Participating at School: Hear my Voice!

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Inclusion Europe

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

THE **"HEAR OUR VOICES!"** PROJECT PARTNERS:

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

And in collaboration with Lumos: www.wearelumos.org

This publication has been mainly written by staff from Down Madrid (Sonja Uhlmann and Marta Albert) as part of the European project "Hear Our Voices: Promoting and encouraging the participation of children with intellectual disabilities". "Hear Our Voices!" aims to explore, pilot and share methods that empower participation of children with intellectual disabilities and promote their participation. For more information: 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.

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Layout by Orangemetalic.be

ISBN: 2-87460-148-9

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"These cooking classes took place on a monthly basis. As examples, there were specific classes for pizza-making, cupcakes and Easter eggs."

Background

Article 24 of the United Nations Convention on the Rights of Persons with Disabilities which ensures that disabled persons can access inclusive education on an equal basis with others has been analysed exhaustively by teachers, families and anyone whose daily work is in the educational field. Discussions have taken place about the differences between inclusion and integration and strategies have been designed for transforming schools into inclusive ones. However, very little attention has been paid to Articles 29 and 30, which deal with the right of disabled persons to participate and how to achieve this goal. Does it make sense to describe a setting inclusive if a child with an intellectual disability is either not able or not allowed to participate?

From early childhood on, it is we, families and professional educators, who decide what is best for "our" children and what they want and need. This is especially true when the child has an intellectual disability. We are the ones who "know", who make decisions and set goals for them. During this whole process, the voices of children are either never heard and taken into account, or are only listened to very infrequently.

To this end, it is essential to support children and to equip them with the skills and knowledge necessary so that, with the proper help, they can participate fully in all aspects of their lives. If we do not teach decision-making, self-determination, knowledge of rights and how exercise rights as along with participation from a very early age, it will be difficult for these children to have their voices heard. They need to understand that as persons, they are individuals who enjoy the same rights as others and that participation is one of their fundamental rights.

Previous research conducted by Inclusive Europe shows that children with disabilities are less involved in society than their non-disabled peers because they participate less in social activities. Forming friendships, participating in group activities and joining clubs are all ways to learn how to become engaged in society, and these activities make an essential contribution to all children's social and personal development. However, participating in these activities is not always easy for children with disabilities and they need special support to do so.

Participation involves two main aspects. On the one hand, it is extremely important to listen to children with intellectual disabilities, and on the other hand it is important to support them so they can participate not only in formal education, but also in social activities.

A third aspect we must bear in mind is that children with and without disabilities can play a significant role as agents for social transformation. Our aim is to strengthen children's ability to participate, taking into account their age, maturity and social context. We uphold children's rights to be listened to, to express their opinions on matters that affect them and to be made to feel free in assuming their roles and responsibilities while simultaneously respecting their parents and others in authority. When children learn to communicate their opinions, to take responsibility for their actions and to make decisions, they are able to improve their standing as both students and citizens.

It is through the Hear Our Voices project that we wish to empower and train children with and without intellectual disability to participate in all the issues that affect them directly so they can be masters of their own lives.

Chapter 1

THE PROJECT AT DOWN MADRID

1. Our school

The different tools and methodologies discussed below are used by the Fernandez-Miranda Centre for Special Education, a newly-created school (since 2012) run under the auspices of the Down Syndrome Foundation of Madrid (or "Down Madrid"). The mission of the centre is to improve the lives of its students and their families through the action plans and goals defined in its educational programme. Indeed, it is thanks to a quality educational programme that the students can develop in an integral way that allows them to use, control and enjoy the environment in which the daily life of the school takes place. This educational programme provides students with support and the necessary resources accompanied by trained and committed personnel united in a common project including all the members of the educational community.

The fundamental goal of the programme's design is for our students to personally achieve success. This goal will be accomplished thanks to a carefully constructed educational model based on values such as respect for diversity, autonomy and social inclusion as well as the premise of an integral, person-centred education. The pedagogical requirements of this model are commitment, participation and intercommunication between all the members of the school community, including families and close acquaintances. We are convinced that it is imperative to offer children opportunities to participate from the earliest ages. Therefore, we believe that taking part in the Hear Our Voices project has been a unique opportunity for everyone to master the necessary skills needed to train a child toward participation.

We hope that with this project, school-children will learn to become their own decision-makers, especially about issues that affect their futures. We also hope to receive the full support of their family members, their close acquaintances and their teachers. This is how these children, who have their own hopes and dreams for the future, will benefit from our positive reinforcement and support, and we must never forget their wishes for the future.

2. Are we promoting participation?

Before we began our project we discussed at several staff meetings about what participation means for us and how aware we are of the importance of this aspect of our school.

Below is an example of a questionnaire that helped guide our discussion.

CHALLENGE	ORGANIZATION SCORE (CIRCLE)
Children are informed about changes that are going to happen	1 2 3 4 5
Children are informed why changes are taken place	1 2 3 4 5
Children's opinions are taken into account before changes happen	1 2 3 4 5
You teach children what their rights and duties are	1 2 3 4 5
You teach them how to complain if they don't like something	1 2 3 4 5
Children can choose among different leisure activities	1 2 3 4 5
Children can choose which books are bought for the library	1 2 3 4 5
Children have the chance to give their opinion on different issues	1 2 3 4 5
Children have an alternative communication system if they need it	1 2 3 4 5
The school has informative pictograms for the ones who need support in communication	1 2 3 4 5

5 - always / 4 - quite often / 3 - often / 2 - sometimes / 1 - never

3. Action steps taken:

To organize work at our school, we divided the actions we want to take according to this scheme:

a) Actions concerning the culture of our school:

- Inform parents and professionals of the values and guiding principles concerning child participation.
- Write these values and principles down; organize a small working group with students, parents, teachers and staff members to develop this document.
- Make the document public and try to get everybody involved in it.

Remember:
The document has to be accessible!

b) Actions concerning the objectives of our school:

- Organize concrete actions to promote participation at our school.
- Pay special attention to measuring how many actions we develop to promote participation during the school year.
- Put photos and pictures from the actions on a visible wall so everyone is aware of them.
- Measure whether students feel they can participate in the actions and that their voices have been heard.
- Let students know how many of their proposals have been put into practice or have been seriously considered.

c) Actions concerning our school structure:

- Organize a specific place for a "suggestions" box.
- Provide a meeting place and specific timeslot within the schedule where students can meet each other and start discussions on issues important to them with respect to the structure.
- Provide a specific time where the headmaster can receive students to hear their suggestions with respect to the structure.
- Offer students a place on the school council.

d) Actions concerning pedagogic practices:

- Include training about children's rights and how to claim them at each level of the curriculum.
- Include games to develop skills like assertiveness, active listening, problem solving, etc., for each age level.
- Analyze and discuss the challenges our organization faces and how far we have advanced on the issue of Child Participation.

4. Two concrete student case studies: Javier and Raúl

The case of Javier

Javier is a 12-year-old boy with Down syndrome. Before enrolling at our centre, he attended an inclusive school. His mother is a secondary school teacher and is in favour of her son's active participation in planning his own future.

The case of Raul

Raul is a 14-year-old boy with Down syndrome in foster care. Before enrolling at our centre, he attended an inclusive school. His foster parents are committed to providing Raul their full support so he can be the protagonist of his own life.

Raul has many support needs, especially in the area of behavioural self-regulation. He uses an alternative communication system (pictograms) to improve his behaviour.

Steps taken with both students

The methodology used is based on Person-Centred Planning (PCP), but it does not follow the rules of that system. The schoolchildren themselves, their families and their educators work out an Individual Development Plan for each schoolchild. After taking into consideration personal history, the skills to be achieved, the abilities to developed and the schoolchild's wishes, this Individual Development Plan makes it easier for a schoolchild to identify (either directly or with the assistance of others) the goals he or she wishes to reach in order to improve his or her life during each school year. The schoolchildren rely on the commitment and strength of a support group in order to reach l their objectives.

