





### Hear Our Voices!

### Promoting and encouraging participation of children with intellectual disabilities



This project was co-funded by the European Union

# What does participation means



# Just imagine what it means not to be able to take any decision in life

- People doesn't speak to you but they speak about you while you are there
- Imagine that other speak about in a low voice and you can't hear what they are saying but you know it is something about you
- Imagine that people take you to places but you don't know in advance where you are going
- Imagine that each time you try to think about what to do somebody tell you what to do
- Imagine if sombody speaks always to you as if you are a child
- Imagine if you can not participate in your OWN LIFE

"We had been told that there was evidence of systemic sexual abuse going on at M.'s school. We needed to decide if we wanted to leave him there or bring him home. We were really shocked that she didn't seem concerned about whether or not M. had been abused.

The school wouldn't answer any of our questions and just said we had to talk to their lawyers, which was no help at all.

To this day we still don't know if he was abused at his school and that's an awful thing for a parent. We just don't know what impact this has all had on M. and can't find anyone to help M. or us."

(UK)

# The Right to Participate is recognized in the CRPD

With a view to enabling persons with disabilities to participate on an equal basis with others

# Children's Rights for all !!







DSP



15





Call Se

### **Previous European research project**

- Children's right for all!
- Research about the implementation of the UN Convention on the Rights of the Child from the perspective of children with intellectual disabilities.

#### Children's rights for all!

Implementation of the United Nations Convention on the Rights of the Child for children with intellectual disabilities









## Figure 1- Extent of implementation of the CRC according to the five areas



### **Recommendations to the EU**

- PARTICIPATION:
  - Include provisions in the European Accessibility
    Act on (alternative) communication methods to
    ensure that children with severe disabilities and/or
    complex needs can meaningfully contribute, be
    heard and understood.
  - The European Commission should adapt its own
    **Disability Communication Strategy** to create
    accessible information for people
    with disabilities

- LIVE IN THE FAMILY :
  - Ensure that EU funds are no-longer used to maintain, renovate or support existing institutional models of care
  - Support the development of national plans for transition from institutional to community-based living that should include a moratorium on new admissions and individual care plans for every child concerned
- PROTECTION AGAINST VIOLENCE AND ABUSE:
  - Mainstream disability in the upcoming EU guidelines on child protection systems

- EDUCATION:
  - Make sure that the next *Education and Training Monitor* includes a section on **measures to promote inclusive education** for children and young people with disabilities in accordance with the obligations of the EU and its Member States under the CRPD.
  - Earmark funding through the Erasmus+ framework for initiatives, such as exchange of good practices in the field of inclusive education, specific exchange programme between teachers of mainstream schools, exchange of School Directors/Leaders of inclusive schools.

- HEALTH:
  - Ensure that the accessibility of medicinal products, services and equipment is covered by the forthcoming European Accessibility Act;
  - Facilitate equal access to healthcare services by children with disabilities through the use of the EU financial instruments, such as the 3rd EU Health Programme and Horizon 2020 Programme; not only disability-specific healthcare, but also mainstream services, such as dental and eye care, sexual health and preventive services

















pour la promotion du bien-être et des droits des enfants et des jeunes







Quip společnost pro změnu



# Hear Our Voices

### **The project Hear Our Voices**

- Training and teaching children with intellectual disabilities to participate in various matters which affect them directly
- At school, in small group homes, in large institutional settings, and in their families
- Development of tools for individual and collective participation

### Meaningful participation means

- Participation of ALL children in ALL environments
- Age-appropriate, accessible information available for children with disabilities
- Alternative communication methods.
- Consultation directly with and involvement of children and their families.

# Evidence for sufficient participation of all children

- The provision of accessible information in a range of alternative formats including complaint mechanisms for children
- Professional trainings for staff working with children
- Participatory mechanisms at schools, in child care services, including in residential institutions
- Findings available on consultation, and policy changes from a child perspective

### **Recommendations – our vision**

- Children with disabilities are integrated into existing child participation mechanisms and have specific mechanisms targeting them.
- Capacity-building and financial assistance to projects and initiatives on participation are available.
- Children with intellectual disabilities and their families are involved and participate fully throughout the policy cycle.

