory activities.*
- *To think about accessible places for children with mobility issues and quiet places where children will feel safe. Crowded, noisy places may often be disruptive and make children uneasy.*
- *To think about providing spaces for privacy or for relaxing – these may be needed for children with high support needs.*
- *To think, especially at the beginning, about effective communication. Somebody who understands what the child wants to say or express may have to be there (someone from the family, a friend or a professional support provider) As for all other children, fun and amusement is an important motivation for children with intellectual disabilities.*

Participatory methods should also be disability- and child- friendly.

This includes not just spatial aspects, but also aspects of time (breaks, short activities), resources, visual and human support and/or different levels and forms of participation depending on each child with intellectual disability and his/her needs.

f) The process must be inclusive

To ensure the meaningful participation of children with disabilities, it is essential that no child is left out of the participatory process. Participation needs to be inclusive, and this is why it is important to consider ensuring the participation of ALL children in ALL settings, including those living in institutions or alternative care, and to recognise and enable the participation of children with severe disabilities and/or complex needs. It is crucial to demystify and pinpoint the abilities of children with intellectual disabilities to express their opinions and judgments, provided that adequate or good conditions are in place for them. Regardless of age and disability, children with intellectual disabilities are capable of forming an opinion and their perspectives must be given due consideration.

All children with disabilities can participate, provided they are given appropriate support. Children without verbal communication skills can contribute and can express preferences, if communication tools and alternative communication systems exist and are in place.

A truly inclusive process means that all children can participate, whatever their level of disability.

When we talk about the participation of children living in institutions and alternative care, we need to acknowledge that they often suffer from so-called learned helplessness. Living in an institution means that choices have always been made for the child by others, so it can be very confusing for the child to make a choice, and they often encourage staff to make the choice for them. It is extremely important, therefore, that staff does not use this as an excuse to make the choice for the child, but instead is even more

⁹ Michel, E. & Hart, D., 2002, *Involving Young People in the Recruitment of Staff, Volunteers and Mentors*, The National Children's Bureau Enterprises, Ltd.

¹⁰ As an example, we can look at Inclusion Europe's child protection policy available at: www.childrights4all.eu

creative about creating opportunities for participation.

g) This process must be supported by training

When necessary (or as often as possible), training⁹ should be provided for children with disabilities and other parties involved in the process, including parents, staff or other persons involved. It is possible that children will need additional training to develop their skills to participate, and also that other parties need training on how to implement participatory processes that take into account everybody's contributions.

Training of children, families and staff offers the possibility to share good practices and can, therefore, be a great stimulus to participation. Staff can sometimes be resistant to change, as they initially may not believe that a child with severe intellectual disability can participate. However, they are much more easily convinced that this can in fact happen if they can see concrete examples from practice.

Involve children with intellectual disabilities as peer trainers or trainers. They can have a very strong impact and play a role for their peers with and without disabilities. They will also be powerful trainers for other groups of people. This requires preparation and capacity-building to strengthen their skills. Motivational interviews and role-playing can be used to select and provide information to children with intellectual disabilities who may want to become (peer) trainers.

h) This process must be safe and sensitive to risk

When implementing processes of participation, a child-protection policy should be in place¹⁰. It should contain all the necessary rules for interacting with children, for reporting any suspected abuse, for reporting to others about the children, as well as rules on the use of images of the children.

It is also important to work with the families of children with intellectual

disabilities and their communities. These families often experience discrimination on a daily basis. For this reason, they may be reluctant to support the participation of their sons and daughters with disabilities in order to avoid situations of abuse or discrimination. It is therefore crucial to involve families in the process, to make sure they understand that the process is safe and non-discriminatory. Families will support such a process and contribute to the creation of a safe environment.

i) This process must be accountable

Participatory processes must be evaluated. Children must be given the opportunity to express their views on how the process evolved and on the final results, giving suggestions for improvement. Feedback must be given to the child, or group of children, regarding how their opinions were taken into account and what effect they had on the final resolutions. This information is vital to maintain a circle of continuous cooperation allowing the child to present new ideas and suggestions and also to show discontent if he/she considers that his/her contributions were not seriously analysed.

Feedback must also be given to the child or the group of children, even for an isolated consultation process. In the case of long term participatory processes, regular feedback and evaluation should be in place to facilitate regular reviews and monitoring of the situation. A specific timeslot and/or a specific meeting place can be dedicated to discuss important issues in group or individually. Children must know to which person specifically they can turn if they need help to express their dissatisfaction or problems.

Children with intellectual disabilities will fully comprehend the dynamic and results of their involvement if their opinions have impacted their lives directly in a concrete manner. For example, children with intellectual disabilities living in one of the group homes of the Cedar Foundation in Kyustendil have been actively involved in the planning and monitoring of

services and in measuring the quality of the services they use by learning how to influence their environment, their food, and their activities.

The concrete steps for developing participatory tools can be read about in the following publication: *Participating in My Life – Hear My voice!*¹¹

2. The Child's Right to Participate: Participation in ALL settings

Participatory processes might be different in each particular case, as participatory methods need to be tailored according to the aims of the consultation and the children involved. The decision as to which processes to undertake must result from a negotiation process between the children and other actors involved¹². Finding the appropriate process may require time, energy and creativity. Initiatives fully run by children do exist, but a pre-requisite for them is that the children have had previous experience with and/or feel comfortable about participating.

Participatory processes should take place in ALL settings - within the family, in alternative care, at a health care centre or institution/services supporting the child with disabilities, at school and in play, recreational, sports and cultural activities, as well as in public decision-making.

Participatory processes are of intrinsic value to the children who participate in them, as they acquire new skills, knowledge, competences and confidence. The children personally learn that they are worth being listened to and feel acknowledged for their opinions. This results in an empowerment of the children, which makes them active, effective advocates for the realisation of their own rights¹³. This is absolutely true also for children with intellectual disabilities.