Unlike a PCP approach, the children are not the ones who choose their facilitators - that remains the function of their teachers. The family still plays a decisive role, as its members will have to be involved and committed from the very start of the programme.

Before starting, the programme is explained to the education team, to the families and to the schoolchildren themselves. During the actual execution of the programme, various person-centred activities are carried out, always with, by and for the individual person. What follows is a description of each step taken as well as the most important activities and tools used.
In order to extract the necessary information, there are several meetings during the school year to fix the goals of the Individual Development Plan. All of the members attending the meeting will agree to the personal goals the schoolchild wishes to achieve and, whenever necessary, will use Alternative Communication systems. Later on subsequent meetings are used for evaluation and follow up.

We used the pictograms developed by Sergio Palao. Source: ARASAAC (http://catedu.es/arasaac/) License: CC (BY-NC-SA)

The steps outlined in the Individual Development Plan are the following:

a) Knowing myself
   - These are my people
   - My preferences
   - My strengths and weaknesses

b) My areas of need and support
c) Identify my support group and the goals I wish to achieve

d) Evaluate the progress made in reaching my personal goals.

A) Knowing myself

Objective: The first objective is for the schoolchild to have a realistic picture self-image.

To reach this objective, we need the schoolchild to show us who is part of his or her closest circle: Family, friends, professionals, others (neighbours, recreation leaders). This ensures that we know specifically which persons are the most important for him. The schoolchild must also show us his daily environments and his favourite places at home, at school, during recreation and while using other services.

We need to know the schoolchild's personal tastes and preferences - what he likes and enjoys, where he feels comfortable and secure, as well as what bothers him, what makes him uncomfortable, what scares him, his strong points are, what he is good at, what is hardest for him, and what his weak points are.

Method Followed:

1. We present our method as a proposed action plan in order to encourage the schoolchild and his family, together with the school support team, to gather the most relevant information about him (aided by his parents and professionals) for

"Javier is a 12-year-old boy with Down syndrome."

presentation to his official support group. This way everyone who cares about the student and is committed to assisting him shares a common vision of his plans for the future.

2. The tutor-facilitator holds a first meeting with the disabled schoolchild in order to comprehensively evaluate him through selected tools. In this first meeting, the schoolchild is made to understand, according to his level of comprehension, the objectives of the proposed action plan and the meaning of the information recorded on each personal file card.

3. The tutor-facilitator carries out the Individual Planning and Evaluation with the help of the schoolchild's natural support network. The main functions of the tutor-facilitator are to ensure that the disabled person's rights, ideas, goals and preferences are respected, thus giving support to the idea that the disabled schoolchild is able to direct his or her own life; to direct and stimulate participation by the official support group, generating a climate of trust and reaching consensus among all its members; to guide the meetings; to follow up; and to encourage the implementation of all the commitments made.

(Video 1) Preparing my meeting

THESE ARE MY PEOPLE

Objectives: Our objective is to identify those who are important to the schoolchild. In order to make the identification process easier, there are several categories: Family, friends, professionals and others (neighbours, etc.). These are persons close to the schoolchild who can be counted on to help her progress towards her goals.

Method Followed:

1. The schoolchild indicates the most important persons in his immediate environment. In order to facilitate this identification, these persons are separated into four groups: Family, friends, professionals and "other persons in my environment." From this relationship map, the student selects persons whom he wants to include in his planning process, i.e., persons who will always be present and who will offer him all the help and support he needs to reach his goals.

2. In all cases, the facilitator will be the class tutor.

3. Planning the process: Once the most important persons are identified, the schoolchild decides whom he wants to include in his official support group.

4. Once the group has been defined, the schoolchild contacts each of the persons he has selected with the help of his family or of the facilitator. After obtaining their agreement to participate, the facilitator will coordinate their schedules so they can start meeting on an official basis.

MY PREFERENCES

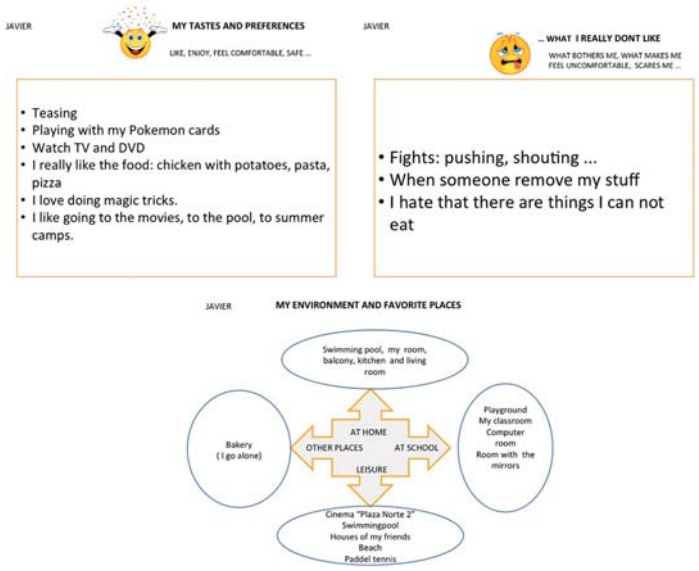
Objectives: To develop a Personal Profile that will help us get to know and listen to the person so we can discover and appreciate his tastes, skills and abilities as well as his difficulties and frustrations.

Method Followed:

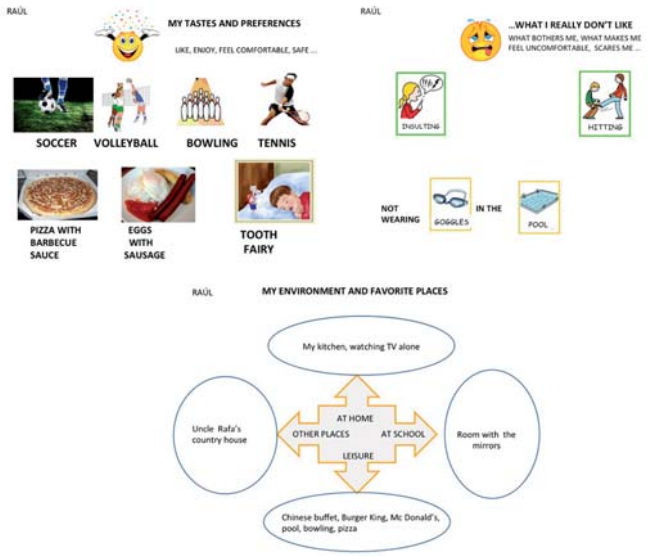
1. The facilitator investigates the best methods for gathering information from the schoolchild, as this information will lead to a better understanding of him or her. To achieve this, the facilitator will prepare materials to help the schoolchild with this process of self-knowledge. The schoolchild should describe how he spends his time, the amount of time he spends either in community or separated settings (the "My Places" List), which activities he likes/dislikes (the "My Preferences" Listand his personal dreams for the future (the "My Wishes" List).

2. With the help of the schoolchild, computerized materials are designed that are very eye-catching, adapted to awaken his individual interest.

Javier



Raúl



MY STRENGTHS AND WEAKNESSES

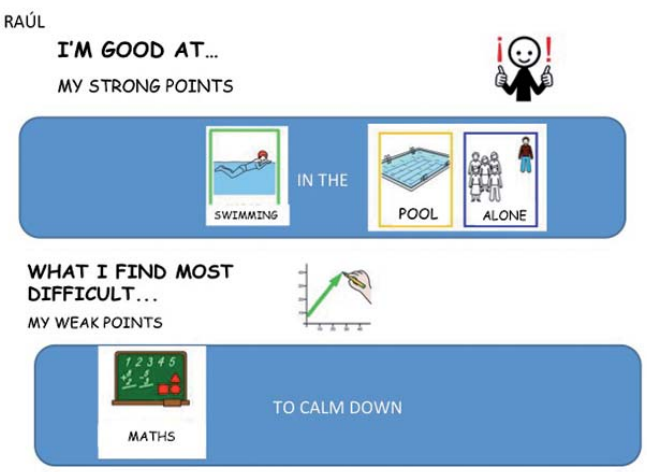
Objectives: To get to know the student well. To discover his talents, what other people admire about him, and his limitations.

