



Lifelong  
Learning  
Programme

**EACEA**  
Education, Audiovisual & Culture  
Executive Agency



"WHAT IS ESSENTIAL  
IS INVISIBLE TO THE EYE"

INSTITUTO  
DE  
FORMACIÓN  
INTEGRAL

RESULTS OF FOCUS GROUPS IN  
SPAIN – MADRID AND GALICIA

## **Report on the results of Focus Group in Madrid-Spain of "What is essential is invisible to the eyes" project**

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## 1. INTRODUCTION

### Methodology

IFI sent invitations to 32 relevant institutions and associations working and giving services to people with Down Syndrome, and were asked to fill a registration form with some questions about their professional profile. These organizations were contacted by e-mail and/or by phone.

The first focus group was held the 25th of April, from 10:00 to 12:30, in a classroom that IFI have in Madrid, in the Business School CEU.

The second and the third focus groups were held simultaneously the 23th of July, from 10:00 to 14:00, in the headquarters of Down Galicia, Santiago de Compostela.

The three focus groups were organized in two sessions; the first one was dedicated to the conception/definition of persons with Severe Down Syndrome, the relation between a person with Severe Down Syndrome and the social professional, and the feeling of limits. In the second session the participants talked about taking care of people with Severe Down Syndrome and their daily work with them. Some minutes were dedicated at the end to talk about their feelings about the weaknesses of the professionals working with Severe Down Syndrome.

### Participants

First focus group:

Seven participants came from the following organizations:

- APANID - Asociación de Padres y Amigos de Niños Diferentes de Getafe (Association of Parents and Friends of Different Children from Getafe)
- APADEMA - Asociación para la promoción y atención al discapacitado intelectual adulto (Association for the promotion and care to the mentally disabled adult)
- Syndrome Down Foundation of Madrid.



The profile of the participants is mostly psychologists and pedagogues, and most of them (5 of 7) are coordinators of centers or services.

Second focus group:

A total of eight participants took part of this focus group. They came from organizations located in different places in Galicia: Down Compostela, Down Coruña, Down Ferrol, Down Ourense, Down Galicia, and Down Vigo.

Participants work in different fields and areas within the services provided to people with Down Syndrome.

Third focus group:

Seven people participated in this third focus group, from Down Coruña, Down Compostela, Down Pontevedra, Down Orense, Down Ferrol, Down Vigo and Down Lugo.

Participants work in different fields and areas within the services provided to people with Down Syndrome.

Some difficulties were encountered searching for participants for the focus group in Madrid, because of lack of time, or that the organizations can not permit the absence of more than two people attending the focus group.



## 2. RESULTS OF THE FOCUS GROUP

### 2.a Person with Severe Down Syndrome

After reading the metaphors, participants said that people with SDS need the support of professionals to fulfil their own interests and preferences, to be satisfied with their life, and they must be considered as citizens.

They also commented their difficulties to discover and know what the SDS want to be or do, and consequently, to personalize the service to each person with SDS. So it is difficult to know the size of the glass due to:

- The full immersion of the professionals in all the programmed activities during the day. Professionals want to offer them all the options and alternatives, but they do not always correspond to the desires of the people with SDS.
- Lack of communication with SDS because of their limit of the language. It is more complicated and time is needed to know what they want to be in their life.
- Although they express their interest, the institutions have other difficulties, as the lack of resources and the own limits of the organizations, which sometimes can not be flexible with the specific needs and desires of SDS.
- Resistance to change of professionals, they are comfortable with the routines.
- Routines within the institutions do not allow any time to listen the person with SDS, and neither to put us in their place.
- Professionals have made much of their behavior, we require more control so they lost their spontaneity, not letting them to be themselves.

The families is an external factor always present in the speeches about the degree of disability of DS, as professionals consider that the attitude of the family and the way they understand their potentialities influence their progresses.

When the participants try to make a definition of a SDS person, the philosophy of the organizations is not to put labels, focusing on the potentialities of the person and giving equal access to every service they provide. This is directly related with the metaphors. Moreover, the severity is flexible, it means that the progress and



the development of the person could be positive and this “severity” could disappear.

The definition of a person with SDS is made by the environment and the barriers that could be able to overcome.

In order to make a definition, it is recommended to consider that they need more support (related with less autonomy), and more tools to progress, and have certain difficulties to communicate and less abilities. The definition should establish a balance between gaps and potentialities.

**Recurrent key words:** routine, difficulty, institutionalization, interests, desires, activity.

**Atmosphere:** Concern, implication, understanding, seriously.

**Non verbal behaviours during the discussion of this topic:** participants in general were very quiet, and when talking about difficulties, the face expression was hard and serious.

## **2.b Relation between a person with Severe Down Syndrome and the social professional**

For SDS a professional is a support to complement their needs, giving them security. To know what the professional mean to them is challenging because of their difficulty to communicate. They sometimes manifest affection and really appreciate the professional, but sometimes they could think that the professional is someone who tells them what to do, a nuisance. They are selective and depending on the person they behave in one way or another, tranquillity or some nervousness or behavioural disorders.