Participation also enriches all policy areas and settings that are relevant to children. The added value of participation is well described by the quote below:

"[Involving children and adolescents with disabilities in decision-making] is in the States' interest, for children and young people with disabilities can enrich policymaking and service provision with their daily experiences

and are uniquely qualified to provide information on whether their needs are being met and their contributions utilized across the full spectrum of issues and interventions [...]. A child who is able to express herself or himself is a child who is much less likely to be abused or exploited."
UNICEF State of the World's Children report 2013, p 84.

Participation is crucial at home, in families, at school, in formal and informal education and in services - **all places where children should to be listened to, should be able to express their opinions, and should feel free to assume their roles and responsibilities.** Participation particularly allows children to express their views and to be heard in the context of preventing and reporting abuse.

- Participating in families: It is crucial to work with and support families of children with intellectual disabilities to help their child participate within the family and/or at home according to their child's development. As stated by the UN Committee on the Rights of the Child "A family where children can freely express views and be taken seriously from the earliest ages **provides an important model, and is a preparation for the child to exercise the right to be heard in the wider society**"¹⁴.
- Participating at school: Both individual and collective participatory methods may be used at schools (e.g., the use of the Person Centred Planning method, Pupils' Council, participatory educational or leisure time projects involving children with and without disabilities)¹⁵. **Participation will have an impact on individual pupils, on educational practices, on the school structure, and on the culture or the environment of the school, which will be more inclusive and will better address the needs of all children.**
- Participating in service delivery and monitoring: Care plans for every child attending a support service or in transition from institutional to community-based living, as well as child-centred approaches and communication systems, should be developed to help each individual child be heard and participate in the decision-making process. At collective levels, children should

¹¹ See the report under www.childrights4all.eu

¹² Adams, E. & Ingham, S., 1998, *Changing Places – Children's Participation in Environmental Planning*, The Children's Society, London.

¹³ Mieke Schuurman, VADEMECUM - children's participation in public decision-making.

¹⁴ § 90 of the UN CRC General Comment n°12 The right of the child to be heard, document number CRC/C/GC/12 of 20 July 2009.

¹⁵ For participation at school you can read the publication *Participating at schools! Hear My Voice!* Available in the tools at www.childrights4all.eu

be actively involved in the planning and monitoring of services and in measuring the quality of the services they use. It is important to create meaningful everyday participatory mechanisms for children in child care services, including children's homes and other residential facilities¹⁶. *Participation will increase the quality of life of each child and increase the quality of the services delivered to children.*

- Participating in public decision-making: Child-friendly consultations on policy can be organised to shape legislation, policies, budget allocations and services. Participation also means actively involving children with disabilities throughout the policy cycle, including in agenda-setting, planning, implementing and monitoring policies, as well as programmes and services that affect the lives of children with disabilities. *Children's participation will have an impact on the decision-making process and the outcomes of the decisions taken*¹⁷.

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

"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."

"Any young person with disabilities has the right and need to have contact with so called 'ordinary' people. We are good for each other."

*Quotes from children and young people with intellectual disabilities collected in the course of the project "Turning Words into Action."*¹⁸

3. The Child's Right to Participate: Methods and Tools

There are several different methods and tools to engage children with disabilities in participatory processes^{19 20}. This section will provide the reader with some general tools that might be used in different participatory processes. Each one of them has to be considered regarding the particular context and the specific child's needs²¹. In addition, the variety of tools and activities is also important to **keep children** motivated and interested. The concentration span of children with intellectual disabilities can be very short, so it is important not only to vary activities, but also to include regular breaks to allow them to relax, as often as needed. It is also very important to develop tools which can be used with children with and without disability in inclusive settings.

The project Hear Our Voices has published two additional brochures about participatory processes at school and in child care services, including in residential institutions, that demonstrate how to develop mechanisms to support the planning and monitoring of services or school. We strongly encourage you to read about these practical tools at www.childrights4all.eu/.

Some general tools and methods are presented in the following pages – they are worth

¹⁶ For participation at school you can read the publication Participating in My Life! Hear My Voice! Available in the tools at www.childrights4all.eu

¹⁷ For participation in decision-making, please read the Vademecum: Children's participation in public decision-making - Why should I involve children?, by Mieke Schuurman, Eurochild available at http://www.eurochild.org/fileadmin/public/O5_Library/Thematic_priorities/O5_Child_Participation/Eurochild/OEJAJ_VADEMECUM.pdf

¹⁸ "Listening Together: Examples of Child Participation in Action", Lumos 2013, results of the project Turning Words into Action, run by Lumos and funded by the EU, in 2011 - 2013.

¹⁹ Lewis, I., 2000, Access for All - Helping to make participatory processes accessible for everyone, Save the Children, London, UK.

²⁰ Wilkinson, J., 2000, Children and Participation – Research, monitoring and evaluation with children and young people, Save the Children, London, UK.

²¹ Ward, L., 1997, Seen and heard – Involving disabled children and young people in research and development projects, The Joseph Rowntree Foundation, York Publishing Services, Ltd, York.

considering and taking into account when making participatory processes accessible to children with intellectual disabilities.

A. Communication tools:

i. Easy-to-read and child-friendly texts and information

Age-appropriate and accessible language and information available for children with disabilities is a fundamental basis for equal participation, and a key to its success is the use of visual support to communicate with these children.

When addressing children with intellectual disabilities, European standards on how to make information accessible²² must be fulfilled. Sentences should be short and simple, instructions should be given as short lists of tasks, and emphasis must be put on the words and expressions that are most important and familiar to the children. Sentences should be pronounced in the positive, and the active voice should be preferred over the passive voice. The most important rule is to keep language simple and easy to understand and not to introduce disturbing elements like technical expressions, complex punctuation, too much information or unnecessary information that will be difficult to understand. When presenting graphics or charts, keep them simple and explain them well. Jargon and words from other languages must be avoided, and verbal language must always be accompanied by body language and facial expressions to help transmit the meaning of the sentences. Examples of daily life must be used to clarify information and metaphors are to be avoided. If acronyms or abbreviations need to be used, always explain them first. Important information must be repeated as many times as necessary.