Method Followed:

1. The facilitator will help the disabled person discover his abilities and the activities he stands out in, including all the tasks he is able to perform well. At the same time, the individual must be conscious of his limitations, of the activities or tasks during which he is prone to make more mistakes, and finally, of behaviour that is inappropriate, either because it is always inappropriate or because it is not appropriate for the moment or situation at hand.

Javier

Raúl



B) My areas of need and support

The second step we must take in order to evaluate the young person's support needs is to identify the main areas in need of support and assistance. The individual is encouraged to follow this thought process: "Given my age and stage of development, together we shall identify the support needs that are important for me and the amount of assistance I need."

Needs during the following activities will be reviewed with the schoolchild: Dressing, personal hygiene, nutrition, personal appearance, domestic tasks, leisure activities at home, self-regulation, communication and language, cognitive processes, motor development, sensitivity level, sleep habits, physical injury, health and security, leisure activities within the community, use of public transportation, money issues, mobility and sense of orientation, motivation, daily routines, decision making, self-defence, social and emotional development, basic social behaviour (social skills) and social interaction (cooperating, showing respect to others).

Javier

JAVIER

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-defense
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.

Raúl

RAÚL

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-defense
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.

C) My wishes and goals

Objectives: To determine what the child is interested in learning and what goals he wishes to achieve inside and outside the classroom during the coming school year.

Method Followed:

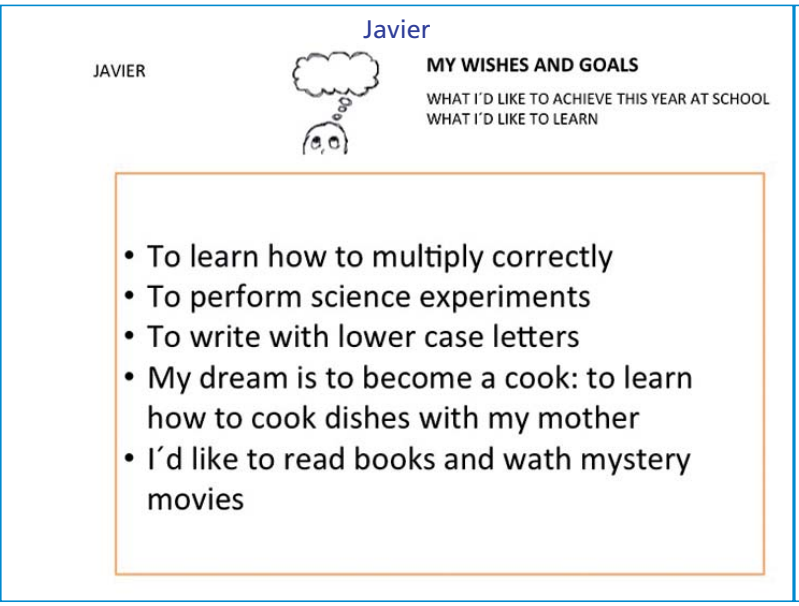
1. The facilitator will help the young person discover his wishes and goals. Before starting his Individual Plan, every schoolchild must stop to think about which of his proposed goals are the most important to him.

2. After completing the Individual Plan we will be equipped with all the information we need about each schoolchild. This way we will have a better knowledge of all the schoolchildren, and they themselves will come away from the interview with the feeling that we care about everything that motivates them. We have to make them understand that many of their dreams and goals can be attained through effort and enthusiasm and with an attitude of active participation. At the same time, we must be constantly aware of all the information they have shared with us and we have to keep our promise to them that they can accomplish whatever they want to accomplish. We have to provide them with the help they need to develop their skills and talents.

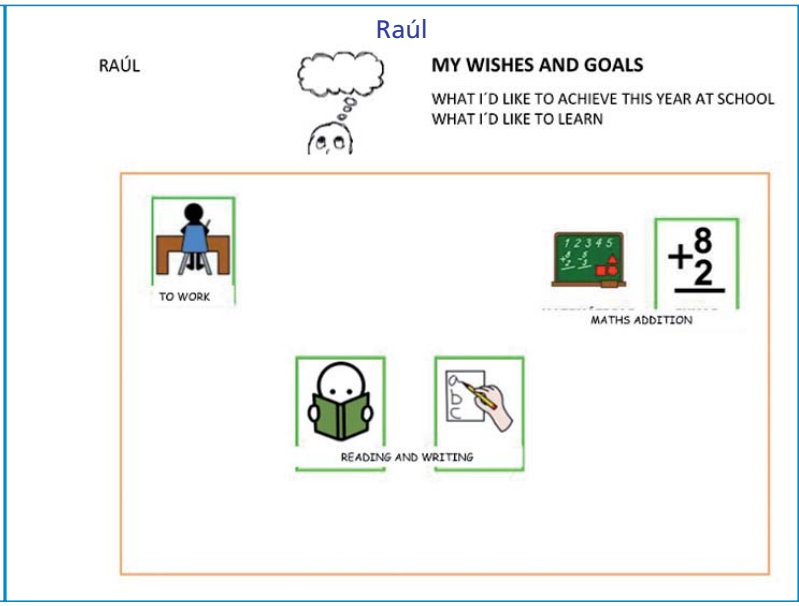
3. It is best to start with simple tasks, one goal at a time, focusing on each unique aspect. Our wish is for the schoolchild's goals and dreams to be fulfilled. However, we must be realistic and commit to goals that are achievable.

4. Finally, we will record in writing the agreements and obligations of each person on the team, specifying their deadlines, locations, etc. Before we begin, we must make sure the schoolchildren have a complete understanding of what was discussed. They need to know that we will support and help them to the best of our ability in every way possible. They must feel protected and supported. At the same time, they will also have to agree to contribute their own necessary time and effort to achieve what they want.

Javier



Raúl



By implementing this programme, we can overcome many of the prejudices society has about persons with intellectual disability, and we can make these young people more willing to manage and participate in their own lives.

We must pay great attention to the goals the schoolchildren set in order to put the necessary tools in place to help them attain those goals.

Javier

JAVIER

MY WISHES AND GOALS

WHAT I´D LIKE TO ACHIEVE THIS YEAR AT SCHOOL
WHAT I´D LIKE TO LEARN

- 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

JAVIER

FOLLOW UP AND EVALUATION

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

.....

SIGNED:Hugo SIGNED:Javier SIGNED:Luisa

SIGNED:Inma SIGNED: Juanjo

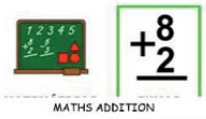
In Madrid ..... (date)

