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"WHAT IS ESSENTIAL
IS INVISIBLE TO THE EYE"

**FUNDACIÓ
CATALANA
SÍNDROME
DE DOWN**

RESULTS OF FOCUS GROUP IN CATALONIA, SPAIN

Report on the results of the Focus Group "What is essential is invisible to the eyes" project

Annex 10. Catalan report in national focus groups - L'essenziale è invisibile agli occhi – INV – 2012 – 3660/001 001

This project has been funded with support from the European Commission. This publication reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the information contained therein. Project Nº 527382-LLP-2012-1-IT-GRUNDTVIG-GMP



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INDEX

1. INTRODUCTION	3
2. RESULTS OF THE FOCUS GROUP	4
2.a Person with Severe Down Syndrome	4
2.b Relation between a person with Severe Down Syndrome and the social professional	5
2.c The feeling of limit in the relationship	8
2.d Taking care of people with Severe Down Syndrome.....	10
2.e Work with people with Severe Down Syndrome	10
3. CONCLUSIONS	14
4. ANNEXES	14
Attendance lists.....	16
Photos of focus groups	17

1. INTRODUCTION

Methodology and participants

Fundació Catalana Síndrome de Down (FCSD hereafter) has organized two different groups and has held one session with each of them. Both sessions took place at FCSD main offices.

- **Group one**

The first focus group, which was held on 2/03/2013, was formed by eight trainers of adults with severe Down Syndrome (sDS). We selected the participants in order to cover a wide range of adult training:

- 1 trainer of the group "Make the most of the mornings" which is addressed to older people with sDS
- 2 trainers of the Painting course
- 1 trainer of Theater
- 1 trainer of Movieforum (they watch movies and discuss them afterwards)
- 1 trainer of Modern Dancing
- 1 trainer of ICT
- 1 assistant trainer on many subjects

Participants were invited to the group by email and due to the wide range of timetables they have, we could only gather them all if we organized the discussion on a Saturday.

- **Group two**

This session took place on 14/03/2013 and gathered 8 participants. In this case, the profile of the trainers was:

- 4 trainers on labour access and integration
- 2 trainers on leisure activities (they go out with people with sDS on day trips, cultural activities etc.)
- 1 trainer on educational support
- 1 trainer of the service 'Independent life'

We did not encounter any difficulties regarding both groups as they were very collaborative and showed interest in the project.

2. RESULTS OF THE FOCUS GROUP

2.a Person with Severe Down Syndrome

Following the metaphors the questionnaire of the FG provided, participants acknowledged glasses should be filled regardless of how big they are. Society, in gross terms, considers the ability of containing a few drops as a failure, but in fact everybody has limitations and disabilities, and everyone is different to the rest. The first step is to get to know which 'glass' each person is, that is, which abilities and limitations everyone has, and start working from there. Socially there is often a negative connotation on small glasses and we only give positive recognition to big glasses. We should reconsider these stereotypes and try to change them.

We all are different (like the trees in the metaphor), however differences are also determined by how they are watered (stimulated), where they live, how have they been taken care of, amongst many other factors. The orientation we take in our work also influences them a lot.

However, during the focus group participants stressed that the quality of the liquid that fills the glass is more important than the quantity. It is important to listen to each individual and leave them space to develop themselves. The key idea here is that everyone should follow their own path.

Often it is not easy to see the water that fills the glasses of people with sDS. Especially if there is a relationship of affection (i.e. family), it is not easy to see how much water there could be into the glass. Professionals have the responsibility of trying to fill them. For instance, when disabilities are very severe, it is sometimes hard to see positive things and potentialities in that person when of course she/he has them. If for professionals that is a hard thing, for people who have a relationship of affection or are related, it is even harder. Sometimes for families it is complex to imagine how much their sons and daughters with sDS can achieve, especially when they are children. In this sense, following the metaphor, it is very important to 'water' them, to stimulate and value them in order to facilitate that they could fill the glass.

In this context, it is common that individuals surprise you when they are able to get to do things that in the beginning it was not obvious they could do. Surprise is an

important and great element in this context, when you acknowledge that the 'glass' is bigger than what you actually thought. Specific situations of surprise trainees have been through have made trainers open their minds a lot. All participants in the FG agree on this issue and think it is very important.

Issues that trainers are worried about are extrapolated to the group. An important premise here is: treat others as who you would like them to be, and they will get to be it.