Fonts that are easy to read must be selected and the size increased. Fonts

that look like handwriting or are closely spaced must be avoided, and capital letters and italics should not be used in blocks of text. To facilitate the children's reading, adequate spacing between letters, lines and paragraphs is necessary. Splitting words at the end of sentences and text justification should also be avoided since it creates irregular spacing between words, making the reading more difficult. Colour and paper also need extra attention. Greater contrast between the background and the text is essential. The document in itself should not be too extensive; if necessary, shorter versions must be made so that the entire document is addressed as several parts.

ii. Visual aids, audio or videos

For children who do not use written communication, visual aids, audio or video are of great utility in complementing or substituting for written information. These tools can be created and used individually or collectively. They can be prepared for children by others or developed by the children themselves. Children can use drawings as a way to describe and comment on their lives and their environments, as well as to voice their opinions.

A French association worked with a comic book writer to support children relating and expressing their feelings about disability and about discrimination. Thanks to the development of a small comic strip, the children managed to raise difficult topics and share experiences among themselves. At the same time they learned, with the support of a professional, how to produce a small comic strip, and they have been empowered by producing something they could take away with them.

Videos or animated movies can open up and facilitate discussion, especially on some sensitive issues or difficult topics. Children can comment on videos, but they can also shoot them themselves as a way of formulating their points of view.

²² Project Pathways, 2009, European Standards on how to make the information accessible, Inclusion Europe, www.easy-to-read.eu

Turning Words into Action brought together children and young people with intellectual disabilities, their parents, policy makers and health and educational professionals in Bulgaria, the Czech Republic and Serbia with the aim of bringing the 'Better Health Better Lives' Declaration to life through meaningful and effective child participation activities and outcomes. An animated movie, narrated by one of the participants from the *Turning Words into Action* project takes the user through their 'tour of dreams' journey. The group has challenged governments to make a real, sustainable change to the lives of young people everywhere.

It is important that all the tools selected be available and adapted to the needs and abilities of each child with disabilities involved.

B. Tools for interacting with children and getting their opinions

i. Interviews and Focus Groups

Interviews and focus groups are two of the most common tools used to collect opinions and statements from children, since they create a privileged space for sharing information and of mutual understanding. Both interviews and focus groups have to be conducted in a manner in which the child feels comfortable to share his/her point of view and feels that he/she has control over the process and the situation. Again, accessible and age-appropriate language must be used – visual aids can also help children during interviews or focus groups.

Children can also interview one another, or interview other interlocutors of their community. The preparation of the interviews and material should take the child interviewers' abilities and needs into consideration. The material should be accessible, easy to use (with enough space to take notes), and pictograms may facilitate the interview process; children may learn to interview in pairs, for example, in order to support each other: One can ask the questions while the other writes down the answers.

In a Nepalese refugee camp, focus groups were developed for Bhutanese children with disabilities to express their views, since they were one of the

most vulnerable groups within the camp. The children were aged six to 14 and the focus groups were implemented with the presence and participation of their parents. The children were introduced to each other using several different games. The issues to be discussed included theirs and their parents' perceptions of disability, the effects of disability, isolation and the need for additional support, both for them and their families. Children and their parents made several remarks and recommendations that were later used for the development of a project in this area²³.

ii. Easy-to-understand questionnaires or written consultations

Materials involving written languages need adjustments to be accessible by children with intellectual disabilities. Again, European standards on how to make information accessible must be taken into consideration²⁴. Images, drawings or symbols may be used to facilitate the understanding of a text, but care must be put into the selection of such visual aids in order that they not become obstacles. It is important to remind people that pictograms and drawings should be adapted to the cultural background of the children concerned. Often, the way to depict things is quite different from country to country, as images reflect cultural background.

Questionnaires about participation can be developed for children and young people with intellectual disabilities provided they are adapted to their age and abilities.

For example, the Carmen Fernández-Miranda school in Madrid developed questionnaires to discover information about how students perceive their individual participation in the school and whether they feel a certain level of satisfaction. For each age group a different easy-to-read questionnaire is developed, adapting the level of the questions to the age. The questionnaires are also adapted for the special needs of students with reading, writing or communication difficulties, using pictograms and smiley faces to assess the level of satisfaction.

²³ This project was run by the by the organisation Save the Children see Giri, G., 1995, Focus Group Discussion - Special Needs', Save the Children, Jhapa, Nepal.

²⁴ Project Pathways, 2009, European Standards on how to make the information accessible, Inclusion Europe, www.easy-to-read.eu

For the younger ones, depending on the support needs of the student, the questionnaire can be completed on an individual basis or with the help of a group. The teacher or the student reads the questions. Once it is clear that the students have understood the questions, they are encouraged to answer them individually.

In this way, all the students, with and without disabilities, have been able to give their views about the school. The questionnaire results raised new questions and allowed the staff to implement new action plans and ideas to better answer the needs of the children.

See more details in the publication: Participating at School: Hear My Voice! pp. 18 and 21-24 ²⁵.

iii. Role-play, games, drama

Role-play, games and drama can facilitate the participation of all children, but especially children with intellectual disabilities who may not feel comfortable in an interview if they have difficulty communicating. Role-play and drama also can help children with intellectual disabilities to better understand concrete situations, try out different situations, and comment on them rather than talking about them in a theoretical way. There can also be puppet shows.

All these activities allow children to present their doubts and problems and clearly state their opinions and feelings on the matter.

LicketyLeap is a piece of drama-led early intervention. It is delivered in Nurseries, Early Years Centres, Family Centres and Arts and Community Centres. The LicketyLeap project has been engaging 'hard to reach' families in the most deprived areas of Scotland and 1 307 parents/carers have attended a session in nurseries (75 % of children represented). Parents/carers sign up to Licketyspit Children and Family Network. LicketyLeap has been delivered to a wide range of Scotland's most vulnerable children including children from multiple ethnic backgrounds

(e.g., it was delivered to 60 largely Roma children with minimal English) and has engaged children with a range of additional support needs, including Autism, Asperger Syndrome, Attention Deficit Hyperactivity Disorder (ADHD), visual impairment, hearing impairment, Downs Syndrome, speech and language/communication difficulties, elective mutism, trauma, developmental delay and mobility difficulties. At least 21 different languages have been recorded as the participating children's/families' first or only language. All responded very positively and successfully to LicketyLeap ²⁶.