Raúl

RAÚL

MY WISHES AND GOALS

WHAT I´D LIKE TO ACHIEVE THIS YEAR AT SCHOOL
WHAT I´D LIKE TO LEARN

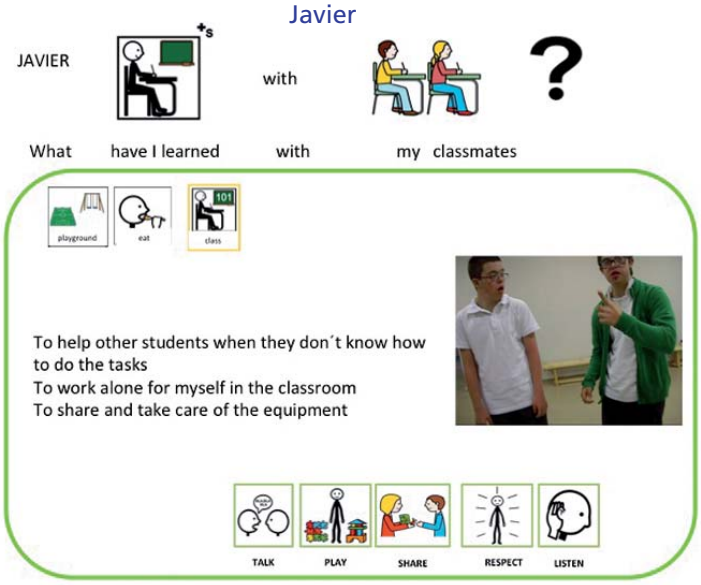


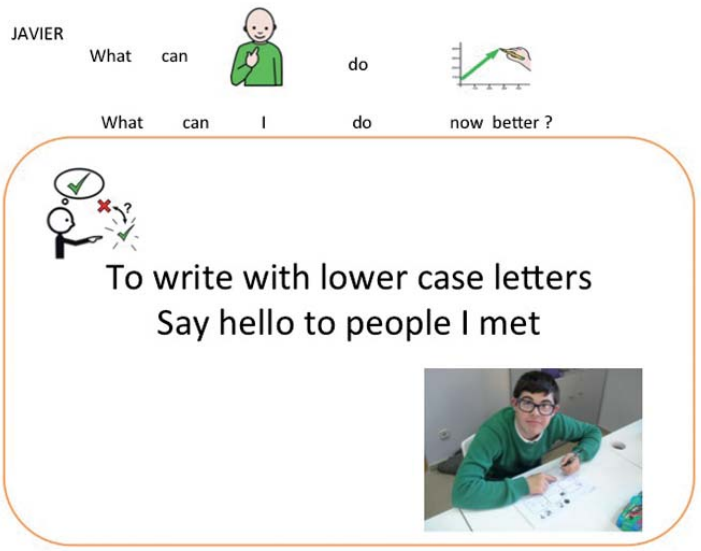
D) Evaluating the progress made in reaching my personal goals

The tutor-facilitator will ensure that the goals and activities proposed for each schoolchild are being implemented. To this end, the tutor will call periodic evaluation and progress review meetings.

In our case, these review meetings took place every four to five months. We started the programme in September, held our first progress review meeting in February, and held another in June.

Javier



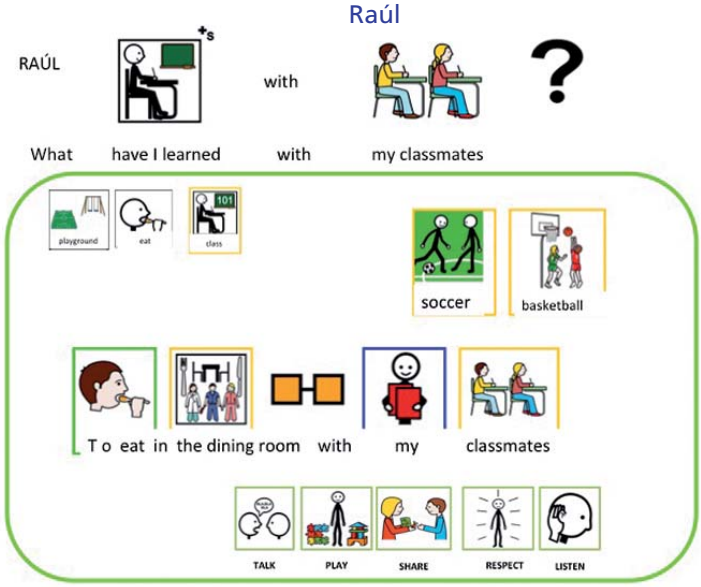


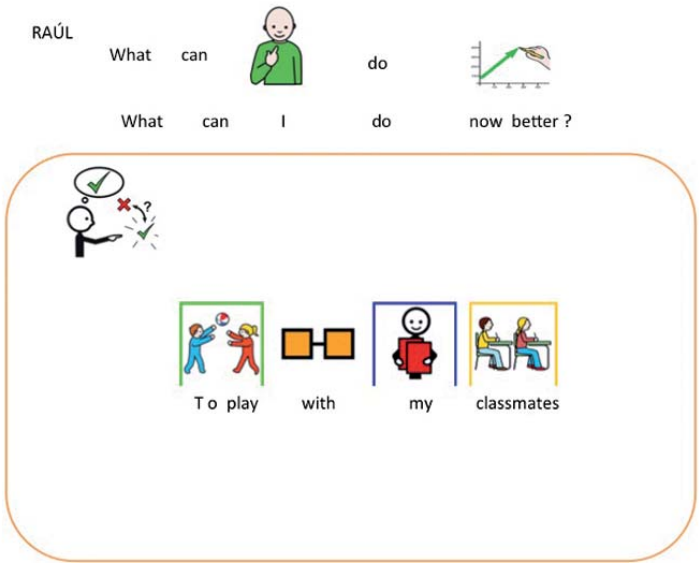
JAVIER

What are we going to do now?

Goals and dreams	New agreements
To learn how to multiply correctly	1. Work with approximation, rounding 2. Work at home 15 minutes per day 3. Deal with money
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	1. To cook with my father 2. To cook at home 3. To eat without throwing food at the floor
To read books and watch mystery movies	Achieved

Raúl





RAÚL

THIS IS MY MEETING

1º KNOWING MYSELF

Get a realistic picture of who he is.

2º MY AREAS OF NEED AND SUPPORT

Identify important areas where support is needed and establish amount of support needed.

3º "MY WISHES AND GOALS"

Know what he'd like to learn, what he wants to achieve, inside and outside the classroom…

4º EVALUATION AND REVIEW

Measure the progress he has made in reaching his goals.

1º KNOWING MYSELF

Raul shows us that the most important persons in his life are his parents and his brother, a few teachers and some classmates.

He likes to engage in sports, but does not like to get nervous or to hit, nor does he like forgetting him swimming goggles.

He identifies his strong point as being a good swimmer, and he says his weak point is his inability to calm down.

He is able to identify his favorite place.

2º MY SUPPORT NEEDS

Needs support mainly to control his emotions and improve social skills.

3º "MY WISHES AND GOALS"

Raul's wishes: to improve his reading, math skills and to make friends.

4º EVALUATION AND REVIEW

1º KNOWING MYSELF

Javier shows us that the most important people in his life are his parents and his brother, a few teachers and some classmates.

He likes to play jokes on people, his Pokemon cards, watching TV and dvds. Favorite foods: chicken and potatoes, pasta, pizza. Performing magic tricks. Going to the movies, the swimming pool or to camp. He does not like fights: pushing, yelling…, when someone takes his things away from him or when there are foods he isn't allowed to eat.

He identifies his strong points as being fun to be with, friendly, and he is very good at acting in plays and writing stories. He is neat. It' s hard for him to obey his mother and his teachers and to show respect toward his classmates or to stop playing jokes when called for. It is hard for him to share with others and respect other's belongings.

He is able to identify his favorite place.

2º MY SUPPORT NEEDS

He mainly needs support during leisure activities at home. Also with his social and emotional skills.

3º "MY WISHES AND GOALS"

Javier's wishes: to learn how to multiply well, to perform science experiments, to write better in lower-case letters. His dream: to be a cook. He would like to read books and see mystery movies.

4º EVALUATION AND REVIEW

Javier has been able to relate more and socialize with his classmates. He has cooked with his mother and father. He has improved his writing.

JAVIER

THIS IS MY MEETING

1º KNOWING MYSELF

Get a realistic picture of who he is.

2º MY AREAS OF NEED AND SUPPORT

Identify important areas where support is needed and establish amount of support needed.

3º "MY WISHES AND GOALS"

Know what he wants to learn, what he wants to achieve this year inside and outside the classroom…

4º EVALUATION AND REVIEW

Measure the progress he has made in reaching his goals.

5. Participation in the classroom

> *"One learns from experimentation, everything else is mere information. - Albert Einstein"*

Educational centres are an ideal setting for teaching schoolchildren about participation. We can encourage participation by providing them with the appropriate tools for learning how to make choices and decisions, thus encouraging the creation of attitudes and values such as a sense of responsibility, respect for others, autonomy and solidarity. Furthermore, it is by participating that one learns how to participate. This implies that the techniques and dynamics used during these working sessions need to be participatory in nature so schoolchildren can experience first-hand what participation is all about. As we work toward ensuring their greater participation, we are heading towards a more inclusive educational system and towards greater personal self-sufficiency - in other words, towards a better quality of life for everyone.