### **Recommendations – our vision**

- Schools provide opportunities for children to be heard, and equip children with the necessary skills
- Children are actively involved in the planning and monitoring of services, and in measuring the quality of the services they use.
- Disabled children and their parents are supported and trained to become advocates and parents to actively listen to their children.

### Some highlights

- Most countries provide **very limited statistical picture** of the lives of children with intellectual disabilities.
- Little information available about the forms of abuse reported – lack of empirical research and data
- Inadequate measures for children with intellectual disabilities to express their views and to be heard and lack of appropriate supports to victims (absence of alternative formats, communication barriers, lack of staff training)

Children Rights for All! Inclusion Europe, 2010

## Some highlights

- Attitudes reduce the opportunities for informal learning and social interaction with peers.
- Children with intellectual disabilities are hardly ever provided the opportunity to express their views
- Absence of provisions on the right to participate for children with intellectual disabilities

Children Rights for All! Inclusion Europe, 2010

### The partners

- Inclusion Europe, Belgium <u>www.inclusion-europe.org</u>
- Eurochild, Belgium <u>www.eurochild.org</u>
- QUIP , Czech Republic <u>www.kvalitavpraxi.cz/en</u>
- Cedar Foundation, Bulgaria <u>http://www.cedarfoundation.org/en/</u>
- Down Madrid
  <u>www.downmadrid.org</u>
- With the support of Lumos <u>www.wearelumos.org</u>

# We demonstrate that meaningful participation means

- Participation of ALL children in ALL environments
- Age-appropriate, accessible information available for children with disabilities
- Using alternative communication methods
- Using person-centered methods
- Consultation directly with and involvement of children, their families and/or their closed people.

### Participating in my life!

Participating in my life: Hear my Voice!



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

- Participatory mechanisms in child care services, including in residential institutions
- Mechanisms support planning and monitoring of services, and their quality.

### Participating at my school!



REPORT OF A PROJECT LED BY INCLUSION EUROPS

a lost on Huse

- Participatory mechanisms at schools.
- How schools provide opportunities for children to be heard, and to participate.
- Children and their parents are supported and trained to become advocates

## The project Hear Our Voices!

- ensure the visibility of children with intellectual disabilities in child rights policies, legislation and practices at national, European and international levels
  - developed a policy briefing on the EU strategy on children rights from a CRPD perspective with recommendations
  - organised a meeting at the UN with both CRC and CRPD Committees members.

### **GENEVA October 26 2014**



# Developing a model for schools



## Hear my voice!

To learn how to multiply correctly

To improve my writing in lowercase letters

My dream: to become a professional cook

Z

 ${\color{black}{\frown}}$ 

 $\overline{}$ 





### FAMILY

Inma (mum) Juanjo (dad) Mariano, Santi, Hugo, Silvia, Adriana, Sandra, Mª Ángeles, Mª Ángeles (grandmother)



### FRIENDS

Pablo, Sergio, Alonso, Helena, Moisés and Ana Aaron (paddel tennis)











OTHERS (neighbours, leisure activities...)

Virginia, Héctor, Juanjo, Luis Mario (swimming pool)



### THESE ARE MY PEOPLE ( RAÚL)

#### FAMILY

Dad, Mom. <u>Ma</u>ría, Pedro, Antonio, Ana

Grandpa. Aunts: Reyes, Elena. Uncles: Gonzalo, Joaquín,. Cousins: Cristina , Marta, Gonzalo. Fifi ( dog)



### FRIENDS

Alonso, María, Sergio, Helena, Leila and Marta.

### PROFESSIONALS











OTHERS (neighbours, leisure activities....)

Ceci (Mum's friend)

JAVIER



- Teasing
- Playing with my Pokemon cards
- Watch TV and DVD
- I really like the food: chicken with potatoes, pasta, pizza
- I love doing magic tricks.
- I like going to the movies, to the pool, to summer camps.

JAVIER



#### ... WHAT I REALLY DONT LIKE

WHAT BOTHERS ME, WHAT MAKES ME FEEL UNCOMFORTABLE, SCARES ME ...

- Fights: pushing, shouting ...
- When someone remove my stuff
- I hate that there are things I can not eat

JAVIER



RAÚL



#### **MY TASTES AND PREFERENCES**

LIKE, ENJOY, FEEL COMFORTABLE, SAFE ...