C. Promoting Self-Advocacy

Promoting self-advocacy and training young people with intellectual disabilities on self-advocacy from an early age empowers them at an early stage. Self-advocacy is a powerful tool, as young people are the ones who take the lead in promoting discussion and expressing their opinions on subjects considered relevant by them, if not by others. They decide about the topics they want to address or discuss and they control the whole process of taking action and participating in different activities and decisions. The supporter's role is to help them in this process, not to lead them. It is based on the principle that young people themselves must be able and be given the conditions to identify the issues that are meaningful to them and what actions and strategies they want to use to achieve their goals. The power to make decisions remains in the hands of the children, with the recognition that they are capable of doing it themselves. Adults participating in this process are counsellors, facilitators or supporters and must fully respect the autonomy of young people to carry on the process of change.

The self-advocates of Down Madrid: the group meet twice a month to speak about their problems and feelings and about how to defend their rights. They also participate actively in meetings and conferences. Last December a female member of the self-advocacy group participated as a speaker in Brussels at a conference about the rights of

²⁵ Available at: www.childrights4all.eu

²⁶ A link to a video is available upon request, you can contact Virginia Radcliffe at virginia@licketyspit.com

persons with disabilities, organised by the EU on the European Day of Disabled Persons.

D. Child-centred methods

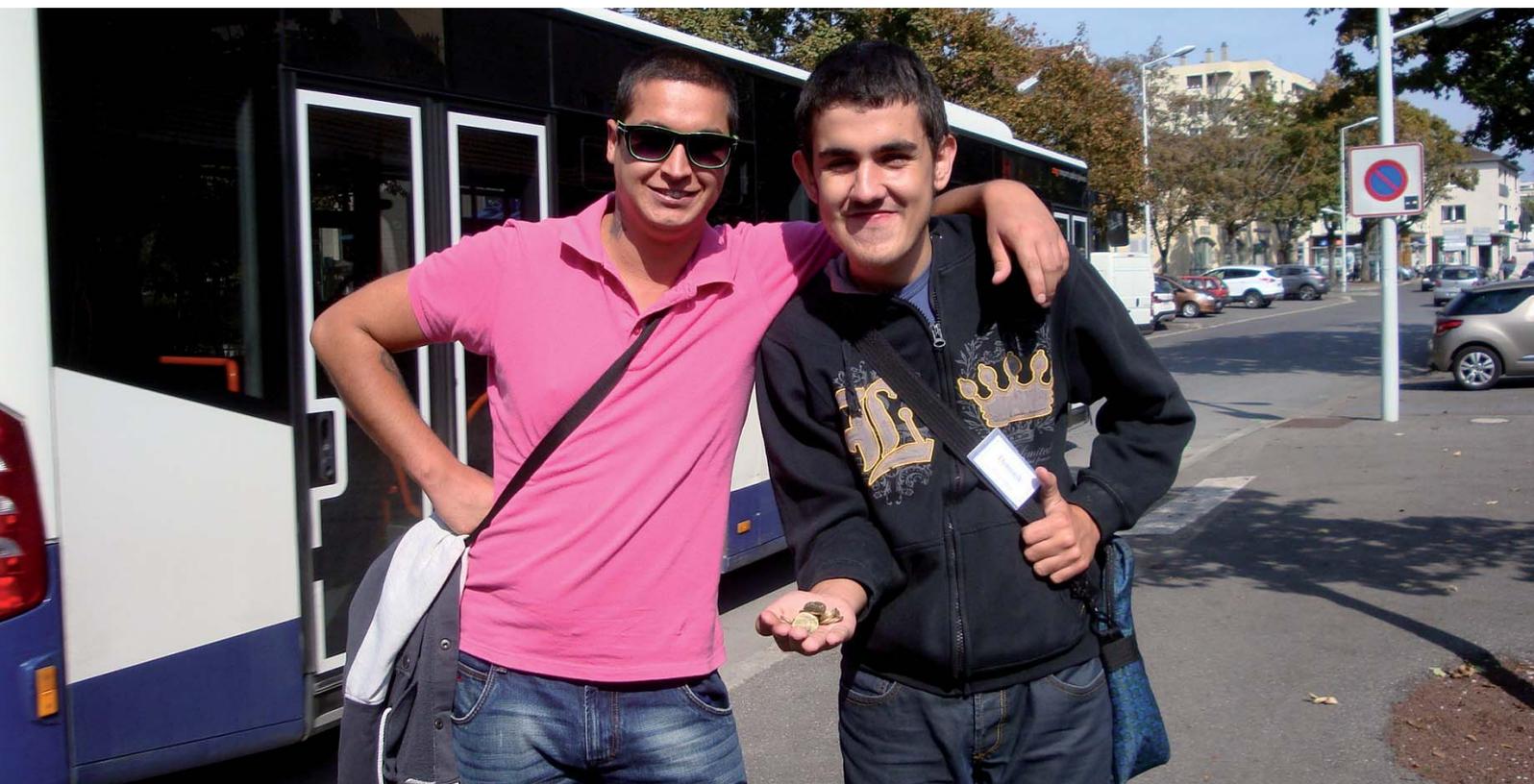
The techniques and tools resulting from Person-Centred Planning (hereinafter PCP) have proven to be very efficient for work with children with intellectual disabilities. The PCP tools can help involve children in decision-making because they create space for identifying and respecting the opinions of persons with assistance and support needs. PCP is a specific approach to planning support and assistance for a person with a disability in everyday life or for specific changes in his/her life. PCP takes into consideration the community and the circles of each individual.

PCP tools have been successfully used to support children both in the school environment, in services provided by professionals, or for children living in their families. However, PCP tools need to be used over a longer period of time – this cannot be a one-off activity, as it requires long-term cooperation with an individual (the approach may also include the creation of communication charts during the beginning of individual work).