Participation requires the will to participate, knowledge and empowerment. Schoolchildren need to understand what it means to participate and what the educators mean by this: Providing opportunities and eliminating barriers (cognitive barriers, language barriers, etc.). In order to encourage participation at our school, we must create special spaces designed to promote communication, cooperation and dialogue among all of us.

Active participation is one characteristic of an "efficient school." (Sandoval 2011, p 115). Taking into account schoolchildren's opinions of the situations that affect them directly (the teaching and learning process, school environments and settings, etc.) becomes indispensable to the building of schools that are more participatory. It is important to take our schoolchildren's voices into account and consider them tools for change in the culture and practices of the educational centre. This attitude implies recognizing them as active, competent subjects with knowledge and the capability to participate in everything that affects their lives (Echeita 2008). Paying attention to their voices implies recognizing them as true social actors (Sandoval 2011).

Based on the Hear our Voices Programme we began to implement programmes designed to improve participation.

Three Tools were used:

- The School Assembly
- The Annual School Research Project
- Training in Problem-Solving Skills

TOOL 1: THE SCHOOL ASSEMBLY

Objectives: The purpose of school assemblies is to provide a specific place that encourages meaningful participation and provides an opportunity for schoolchildren to voice their opinions, which, in the words of Sandoval (2011), is the same as using new arguments to demand that *"nothing about us without us."* (p 119) Through this initiative, schoolchildren acquire a greater leadership role and a greater ability to provide meaning to their life experiences as well as a greater sense of responsibility during their school life. The assembly also provides the teaching staff with a tool that allows them to better recognize their schoolchildren's participation abilities. (Susinos, 2009).

These School Assembly meetings take place once a week. Assessment of an assembly focuses on quantitative variables such as the number of schoolchildren attending, the quantity of their responses generated, and data indicating whether or not they are participating. Qualitative aspects examine whether or not schoolchildren feel comfortable during the assembly and whether or not proposals made are duly noted and taken into consideration, etc.

Participation has group and social dimensions. When applied to a group situation, participation implies giving and expressing our opinions as individuals and sharing them with other group members. This process requires improved dialogue, the display of empathy towards others, and cooperation.

Method followed:

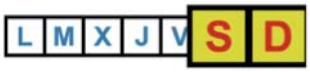
A secretary and a moderator are chosen among the children. These positions will rotate. The secretary's function will be note-taking. The moderator will remind the

participants about the different parts of the meeting and give the floor to the participants, one by one.

The assembly consists of these parts:

NEWS

ANNOUNCEMENTS



WEEKEND

In the "News" portion of the assembly schoolchildren can talk about some recent world event (or sometimes personal ones). The "Announcements" section deals with something from daily life that will take place in the future, while during the "Weekend" section schoolchildren are able to choose the most significant occurrence(s) from their weekend.

During the meeting attendance will be taken and participants will carry out a self-evaluation of the progress made during the assembly.

TOOL 2: THE ANNUAL SCHOOL RESEARCH PROJECT

Students from different grade levels participate in the annual school research project. Their ages are between 12 and 15. Together, they agree upon a topic for the project after being offered three topics to choose from. Once they have thought about the different options, they are given the opportunity to defend their choices with arguments meant to convince the other participants. Then a secret vote is held and the winning project is announced to the group. The students are obligated to accept the project chosen by the majority and to actively work on it.

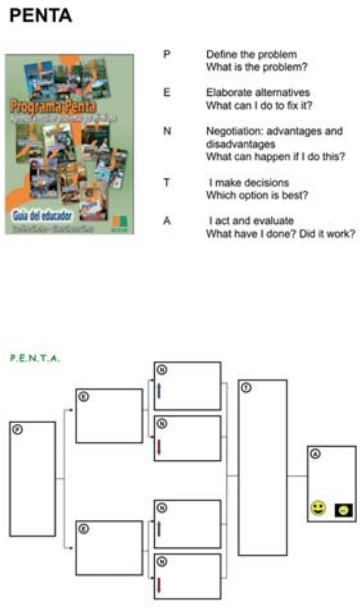
TOOL 3: TRAINING IN PROBLEM SOLVING SKILLS

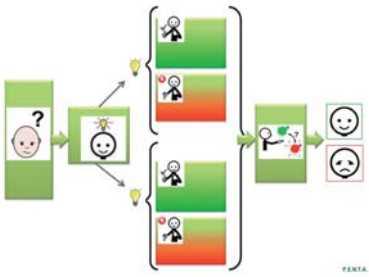
Here we follow the methodology described in the programme "The PENTA Programme: I learn how to solve problems by myself" designed by Luz Pérez Sanchéz and Diana Cabezas Gómez and published in 2006 by the Calasanz Institute of Educational Sciences, Madrid.

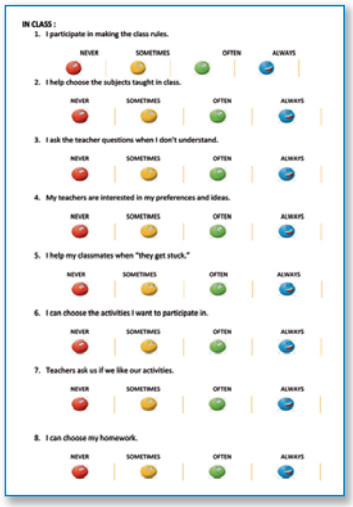
The programme consists of the following 10 workbooks:

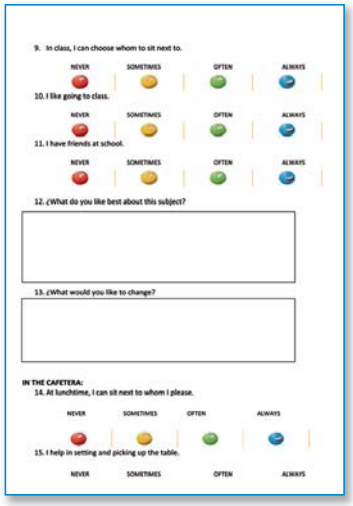
1. Introduction to the programme.
2. Motivation for the programme.
3. The PENTA Programme.
4. Situations/problems arising from interpersonal relationships.
5. Situations/problems arising in the home environment.
6. Reinforcement Unit.
7. Situations/problems arising while using means of transportation.
8. Situations/problems arising in the immediate neighbourhood.
9. Situations/problems arising during recreational activities.
10. Reinforcement Unit.

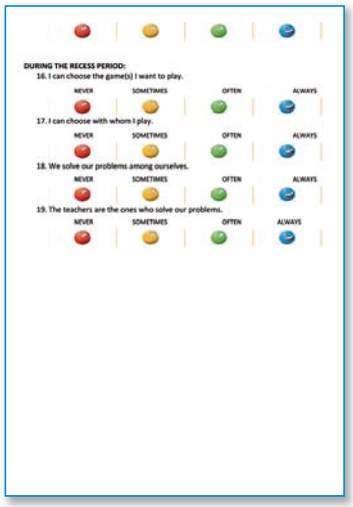
We have made some slight changes to the programme to adapt it to our needs.











6. Participation at the educational centre level

Two tools were used:

- Questionnaires
- Responsible participation in official representative organizations

TOOL 1: QUESTIONNAIRE ABOUT PARTICIPATION

Objectives: Questionnaires are developed to provide information about how students perceive their individual participation at the centre and whether they feel a certain level of satisfaction. Each questionnaire is designed according to the student's grade level, one for the students of the Middle School (age 12-16) and another for students in the Transition to Adult Life Programme (TAL) and the Vocational Training Programme (VTP) (age 16-21 years).

The older students were presented with the sample questionnaire found in the "Guide for the participation of intellectually or developmentally disabled persons," (FEAPS, 2013). This questionnaire was adapted to the characteristics of our centre.