SDS behaviour depends on the attitude and mood of the professional. Empathy, fun, motivation, and an environment of respect in the organization, are needed to have a good relation between the SDS and the professional.



Professionals believe that it would be valuable to know easily what they think about their relationship. SDS have to learn to live with the professionals. In certain services the relation is only of accompaniment (supervised apartments). In some services the relationship is only accompaniment, mainly when they are adults, and in the educational services, teacher and tutor has a closer relationship and they more confident.

### **Time dimensions in the relation**

It is important to work on the basis of certain values and principles, and because of the respect to them and their right to live a decent life, professionals have to work with less ambitious goals, simple ones, tailored to their pace, without expecting any short-term result, and believe in the future change. It is intended that routine behaviour does not reach the mental illness, for that professionals should be alert.

With the necessary support, SDS are able to improve, professionals work to develop their potential, the goal is to improve, no matter when. They do not use to work individually and the people with more difficulties tend to stay apart, and professionals focus on people with more autonomy, and because of ease and comfort, they tend to work more with persons with fewer difficulties, as they can see before the results and it is more rewarding. With SDS is more difficult to work, requires more time and more support, and professionals have to manage resistance to frustration.

Some of the participants are committed to having more quality activities in the sense of adapting to the needs and interests of the people, and less quantity. The professional must also protect the rights of SDS, analyse the best for them and transfer it to the families. It is also important to listen to the family.

### **Joyfulness dimension in the relationship.**

Generally professionals enjoy when an improvement is achieved by the person, and when they have a good professional attitude. Form their speech can be concluded that it is more difficult enjoy working with people of SDS, with which you have to have more patience to communicate and understand.

**Recurrent key words:** potentiality, security, families, change.



**Non verbal behaviors during the discussion of this topic:** smiles when a positive change in a SDS is explained by a participant. Serious when difficulties are explained.

## 2.c The feeling of limit in the relationship

The disability define the activities and supports to be developed, they are obliged to follow a concept and a theory to be articulated. The starting point is not a disable person but a person, but it is necessary to have a framework to know the supports they need. Other participants consider that the disability is produced when you find barriers in interaction with the society, so disability is maladjustment between the demands of the environment and your competences. So professionals assess the support needed to eliminate barriers and work on the competences needed to interact with the environment.

In one of the groups participants said that the feeling of the limits disappear progressively, and make you focus on the potentialities. They work for their autonomy, starting with the possibilities that the person have, not from the limits. Moreover, the slogan and the message they want to give to the society is that these people do not have limits.

**Recurrent key words:** supports, environment, competences.

**Non verbal behaviors during the discussion of this topic:** nod, confirmations, statements.

## 2.d Taking care of people with Severe Down Syndrome

Care and education are always present in all types of services, regardless of the level of SD. They try to make practical, educational and fun assistance activities, as a workshop.

Time ago the medical and assistance care had greater importance, but it was fought to not be the only activity to be done, and there has been a major change to include educational activities. It is necessary to translate to families the importance





of the educational part, and increasingly younger families are claiming this kind of services.

Once covered the assistance care, which can be up to 20% of the time, the rest is educational. The health care is vital to their life, and if not covered can cause isolation. Both dimensions should be integrated.

Disabilities limit and make suit educational activities to their health, posture and hygiene needs and it is necessary to think how to customize according to their needs in all areas. It requires teamwork of all professionals working in both dimensions and adapt the intervention with each person.

**Recurrent key words:** needs, important, adapt.

**Non verbal behaviours during the discussion of this topic:** participants in general were very quiet and serious talking about this.



## 2.e Work with people with Severe Down Syndrome

For all participants is hard to select one person with whom have a good relationship, because of professionalism they must have a good relation with all the users. Some of them said that they have a “favourite” person as a natural thing, as with the rest of relations in your life.

The feelings that emerge more frequently are suffering, apathy, negative attitude, etc., and also desires. People with SDS have a complaint or negative attitude in order to express a desire or dream they can not reach, either because it is not provided or is not viable within the institution.

People with SDS express that what they do does not correspond with what they want with an aggression or falling down from the wheelchair, or any other alteration in the behaviour.

What emerge with less frequency are aspirations and dreams, doubts often arise at the end of the week.

Some of the participants remarked that professionals have to take in mind if their desires (mostly guided by their own routine) are good for them, and to mix the activities they want to do with others good for them, using the resources of the community, where sometimes they find difficulties and obstacles. Professionals should have the ability to investigate the things they like.

In the speech sometimes arise doubts in the professionals about the feelings of the people with SDS they work with, and the reasons why they are, for example, happy or sad (of if they want only to look like happy when they are not).

In the work plan, professionals try to manage these feelings individually, to the extent that the institution permits. The starting point is a group, and often these feelings and desires are tailored to the group, and sometimes these particularities are treated, with the limitations of the rules.

Professionals work with general programmes, and they try to make individual adaptations according the capacities of the users, in order they can participate as



much and better as possible. It is important to make visible the achievements and recognize them through positive reinforcement.