Mathias, a young boy with intellectual disabilities who does not communicate verbally, has been

supported with PCP tools that allowed the creation of communication charts that respond adequately and consistently to his behaviour. The staff supporting Mathias previously interpreted his behaviour as misbehaviour. Once the communication chart was developed, Mathias could be helped on several issues related to his life: His afterschool activities as well as his school placement. These important decisions could be made with the full involvement of Mathias in the decision-making process. Inclusion Europe, Participating in My Life: Hear My Voice! pp. 19 to 23.

A combination of all these methods can and should be used if it will be more productive and effective for achieving the aims and promoting motivation throughout the process. All of these methods and tools allow for the addressing of different themes, with the children using the methods that they felt were most adequate for each theme. Methods like games, taking photos, drawing, puppetry, group exercises, discussions, storytelling, outdoor activities, the life situation methods and others should be used and combined to explore different themes concerning children's lives and worries. The utilization of multiple strategies and tools allows for the establishment of a more interesting, creative environment that is propitious to the development of children's skills.



PROMOTING PARTICIPATION FOR CHILDREN WITH DISABILITIES - INSPIRING CASES

Several inspiring practices are being implemented worldwide regarding the promotion of the right of children with disabilities to express their opinions. Depending on the aim, the cultural context, and the needs of the community and children involved, different tools can be used. The following projects are presented as inspirations for involving children with intellectual disabilities in participatory processes. Not all the examples have necessarily included children with intellectual disabilities, but we have chosen them because we believe they might be inspiring for children with intellectual disabilities as well.

1. Health

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

"Turning Words into Action"²⁷ was a project funded by the European Commission and developed in Bulgaria, the Czech Republic and Serbia. The aim of the project was to improve life chances, inclusion, access to rights and participation of children with disabilities. Within the scope of the project's activities a three-day workshop with 65 participants was developed addressing the topic of health services provision to children with disabilities. Children and young adults with intellectual disabilities from Bulgaria, the Czech Republic and Serbia involved in the project were invited to join the event and express their opinions on the quality, format and flaws of the health services they were provided with. Policy makers, project workers, academics, service providers and welfare professionals were also present at the workshop and participated in the discussion. The children gave their opinions and ideas on how they thought their lives could be improved regarding health services, suggesting new ways of working together and changes that would improve the government's policies in this matter.

b) In Spain, the organization Ceapat – Imserso developed a project with children with disabilities called *"Yo te cuento, cuenta conmigo"*.²⁸ The project aims at improving health care for children with disabilities by clarifying and training health sector personnel,

like doctors and nurses, on communication strategies, namely Alternative and Augmentative Communication. Communication impairments often interfere with treatments because doctors and children cannot communicate properly regarding the details of the children's needs. The dynamics of the project consist of a notebook explaining different types of communication that can be used; children take the notebook with them to an appointment and use it to help doctors and other health care staff members to communicate with them. By promoting this type of flexible communication, the children were given the opportunity to express their opinions and feelings on the treatment and results concerning their health²⁹.

2. Education and Work

a) A research group of pupils with visual impairments were invited to join a participation project on evaluating integrated education for children with disabilities. Its output is the report *"Integrated Education for the Visually Impaired – Some Insights"*.³⁰ Participatory techniques, like drawing, focus groups, role-play, interviews, etc., were used with the children to seek their opinions on how the school was responding to their needs and how they believed it should be different and improved. They were asked what their idealized classroom would be like, what objects should be there and where they should be placed. They were also asked to complete the statement "I learn better when my teacher..." in order to give their opinions on successful teaching/learning techniques.

The children also had the opportunity to express how they were feeling about the general experience of being at an inclusive school and having peers. The results showed that improvements could be made in order to provide children with disabilities with a more effective relational and educative experience, namely, training to the teachers had to be provided, more materials in Braille needed to be available, and some methods used by teachers actually kept them from participating (like using maps or playing ball games). This was a successful experience that provided the school with more insight into how to promote effective education for children with disabilities and enhance their participation.

²⁷ Lumos, 2013, Turning Words into Actions, <http://www.wearelumos.org/stories/turning-words-action>

²⁸ Centro de Referencia Estatal de Autonomía Personal y Ayudas Técnicas, 2012, Cuaderno de apoyo a la comunicación con el pacient, Centro de Referencia Estatal de Autonomía Personal y Ayudas Técnicas, Ministerio de Sanidad, Servicios Sociales e Igualdad, Gobierno de España.

²⁹ More information is available at <http://www.ceapat.es/InterPresent2/groups/imserso/documents/binario/yotecuento.pdf>

³⁰ Nair, D., 1996 Child-Centred Participatory Research: Integrated education for the visually impaired, some insights, Save the Children UK, London in Wilkinson, J., 2000, Children and Participation – Research, monitoring and evaluation with children and young people, Save the Children, London, UK.

b) *"I am autistic and dyspraxic. So here I am speaking in public and running a slide show!"*

Several schools and regional authorities across Wales, including The Trinity Fields School and Research Centre, Learning Disability Wales, Welsh Centre for Learning Disabilities at Cardiff University, Elite Supported Employment Agency and others, developed a project called **"Real Opportunities"**.³¹ The aim of the project was to help youngsters with disabilities and their families to plan and prepare their transition from school to work. The project team worked with the children and youngsters and their families applying methods based on Person Centred Planning to help them find opportunities of development and independence. The focus of the work was to motivate children by making them aware of the importance their opinions and decisions have now and will have in their present and future lives. The project included training for the children and their families, supported employment opportunities and provided children tools for engaging in interesting activities for themselves. The project based some of the interventions in a Peer Mentor approach so that children felt more comfortable in talking about their needs with other youngsters and children like them. The interaction with a peer improved their communication skills, promoted self-esteem, and made them realize the importance of conducting their own lives and making their own choices, empowering them to be more participative in the community.

c) *"I am the winner of the short stories competition! We are all equal and we don't deserve to be underestimated"*

"Step by Step" Youth Group, Spain

Within the framework of Project Hear Our Voices, and in line with the main objectives of the Down Syndrome Foundation, people with disabilities themselves can convey and demonstrate how to participate in society and why. Promoting inclusion and participation of people with intellectual disabilities in the mainstream environment means also raising awareness in society about people's chances of participation, their skills, and their rights and duties, among other things. The "Step by Step" group brings together young people with and without disabilities between 14 and 18. The group aims to think about, design,

promote and implement actions based on the young people's own vision to promote the inclusion and participation of people with intellectual disabilities. The young people belong to different schools, both inclusive and special. During their monthly "brainstorming" they produced a large number of ideas. The ideas were shared with visual support on a board. From there, with the ideas generated by the group of young people, different activities were implemented. In one school year, they organised different activities such as talks in schools for students with and without intellectual disabilities, shooting a video about the possibilities and capabilities of persons with disabilities, organising a short essay competition, and organising workshops on inclusive cuisine, inclusive sports days and a video competition³².