The questionnaire is divided into three sets of questions. In the first section, students are asked if they feel that their opinions and ideas are being taken into consideration. The second section asks them if they feel they are really participating and the third section asks them to suggest (through open questions) changes for improving classroom activities.

The format of the answers provided follows a Likert-type scale, adapted with pictograms. The four possible answers are: "never", "sometimes", "often", and "always."

The questionnaire presented to the younger students used an adapted version of "The Disability Toolkit for Identifying and Collecting Disability Data," (Porter, Hacker, Georgeson, Daniels, Martin and Feiler, 2010).

This toolkit takes a survey using items to evaluate "the good things and the bad things about our school." It has been adapted for the special needs of students with reading, writing or communication difficulties. First they are asked general questions about whether or not they like going to school, doing homework, or attending meetings where they are the main topic of discussion.

Next they are asked about their experiences during various school activities (the School Assembly, the cafeteria, their recess time). They are also asked if they like the different subjects taught at the centre. Finally the students are asked to give an opinion on whether or not they experience difficulties during these school moments and what work habits they prefer (studying by themselves, in a classroom group, with their School Research Project group, or one-on-one with the teacher).

Method Followed:

The questionnaire is developed in easy-to-read language.

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 we have convinced ourselves that the students have understood the questions, they are encouraged to answer them individually.

In the case of the open questions found on the older students' questionnaires, the students also answer individually with the assistance of their teacher.

A sample of the survey questions used for the Transition to Adult Life (TAL) and the Vocational Training Programmes (VTP) is provided in the margin.

TOOL 2: RESPONSIBLE PARTICIPATION IN OFFICIAL REPRESENTATIVE BODIES

A student representative is included among the members of the School Board. In order to encourage the student's participation, the following activities are included in the Board agenda:

- Documents are prepared in easy-to-read so that they are accessible (Board Meeting Agenda, budgets, etc.)
- The student representative is asked to

meet with all the classes to gather their ideas and concerns.
- The student representative relays their complaints and suggestions to the School Board.

7. Different educational centres participating together

Participation through Support Activities (Voluntary Work)

It is important for persons with intellectual disabilities to participate in activities whose aim is to help others, since more often than not such roles are reversed and it is the persons with disabilities who usually receive assistance. The students at our educational centre met with other students from an inclusive school in the same community. Together they raised funds for a non-profit sending money to the victims of a natural disaster that recently took place in the Philippines. The students chose the cause they wanted to raise funds for.

We organized a Sports Day of basketball free shots with mixed teams. Each student had to find sponsors for his or her team. Each sponsor committed to making a contribution for each shot executed. The event was a success, and all the money raised was sent to the NGO.

Increasing awareness and learning through participation: "Group of Young People in the Step by Step Programme"

The Hear Our Voices participation project, in accordance with the goals of Down Madrid, wishes to underline its mission to act as "facilitators and promoters" of the social inclusion of persons with intellectual disabilities. To this end, we consider that in order to encourage inclusion and increased participation by persons with intellectual disabilities in their day-to-day environment, it is necessary to make society – and, thus, the education community- increase its awareness of the abilities of intellectually and developmentally disabled persons. This objective will be reached by increasing society's knowledge of the latter's ability to participate, including their strengths, their rights and obligations, and other issues they face. It is up to the persons with disability and their classmates to transmit and demonstrate the achievements and abilities enabling them to be true participants in society.

The Hear Our Voices project gathered a group of adolescents between the ages of 14 and 18, both with or without disabilities, to form the official "Step by Step" group acting as promoters of inclusion. Their objectives

were to think about, design, develop and execute action plans to promote the inclusion and participation of all persons with intellectual disabilities.

Forming the group:

Since we wished to encourage the participation of young people both with and without disabilities, we thought of joining them together in a group. The first challenge was to find a way to attract young people without disabilities to join. First, we searched for young people who had already come into contact with disability for various reasons: They had siblings with a disability, or their parents were working with disabled youngsters. These young people served as the first launching ground and subsequently brought their own friends to join the group.

Methodology:

Participants: Taken from a group of young people (15-18 years old) with or without disability who belong to various inclusive or special needs educational centres.

Time frame: Monthly meetings (on the last Friday of the month).

Tools:

The meetings took the form of brainstorming sessions. This is a creative thinking technique used to stimulate the production of new problem-solving ideas, within a group.

The different phases of this process are as follows:

1. Introduction to the brainstorming session: This includes explaining the nature of the meeting, its objectives, the procedure to be followed and the length of the work session.

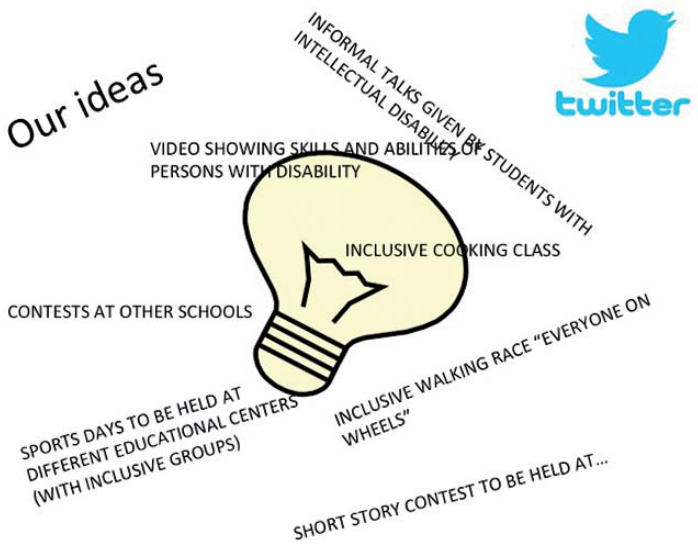
2. Generation of new ideas: These appear as visual supports on a blackboard or screen. Ideas to be discussed are always presented in the form of a question. Usually, a measurable goal is set as to the number of new ideas to be proposed.

3. Idea improvement: Here the dynamic role of the group moderator is key. This is the moment when the ideas voiced by the group are fine-tuned and synthesised.

4. Review: The ideas are reduced to a specific list.

From this moment, once the different ideas generated by the group are established, the implementation process begins.

The ideas our group came up with are the following:



Chapter 2

MEASURED RESULTS AT DOWN MADRID

I. Participation of each student

Using the "This is my meeting" programme has allowed us to achieve positive results for each student. Students acquired greater self-knowledge and more motivation to participate in the learning process. Our students felt they had acted as participants and key figures during the whole process, and they collaborated actively in the formulation of the goals that needed to be reached.

Time and time again, it has been shown that when our students are offered opportunities to participate, they take full advantage of those opportunities.

In the next school year, we will follow the same course of action, offering more opportunities for student participation in all areas.

We hope that as the students steadily increase their ability to participate, they will increase their sense of well-being and quality of life.

II. Participation in the classroom

Through the use of the tools described above, the following progress was achieved:
The School Assembly concept allowed each individual student to become more respectful of other students, to listen more to others and value the contributions of their fellow students. Slowly but surely, the level of student participation and commitment increased. Attending the meetings also made students more focused on and attentive to current world events.

With the Annual School Research Project, the students acquired new knowledge and skills as well as the ability to participate. Their motivation and their commitment towards their work also increased.