**Recurrent key words:** suffering.

**Non verbal behaviours during the discussion of this topic:** smiles, moving hands like establishing limits.

### 3. CONCLUSIONS

Professionals in general feel that they can work better with SDS but some limits exists to improve their work: in one hand, the routine and rules of the institution, and in other hand, the limit of the disability, as the difficulty of communication and expression of interests and desires.

Concerning the weak points of the people working with SDS, participants said that direct care staffs often are geriatric or nursing assistants and that world is purely related to care, and most of them do not have knowledge on the educational dimension and how to develop activities in this area. Most of them have even difficulties to understand the language used.

Participants feel that they have no specialized staff as a health center or geriatric. There is a new vocational training, called "Social and health assistance", which gives competences about education and social insertion, and they are prepared to work with SDS, but it is needed more.

Most of people working with SDS do not have specific knowledge about this disability and they learn by working experience.

There is also the difficulty of the terminology used, as the staff comes from different degrees and often do not know the specificity of the deal with people with SDS.

They complain about missing resources and lack of time to be rigorous and to have a record of evidences that allow professionals to know, for example, that certain interventions work with some people, a record of actions and how it works with each person.










It was discussed the training needs of managers of the centers, and they think that there is a need of change the leadership, to humanize it, and make them aware and flexible to develop in a better way the necessary activities. Whereupon managers also need training on new intervention models and changing beliefs, be up to date in terms of this group in order to best organize work.

In conclusion, according the results of this FG, and thinking in the next steps of the INV project, it can be said that professionals working with SDS have the following training gaps:

- Specific training in dealing with people with intellectual disabilities, particularly in SDS, educational intervention, latest intervention strategies, how to work with families to be more active. They need to know about general aspects of disability.
- Skills and professional competences necessary to work with this collective:
  - Social skills: empathy, assertiveness.
  - Management of stress that this concrete work causes.
  - Emotional intelligence.

## 4. ANNEXES

### Attendance lists

Nº	NOMBRE Y APELLIDOS	ORGANIZACIÓN	FIRMA
1	ANTONIA VIERA SANCHEZ	APADEMA	
2	INHACULADA RODELGO ACRANZ	APADEMA	
3	DOLORES CABRERA BENAVIDES	APAMID	
4	ESTHER SANTOS ROMERO	FUNDACIÓN SANDROE DOWD MADRID	
5	MARTA PINO GUINDARIO	FUNDACIÓN SANDROE DOWD MADRID	
6	CARITEN VIRENIEZ DONALES	APAMID	
7	IRIS ROSA RODRIGUEZ LACRUANO	APAMID	
8			
9			
10			






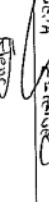

**Grupo de discusión Proyecto Grundtvig 'Lo esencial es invisible a los ojos'.**  
Jueves 25/04/2013, de 10:00 a 12:30 h  
INSTITUTO DE FORMACIÓN INTEGRAL

Instituto de Formación Integral





**Grupo de discusión Proyecto Grundtvig 'Lo esencial es invisible a los ojos'**  
Martes 23/07/2013, de 10:00 a 14:00 h.  
DOWN GALICIA

Nº	NOMBRE Y APELLIDOS	ORGANIZACIÓN	FIRMA
1	Alicia Campos Viqueira	Teima	
2	MARTA MUÑO ELLUEIRA	D. FERREI TEIMA	
3	Nº José España Aldao	Down Coruña	
4	Ama Nª Tractuer Gasho	Down Galicia	
5	Lucia Ellueira Faro	Down Vigo	
6	ELENA VAAHONDE SALGADO	DOWN OURENSE	
7	MARTA GARCIA RODRIGUEZ MANERO	DOWN COMPOSTELA	
8			
9			
10			

Instituto de Formación Integral






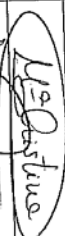





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**Grupo de discusión** Proyecto Grundtvig "Lo esencial es invisible a los ojos".  
Martes 23/07/2013, de 10:00 a 14:00 h.  
DOWN GALICIA

Nº	NOMBRE Y APELLIDOS	ORGANIZACIÓN	FIRMA
1	Xhea Peña Machneke	Down Coruña	
2	BLANCA TABOADA PENIDE	DOWN GONISTEIA	
3	SANDRA PEÑA DÍAZ	DOWN ROSTIEDRA "XUNBS"	
4	SILVIA ÁUREA FERNÁNDEZ	DOWN OURENSE	
5	BEATRIZ MÉNDEZ DAPROCIA	TEIMA DOWN FEAREL	
6	Mª CRISTINA RODRÍGUEZ SEITAS	DOWN LUGO	
7	SUSANA PEÑA LUCIANO	TEIMA DOWN FERROL	
8	Lina TEBEDA VIDAL	DOWN VIGO	
9			
10			



## Photos of focus groups

### Focus group in Madrid







Focus group 1 in Santiago de Compostela



## Focus group 2 in Santiago de Compostela