3. Community and Leisure

a) *"Bicycle, me drive bicycle"*

The Cedar Foundation Person-centred Person-Centred Planning Initiative³³

This project was oriented toward the provision of training and exchange of good practices in the field of care for children and young adults with intellectual disabilities, with a particular focus on empowering social services users in decision making related to their life and daily activities. The project aimed to provide opportunities for children with intellectual disabilities to play a more significant role in decision-making process that have a direct impact on them, as well as to improve their skills for independent living and social integration for a better quality of life.

Through a series of study visits and trainings, support workers in "Siyanie", a community-based small group home service in Kyustendil, were introduced to the concepts and practical methods of Person-Centred Planning (PCP). With the clients of the service – children and youth with intellectual disabilities who had recently exited large institutions after their closure – staff members began to implement PCP through individualized work with the children using specific tools identified during their studies. These activities were aimed at beginning the process of helping staff members listen closely and creatively to the children and young adults, many of whom do not communicate verbally, and all of whom were suffering the effects of living previously

³¹ Real Opportunities, 2013, www.realopportunities.org.uk

³² More information about the project and this particular activity can be read in the publication Participating in my school: Hear My Voice! available on www.childrights4all.eu

³³ For more information about PCP and The Cedar Foundation's initiative, please refer to: <http://www.cedarfoundation.org/Participation-Project-HRDP/project-summary.html>

in large institutional settings where choice and participation were rarely offered, creating a sense of “learned helplessness” within them. This information, which includes the child’s likes and dislikes, wishes and dreams, fears and nightmares, closest relationships and most important places, is then used with the client to help guide the process of planning his or her care and support. For example:

“Katya”: While creating a Communication Dictionary with Katya, staff began to think about the places that are important in Katya’s current life. They realized that Katya could name only three places which she visits regularly: Her residential small group home, her school, and the rehabilitation center. All three places are inevitably very important for Katya and when compared with her life in the institution they are a drastic improvement, but staff noticed that no other community spot figured anywhere in her life. While Katya is a communicative, outgoing and bright girl, staff acknowledged that she is not living a life in which she is learning anything about the world outside these settings³⁴.

The process of PCP helped staff recognize where they were going wrong with Katya’s individual plan and helped them identify additional goals which would help her become more independent and integrated into society.

Some of the children began to express concretely what they want for themselves. This project brought about a change in the way support personnel and service management now view the children and youth in their charge, but it also represented a step toward their real participation and fuller social integration.

b) “Really listen and understand”

The **“Two Way Street”**³⁵ project aimed at improving the communication skills of people who relate to children with disabilities through their work, whether directly or indirectly. Children and professionals in the project made a video showing how children with disabilities communicate with each other and with adults. It showed there are several different ways in which children with disabilities can communicate, namely, through their behaviour, signs, symbols, body language, eye pointing, facial expression, gestures, play, use of art, objects of reference, speech, vocalisation and physical movement. The

children involved in the project shared their experiences with the professionals involved and gave them advice on how to communicate better. Professionals were also asked to reflect on their practices and difficulties when relating to children with disabilities. Children participated in the project from the beginning, giving opinions on how it should be implemented, how to approach other children and how to prepare the environment for children to feel supported. Results from this project revealed that children felt misunderstood by professionals because of their difficulties in expressing their views and also that they sometimes felt a lack of effort from adults to communicate with them. It also showed that some of the children’s opinions were not coincident with what professionals thought their opinions were, and some of them were even conflictive. Children with disabilities from ethnic minorities were also included in the project so attention to cultural and linguistic specificities, even in sign language, had to be addressed. The main achievement of the project was to allow children with disabilities to state that communication can be approached in several different ways, not only through speech, and that communication processes must be based on respect for differences as a fundamental value in order to provide the children with a full sense of belonging.

c) “I would say that it is my decision (volunteering), let me do it because it’s good and I feel good doing it”

Participation in community activities is a crucial area of inclusion. **“Crossroads”**^{36 37} is a project that promoted the participation of children with intellectual disabilities in community leisure activities in Madrid. The project addressed the issue of the participation of children with intellectual disabilities in leisure activities developed in their communities by providing the children what they needed in order to facilitate their involvement. Children were asked what type of activities they wished to participate in, and the project acted as a mediator with other services, arranging technical support, transportation or other types of responses, to allow these children the opportunity to be included in regular community activities, not just in activities promoted by institutions specially oriented toward disability services provision. By doing so, the project enhanced the children’s right to express themselves about their interests and

³⁴ Cedar Foundation, 2013.

³⁵ The Joseph Rowntree Foundation, 2001, Consulting with Disabled Children and Young People, www.jrf.org.uk

³⁶ Vicente, J., 2009, Cruce de Caminos. Programa de mediación para la participación de personas con discapacidad intelectual en actividades de ocio comunitario, Revista Española sobre Discapacidad Intelectual, Vol. 40 (3), Num. 231, pp. 87 -102

³⁷ Project Crossroads, http://www.feapsmadrid.org/Cruce_de_caminos

³⁸ The Joseph Rowntree Foundation, 2001, Consulting with disabled children and young people, www.jrf.org.uk

³⁹ Schuurman, M., 2012, The Speak Up! Project, Giving a voice to European children in vulnerable situations - Project Report, Eurochild.

wishes, and enhanced their full inclusion in the community by becoming involved in normalized response to their needs.