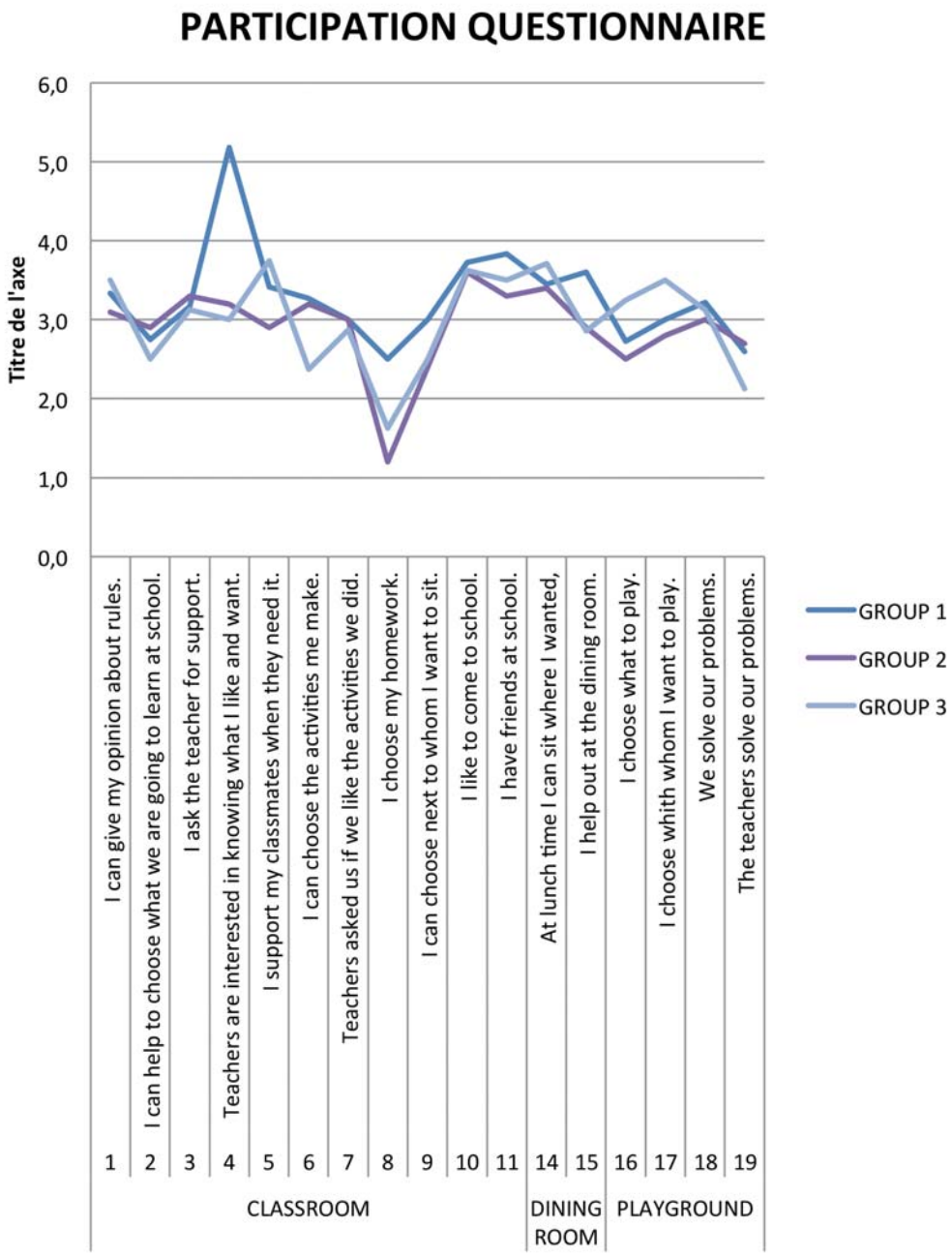
As for the group itself, it demonstrated more cohesion, motivation and enthusiasm and as well as a need and willingness to learn. In short, it behaved like a group well-versed in the art of participation.

III. Participation at the education centre level

The questionnaire results forced us to raise new questions and implement new action plans at our centre:

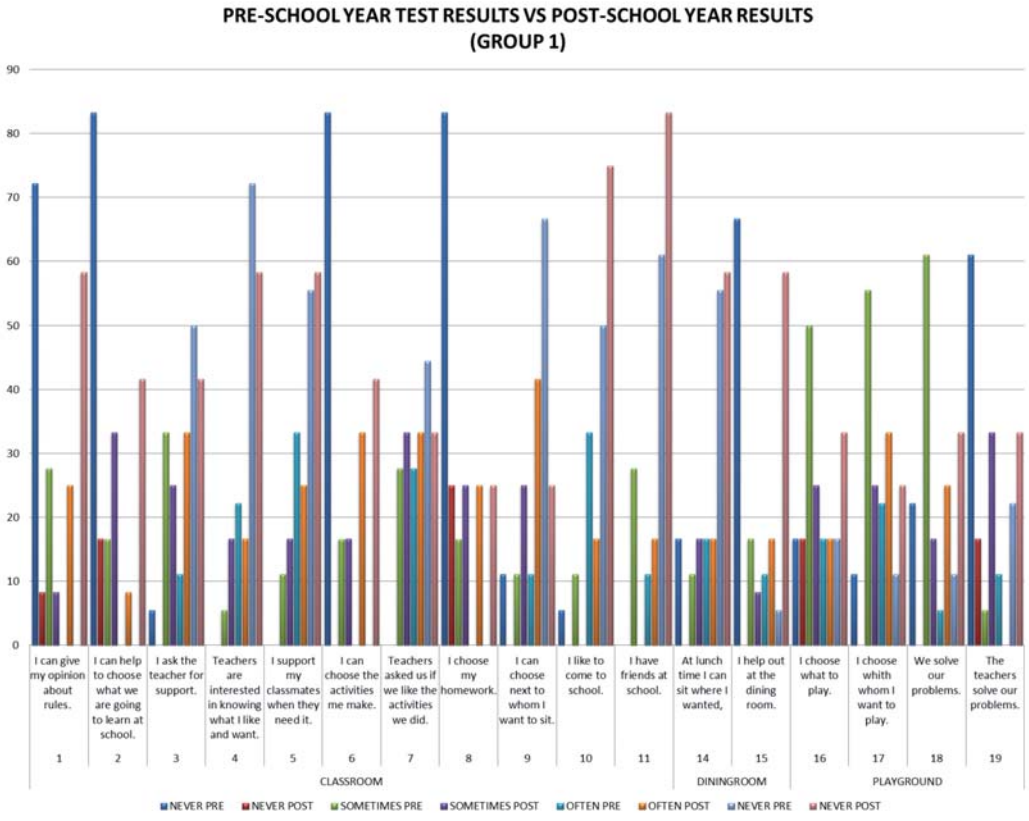
- We were able to obtain more precise information about the wishes and special needs of our students.
- We made changes in our school organization: Classes and activities had to be separated before the end of each study cycle.

RESULTS


PARTICIPATION QUESTIONNAIRE
Titre de l'axe
6,0
5,0
4,0
3,0
2,0
1,0
0,0
I can give my opinion about rules.
I can help to choose what we are going to learn at school.
I ask the teacher for support.
Teachers are interested in knowing what I like and want.
I support my classmates when they need it.
I can choose the activities me make.
Teachers asked us if we like the activities we did.
I choose my homework.
I can choose next to whom I want to sit.
I like to come to school.
I have friends at school.
At lunch time I can sit where I wanted,
I help out at the dining room.
I choose what to play.
I choose whith whom I want to play.
We solve our problems.
The teachers solve our problems.
1 2 3 4 5 6 7 8 9 10 11 14 15 16 17 18 19
CLASSROOM
DINING ROOM
PLAYGROUND
GROUP 1
GROUP 2
GROUP 3

The following are the results obtained in the two questionnaires that were presented to the Transition to Adult Life (TAL) group, both at the beginning and at the end of the school year. Comparing the results between the questionnaire presented at the beginning of the school year with the questionnaire presented at the end of the school year, the results clearly show that the perception of the students in the Transition to Adult Life (TAL) programme was that they had participated more as reflected in the end of school year questionnaire.