SOCCER VOLLEYBALL BOWLING

TENNIS



PIZZA WITH BARBECUE SAUCE



EGGS WITH SAUSAGE



tooth Fairy RAÚL



#### ...WHAT I REALLY DON'T LIKE

WHAT BOTHERS ME, WHAT MAKES ME FEEL UNCOMFORTABLE, SCARES ME ...






RAÚL



I'M GOOD AT ... MY STRONG POINTS



I am funny, friendly, I am very good playing theater and writing stories

# WHAT I FIND MOST DIFFICULT...



MY WEAK POINTS

Follow the rules Stop cheating Share my staff with others Say hello to people I met Organized RAÚL

### I'M GOOD AT ...

#### MY STRONG POINTS





# WHAT I FIND MOST DIFFICULT...



MY WEAK POINTS



## I NEED SOME EXTRA SUPPORT



Identify relevant areas in need of support				
Dressing	Communication and language skills		Social interaction (cooperation, signs of respect)	
	Procesos cognitivos	Leisure activities	Basic social behaviour (social skills)	
Personal Higiene	Motor skills	Using of public transport	Emotional development	
Eating habits	Sensitivity level	Money		
Personal appearance		Orientation and mobility		
Domestic chores	Sleep	Motivation	Self-defence	
Leisure time at home	Personal injury	Daily routines	Decision making	
Self managemement	Personal health and Security			

Keeping in mind my age and stage of development, we will identify the relevant areas in need of extra support and the intensity of support which I need.

## I NEED SOME EXTRA SUPPORT



Identify relevant areas in need of support				
Dressing	Communication and language skills		Social interaction (cooperation, signs of respect)	
	Procesos cognitivos	Leisure activities	Basic social behaviour (social skills)	
Personal Higiene	Motor skills	Using of public transport	Emotional development	
Eating habits	Sensitivity level	Money		
Personal appearance		Orientation and mobility		
Domestic chores	Sleep	Motivation	Self-defence	
Leisure time at home	Personal injury	Daily routines	Decision making	
Self managemement	Personal health and Security			

Keeping in mind my age and stage of development, we will identify the relevant areas in need of extra support and the intensity of support which I need.



#### MY WISHES AND GOALS

- To learn how to multiply correctly
- To perform science experiments
- To write with lower case letters
- My dream is to become a cook: to learn how to cook dishes with my mother
- I'd like to read books and wath mystery movies

RAÚL



#### **MY WISHES AND GOALS**





#### MY WISHES AND GOALS

- To learn how to multiply correctly
- To perform science experiments
- To write with lower case letters
- My dream is to become a cook: to learn how to cook dishes with my mother
- I'd like to read books and watch mystery movies

RAÚL



#### **MY WISHES AND GOALS**



#### FOLLOW UP AND EVALUATION

We meet again to evaluate the progress made and to check if we satisfice our agreements



In Madrid ...... (date)



To help other students when they don't know how to do the tasks To work alone for myself in the classroom To share and take care of the equipment











. .





What are we going to do now?

• • •	<u> </u>	
Goals and dreams	New agreements	
To learn how to multiply correctly	<ol> <li>Work with approximation, rounding</li> <li>Work at home 15 minutes per day</li> <li>Deal with money</li> </ol>	
To perform science experiments	In the class: Science Proyect	
To write with lower case letters	To write always with lower case letters. At home 3 pages everyday	
To learn how to cook	<ol> <li>To cook with my father</li> <li>To cook at home</li> <li>To eat without throwing food at the floor</li> </ol>	
To read books and watch mystery movies	Achieved	



WORKING TOOL 3: Training in problem solving skills

## PENTA



- P Define the problem What is the problem?
- E Elaborate alternatives What can I do to fix it?
- N Negotiation: advantages and disadvantages What can happen if I do this?
- T I make decisions Which option is best?
- A I act and evaluate What have I done? Did it work?

P.E.N.T.A.





Different educational centers participating together



We think of ideas to promote social inclusion of persons with intellectual dissability



We develop an action plan





# Step by Step Project



# **Residential Care**



## Many thanks