4. Political and Social Issues

a) *“Show respect and don’t patronise us”*

*“Ask Us”*³⁸ was a project developed in 1999 by the Children’s Society at the request of the British government in order for children with disabilities to be heard about Quality Protects, the government’s program for child protection in England. The consultation process used multimedia consultation and mixed methodologies to find out about the wishes and feelings of children with disabilities with regard to protective services. The children involved had severe learning disabilities and displayed challenging behaviour, some of them did not use speech or sign language.

This project used several different forms of collecting children’s views and opinions: Children with disabilities were placed as researchers working on specific topics. Some of them interviewed other children and their opinions were collected through workshops using drama, animation, art, music and puppetry. The children made video diaries, moderated discussions, and undertook leisure activities and visits. A few orientation questions were asked such as: “What do you enjoy? What do you want more of? What are your experiences of consultation? What are your experiences of participation and services? What do you understand by inclusion?” Children were heard on what they wanted and were not asked to comment on the already-existing system because that would have directed their answers.

The main goal was to implement changes that related directly to the children’s needs. All the children, including the ones with severe learning difficulties and communication impairments, were able to participate due to the flexible conditions and technology put at their disposal and they all felt valued and responsible. Also, by using multimedia approaches, children were able to disseminate their ideas throughout their community and country.

The results from the consultation process showed that children with disabilities are concerned about regular childhood issues such as bullying, discrimination, growing up and

respect, and need regular childhood activities like friendship and leisure. Unfortunately, due to the lack of support for their special needs, they are sometimes deprived of these experiences. These participatory processes also drew attention to the fact that communication aids and other types of technical support need to become available in every context of children’s lives’ for children with disabilities to experience childhood like any other children.

b) *“Some children are from Spain and others come from other countries. We aren’t all the same, but it’s essential that we are all treated as equally important”*

*“Speak Up!”*³⁹ was a project implemented by Eurochild and partner organisations in eight European countries. It aimed to increase understanding of children’s own views of their rights, the protection of those rights, and their opinions about necessary national and European policy actions.

Focus groups consultations were organised with groups of children in vulnerable situations, including deaf and hard-of-hearing children, and control groups of randomised secondary school children.

Results showed that both groups of children, but in particular those in vulnerable circumstances, are insufficiently aware of their rights. Children expressed their sadness about not being given sufficient opportunities to express their opinions because that denies them the possibility to choose their own paths and convictions and to develop their sense of belonging in society. The project developed a methodology for the focus group consultations by using a children’s rights card game through which children in vulnerable situations identified “provision rights”, such as the right to education or health, as the most important. This contrasted with findings from the “control” focus groups, which hardly chose any “provision rights” as a top priority. This leads to the conclusion that the “control” groups might be taking those rights for granted, while children in vulnerable situations are conscious of threats to their need to be provided with food, shelter, health and education and acknowledge the vulnerability of their provisions. The main conclusion is the need to support programmes and campaigns involving children to become more aware of their rights. This needs to go hand in hand with large

awareness-raising campaigns, in particular on the right of the child to be heard so that more participatory processes are developed and more opportunities for participation are created.

c) The OMCYA Inclusion Programme in Ireland

The Office of the Minister for Children and Youth Affairs (OMCYA) in Ireland has the lead role in ensuring that children and young people have a voice on issues that affect their lives under the National Children's Strategy. In 2007 the OMCYA established the Inclusion Programme to develop best practice in participation by seldom-heard young people in decision-making structures. Seven organisations, representing seldom-heard young people, received funding to support the involvement of a number of young people in Comhairle na nÓg, the OMCYA Children and Young People's Forum (CYPF) and other initiatives⁴⁰.

The aim of the programme was:

- to provide meaningful experiences for the young people involved in the programme; and
- to identify good practices in enabling seldom-heard young people to take part in decision-making structures and projects.

Comhairle na nÓg (local youth councils) give children and young people the opportunity to be involved in the development of local services and policies. There is a Comhairle na nÓg in every city and county. Delegates from Comhairle na nÓg are elected to represent their local area at the annual Dáil na nÓg (Youth Parliament).

OMCYA Children and Young People's Forum (CYPF)

The CYPF was established in 2004 to advise the OMCYA and the Minister for Children and Youth Affairs on issues of concern to children and young people. There are 35 young people on the CYPF (aged 12–18) from all over the country. Members are nominated to the CYPF through Comhairle na nÓg and organisations representing seldom-heard children and young people.

Inclusion Ireland is a national representative body for people with Intellectual Disabilities promoting social inclusion, equal rights and citizenship for people with disabilities. Inclusion Ireland supported the participation of two pupils from St. Augustine's School,

Blackrock, at the CYPF. These young people experienced the CYPF to be a powerful mechanism for engaging young people and providing a platform to raise issues of concern within a social policy context.

The two pupils describe the CYPF as a great place to have their voice heard, meet people and have fun. The CYPF provides a friendly environment for meetings and a valuable learning opportunity where young people discuss important issues such as discrimination and racism. They made new friends and had lots of opportunities for new experiences. They participated in meetings/structures that provided them with confidence and enhanced their social skills.

The two members were delighted with the opportunity to participate afforded by the programme and eagerly recommended other students avail themselves of the chance to participate in the CYPF, Comhairle na nÓg and other representative structures. The young people said they really enjoyed the experience of taking part in the Forum and gained confidence in expressing their opinions on relevant issues. This was seen on the Celebration Day, when one of the young people discussed the importance of supports that people with special needs require in mainstream schools with the Minister for Children. The young people gained the skill of public speaking and giving presentations, as well as additional skills of participating in groups and listening to the opinions of others. The young people said they learned the value of trying to understand other people's opinions during their discussions on racism and discrimination.

⁴⁰ For the full report on the Inclusion Programme: <http://www.dcy.gov.ie/vie/wdoc.asp?DocID=120>

Conclusion

Respect for children's right to express their views, and the implementation of inclusive participatory processes for children with disabilities, are far from being achieved. However, principles of intervention and good practices are being developed that can inspire present and future interventions. Children with disabilities face extra difficulties in making their rights prevail so they can enjoy all opportunities as equals, particularly children with intellectual disabilities, to whom the recognition of the right to self-expression and the ability to express themselves has been ignored for so long. It is important to think about these children's participation at an early stage in life, as having a voice provides them opportunities for decision-making, self-determination and social inclusion. It is crucial that children with intellectual disabilities also be offered these opportunities in order to guarantee their quality of life and their role as valuable citizens. Additional support and attention are necessary to promote full inclusion of all citizens regardless of their differences.