PRE-SCHOOL YEAR TEST RESULTS VS POST-SCHOOL YEAR TEST RESULTS – TRANSITION TO ADULT LIFE PROGRAMME (TVA)



	QUESTION	NEVER: 1	SOMETIMES: 2	OFTEN: 3	ALWAYS: 4	GROUP 1	GROUP 2	GROUP 3
CLASSROOM	1	I can give my opinion about rules.				3,3	3,1	3,5
	2	I can help to choose what we are going to learn at school.				2,8	2,9	2,5
	3	I ask the teacher for support.				3,2	3,3	3,1
	4	Teachers are interested in knowing what I like and want.				5,2	3,2	3,0
	5	I support my classmates when they need it.				3,4	2,9	3,8
	6	I can choose the activities me make.				3,3	3,2	2,4
	7	Teachers asked us if we like the activities we did.				3,0	3	2,9
	8	I choose my homework.				2,5	1,2	1,6
	9	I can choose next to whom I want to sit.				3,0	2,4	2,5
	10	I like to come to school.				3,7	3,6	3,6
	11	I have friends at school.				3,8	3,3	3,5
DINING ROOM	14	At lunch time I can sit where I wanted,				3,5	3,4	3,7
	15	I help out at the dining room.				3,6	2,9	2,9
PLAYGROUND	16	I choose what to play.				2,7	2,5	3,3
	17	I choose whith whom I want to play.				3,0	2,8	3,5
	18	We solve our problems.				3,2	3	3,1
	19	The teachers solve our problems.				2,6	2,7	2,1

1-NEVER 2-SOMETIMES 3-OFTEN 4-ALWAYS

The results of the survey questions asked to the younger group show that more than 87 % of the children liked attending school, doing homework and going to meetings to talk about themselves…

These children felt comfortable during various moments of the school day (97 %) and did not face any difficulty in dealing with these moments. They liked working alone, in a group, in the school research project group or with a teacher.

IV. Educational centres participating together

During the first few months, the members of the group worked on getting to know one another and on strengthening the group's sense of cohesion. Slowly, the young people began to offer their suggestions. We present our results below.

The following are the activities that were implemented after considering all the suggestions presented:

1. Students with or without intellectual disability giving talks in other schools.
2. Production of a video about the abilities and skills of persons with disability.
3. The production of a video to inform the general public about the Hear our Voices Step by Step Programme.
4. Inclusive Cooking Classes.
5. Short Story Contest.
6. Inclusive Sports Days (with inclusive groups).
7. "Step by Step" contest (see video).

1. Students with or without disability giving talks in other schools.

Twenty talks took place in different mainstream educational centres. These talks were given by members of the group. During these talks, the term "disability" was explained, and there were various group exercises whose aim was to promote more awareness among the general public.

2. Production of a video about the abilities and skills of persons with disability. The young people produced a video describing the skills of people with disability.

3. The production of a video to inform the general public about the Hear our Voices Step by Step Programme.

4. Inclusive Cooking Classes.

These cooking classes took place on a monthly basis. As examples, there were specific classes for pizza-making, cupcakes and Easter eggs.

5. Short Story Contest.

BASES I CONCURSO MICRO RELATOS

I Concurso de Micro Relatos
para Centros Educativos
"Escribir para incluir"

El objetivo de este concurso es sensibilizar acerca de la inclusión en la sociedad de las personas con discapacidad intelectual desarrollando la capacidad de expresión de los escolares.

BASES

1. Podrán concursar alumnos de 12 a 18 años a través de Centros Educativos del ámbito de la Comunidad de Madrid.
2. Se admitirá, como máximo, **una obras por centro educativo.**
3. La obras presentadas deberán reunir los siguientes condiciones:
   - La temática será la **inclusión de las personas con discapacidad intelectual en la sociedad**
   - Ser originales e inéditas
   - No haber sido presentadas ni premiadas en otro certamen o concurso.
   - Todas las obras han de constar de título y estará firmado con un pseudónimo.
   - El formato de la obra será micro relato de 200 palabras máximo
   - Las obras podrán ser individuales o colectivas
4. Cada obra debe ser presentada dentro de un sobre que incluirá el trabajo original, una copia en formato digital Word (CD o memoria extraíble) y los datos de contacto del autor.
   En el exterior de este sobre, se hará constar el nombre del centro al que asiste el autor y el profesional de contacto del centro.
5. Los trabajos serán recibidos hasta el 14 Febrero de 2014 en la siguiente dirección:

   I CONCURSO DE MICRORELATOS
   Fundación Síndrome de Down de Madrid
   C/ Caídos de la División Azul, 15 - 28018 Madrid
6. El jurado dará a conocer su fallo en el acto de entrega de premios que se celebrará dentro del XI Certamen Literario Down Madrid.
7. No se devolverán los originales ni las copias de los trabajos participantes ni se mantendrá correspondencia con los autores no premiados.
8. Los galardonados cederán los derechos de autor de las obras premiadas, que pertenecerán en exclusiva a la Fundación Síndrome de Down de Madrid.
9. Se otorgará un Primer Premio y dos Menciones de Honor.
10. La participación en este concurso implica la aceptación de estas bases.

Más información: Belén Padilla. Telf.: 91 310 3304 ext. 204. belen.padilla@downmadrid.org

Fundación Síndrome de Down de Madrid Síguenos en www.downmadrid.es

31 short stories from 15 different educational centres from Madrid were presented.

jaime cabanas (jaimecabanasmdu) on Twitter
https://twitter.com/jaimecabanasmdu
¡¡¡¡¡Soy el ganador del concurso de **microrrelatos**! ... Todos somos iguales, y merecemos que nadie nos infravalore **@DownMadrid** #Inclusionpasoapaso.

The young people felt empowered as they discovered they can become agents of change if they take a proactive role in their lives.

6. Inclusive Sports Days (with inclusive groups).

7. "Step by Step" contest (see video)

BASES I Concurso Paso a Paso

I Concurso Paso a Paso

Fundación Síndrome de Down de Madrid

The contest awarded three First Prizes and one Runner-Up Prize among all the works submitted.

First Prize in Science Category:
St. Anne's School, Madrid.

Project Title:
"We are a genetic mosaic".

Runner-up Prize in Science Category:
The British Council School, Madrid.

Project Title:
"A Source of Future Scientists".

Art Prize :
Colegio LaSalle-San Rafael, Madrid.

Project Title:
"Going around Together".

Sports Prize:
Trinity College, Madrid.

Project Title:
Inclusion in Sports.

Concurso "Paso a Paso"

Down Madrid

V. Participation through volunteer work in various events at the Foundation

- Anniversary Celebration of Down Madrid
- Open House Day of Down Madrid

- "Leave a Caring Mark" Day

- Prizes Awarded during the 25th Anniversary Celebration of Down Madrid

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Other interesting resources:

http://www.redasociativa.org/creandofuturo :
Página web de la Red de Educación para la Participación Juvenil. De entre los materiales que ofrecen en el apartado "Descarga de materiales", destacamos:
http://congdextremadura.org/w/wp-content/uploads/2014/05/EL-RETO-DE-LA-PARTICIPACION.pdf

http://www.educacion.alboan.org/es/categories/1200/materials :
Disponen de materiales específicos para trabajar la participación en el aula

http://www.cuadernointercultural.com/ :
Página web de Cuaderno Intercultural, Recursos para la interculturalidad y la educación intercultural. En el apartado "Dinámicas para necesidades generales y especiales" incluye una gran variedad de dinámicas y propuestas adaptables a la temática de la participación.

http://www.cuadernointercultural.com/dinamicas-y-juegos/necesidades-generales-y-especiales/

http://www.integrayparticipa.es/es/proyecto/

http://www.todosporlaparticipacion.org/

http://www.fundacionbertelsmann.org/cps/rde/xchg/SID-47273800-0DADA243/fundacion/hs.xsl/6335.htm

http://www.trama.org/proyecto-de-participaci%C3%B3n-juvenil-en-programas-sociales

Listening Together (Lumos): A resource containing practical advice and ideas for creating a suitable environment for child participation.

www.wearelumos.org/stories/turning-words-action

INCLUSION EUROPE

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

EUROCHILD

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

CEDAR FOUNDATION, BULGARIA

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

QUIP, CZECH REPUBLIC

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

FUNDACIÓN SINDROME DE DOWN, MADRID, SPAIN

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

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

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

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