Among the challenges to making participation a reality we can highlight the issue of time and resources, not only for preparation and evaluation of participation, but also for finding the appropriate method or communication tool to empower each individual child or group of children. This requires a lot of resources from partners and actors on the ground. Even with these important resources, difficulties in sustaining the involvement of children with intellectual disabilities and other seldom-heard children, as well as difficulties in making involvement real once children do participate, may have to be constantly addressed with a critical eye to what has already been achieved. Finally, a commitment to children's participation may be difficult to obtain from the relevant agencies.

We hope this publication will, however, help you to overcome these challenges and to put participation for all into practice!



Resources on participation (selection)

UNICEF (2007), *Implementation Handbook for the Convention on the Rights of the Child*, 3rd revised edition.

Committee on the Rights of the Child (2006), General Comment n°9, CRC/C/GC/9, available at:

<http://www2.ohchr.org/english/bodies/crc/comments.htm>

Committee on the Rights of the Child (2009), General Comment n°12, CRC/C/GC/12 available at:

<http://www2.ohchr.org/english/bodies/crc/comments.htm>

European Parliament, Policy Department: Citizen's rights and constitutional affairs, Committee on Civil Liberties, Justice and Home Affairs (2012), EU framework of Law for Children's rights, Briefing Paper

<http://www.europarl.europa.eu/committees/en/libe/studiesdownload.html?languageDocument=EN&file=72971>

Lansdown G (2001), Promoting children's participation in Democratic Decision-making, UNICEF Innocenti

<http://www.unicef-irc.org/publications/pdf/insight6.pdf>

UNICEF (2007), Promoting the rights of children with disabilities, Innocenti Digest n°13,

<http://www.unicef-irc.org/publications/pdf/digest13-disability.pdf>

Nair, Deepika, Child-Centred Participatory Research: Integrated education for the visually impaired, some insights, Save the Children UK, London, 1996.

Jones, Hazel, Including Disabled People in Everyday Life: A practical approach, Save the Children UK, London, 1999.

Whittles, Sue, Can You Hear Us? Including views of disabled children and young people in decision making, Save the Children UK, London, 1998.

Learning to Listen: Consulting children and young people with disabilities (2001) Save the Children. Available from www.savethechildren.org.uk/development

Clark, Alison and Peter Moss, Listening to Young Children: The Mosaic Approach, National Children's Bureau, ISBN 1 900990 62 8, UK, 2001.

Franklin, Anita and Patricia Sloper, Participation of Disabled Children and Young People in Decision-Making Within Social Services Departments, Quality Protects Research Initiative, The University of York, 2004.

Halldorsen, L., Children Enabling Change: Education, advocacy and action plan for children with disabilities and their families in multi-cultural communities, International Institute for Child Rights and Development, University of Victoria, Canada, 1997.

Joseph Rowntree Foundation, Consulting with Disabled Children and Young People: Research findings, No. 741, JRF, UK, 2001.

Ward, Linda, Seen and Heard: Involving disabled children and young people in research and development projects, Joseph Rowntree Foundation, ISBN 1 899987 48 7, London, 1997.

Are you listening? What are disabled children and young people in Wales telling us about the services they use? (2003) Claire Turner, Barnardos & NCH. Download the report from:

www.childrenfirst.wales.gov.uk/content/framework/

The Participation of Children with Disabilities, Can Child – Centre for Childhood Disability Research; McMaster University, Canada. 2000 – 2006, available at:

<http://www.canchild.ca/en/ourresearch/participatestudy.asp>

How to involve children and young people with communication impairments in decision-making, Participation works, UK, 2009, available at:

<http://www.participationworks.org.uk/resources/how-to-involve-children-and-young-people-with-communication-impairments-in-decision-making>

Promoting the Participation of Children With Disabilities in Sports, Recreation, and Physical Activities; Nancy A. Murphy, MD, ; Paul S. Carbone, MD, and the Council on Children With Disabilities; Pediatrics Vol. 121 No. 5 May 1, 2008 pp. 1057 -1061, available at:

<http://pediatrics.aappublications.org/content/121/5/1057.full>

Northern Ireland Commissioner for children and young people (2012), Review of Transitions to Adult Services for Young people with Learning Disabilities, by Prof. Laura Lundy, Dr Bronagh Byrne and Dr Paschl Mc Keown.

http://www.nickey.org/uploaded_docs/2012/Publications/NICCY%20Transitions%20Report%20-%20final%20sept%2012.pdf

Making Life a Safe Adventure, Strengthening families of children with disabilities to prevent maltreatment, project resource financed under Daphne www.aiasbo.it/daphne (available in EE, DE, GR, IT, LV, PL and PT)

EUROCHILD (2010), Valuing Children's Potential, How children's participation contributes to fighting poverty and social exclusion. http://www.eurochild.org/fileadmin/ThematicPriorities/Participation/Eurochild/ValuingChildren_sPotential.pdf

Supporting the participation of disabled children and young people in decision-making, Franklin, A. and Sloper, P., Children & Society, 23, 1, 3-15, 2009, available at: <http://eprints.whiterose.ac.uk/5228/2/Document.pdf>

Participation of disabled children and young people In decision-making relating to social care, Anita Franklin and Patricia Sloper, University of York, UK, 2006, available at: <http://www.york.ac.uk/inst/spru/pubs/pdf/decision.pdf>

Assistive Technology Supporting the participation of children with disabilities; Sarah A. Mulligan; Beyond the Journal; November 2003, available at: <http://journal.naeyc.org/btj/200311/assivetech.pdf>



Inclusion Europe

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.



changing lives!

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.



With the financial support of the Fundamental Rights and Citizenship programme of the European Commission.