Key words: abilities, diversity, social stereotypes, quality rather than quantity, surprise

Non verbal behavior and atmosphere: In this first block of questions it was a bit difficult for both groups to break the ice, especially for group two. Many of the participants did not participate at all.

2.b Relationship between a person with Severe Down Syndrome and the social professional

Participants in the FG found it difficult to make generalizations in topics like this (focusing on people with sDS 'in general'). It depends on each person, on how they are and they behave, their potentialities and limitations, as well as those of the professionals, of course.

They agree in defining their relationship with people with sDS as offering them guidance, support and accompanying them, but they do not want to think of themselves as persons responsible for them.

FG participants report a wide variety in the relationship regarding the topic they teach:

- Trainers on labour issues point out that if the person they work with wouldn't have sDS it would be the same but with them, language and other communication issues are adapted based on the specific abilities each person has.

- The trainer of the 'Independent life' service says that having a good relationship is especially important for her because she will go into their homes and thus reliability is crucial in this case.
- Theater trainers say they have an advantage because in theatre there always has to be a conflict. It is difficult for them to get into it and understand the conflict. In theater there is a strong group component and this makes things easier. In this context, it is more common that the relationship 'being by their side' emerges, that they see the trainer as one of them.
- Trainers on leisure activities explain that in their case there is often a closer relationship, similar to a friendship, because they spend a lot of time with them and in the context of the trips or holidays together there is space to share personal things with them. However, this changes from person to person of course.
- Some trainers on cultural issues explain that some people with sDS treat them as any of their friends, and that is not the best situation. They want to phone them and so on but they have to put limits.

About the possible point of view of the person with sDS regarding professionals, participants are not sure about it. They point out that think they are seen as referents, as professionals with authority whom they trust. They discuss the concept of authority and agree that the trainer, as in any other training context and with any kind of people (not only with people with sDS), has the authority.

However, some participants don't like this idea because they say it is not easy because often they rely too much on them and this affects their own autonomy. On the other hand, others think authority is a positive thing. It really depends on how this authority has been legitimated, on the relationship that has been established.

There is a debate in which a participant thinks some things can be imposed without dialogue (the learning of basic things for children and young adults, for instance) while the rest think they always should explain things in order than trainees understand them. For example, in a labour context, even if a company has its rules and sDS have to respect and follow them, these cannot be merely imposed but they have to understand that they have rights and responsibilities and that there is a

hierarchy in their workplace and thus they have to do what their boss say otherwise the company can sanction them.

Another way of helping them understand things is reinforcing the positive outcome when they do them (i.e. if there is a problem of hygiene, you can 'impose' that they must shower. However it is better to explain it and when they show up clean you value how good they smell and look, for instance). The best way is when they interiorize it because they understand and value it and thus you do not have to impose anything. It is very similar to the work with people without sDS.

Some participants stress that they would like the view of people with sDS towards them to be as "someone that goes by my side" or equals, but they think trainees see them as referents.

Trainers on leisure activities say that trainees think of them as friends in the sense that they include them in the group dynamics as any of them. Trainers on labour issues point out that this relationship is very influenced by trainers' personalities. Some of them are happy to receive them at their workplace and get advice whilst others see it as an intrusion and are not so open in the relationship.

They also agree that people with sDS in the training context are often seeking to accommodate professionals, that they want to please them. Trainers somehow have the impression that often anything they say, trainees would be ok with it. In this kind of situations, it is important to ask for their opinion and standpoint despite often it is a bit difficult to express them. They are used that trainers have the leading role in the relationship.

Regarding group dynamics and time dimensions, it really depends on the subject and dynamics of the course group. Trainers and the previous group work determine to a great extent the pace of the group and the dynamics that are established. In general, they agree in their relationship there is a good atmosphere and there are good moments in which joyfulness emerges. They express that when the ambience is good everything runs more smoothly.

A good joyfulness situation is for example when a person with sDS overcomes a difficulty, when he/she can eventually do something that was not possible for her/him before. In that moment, joyfulness emerges in the whole group because they all appreciate it.

However, there are other situations in which there is a tense atmosphere because there are problems of any kind or when they have to put limits and they have to speak about them. Sometimes it is difficult for sDSs to connect with the problem, when there are situations of conflict and limits have to be established. In these kind of situations rigidity of some people with sDS affects because for them it is not easy to change their minds and incorporate the message you are trying to give them if they do not like it or it makes them feel uncomfortable.

Key words: diversity of situations, guidance and support, concept of authority, interiorizing rules rather than imposing them, equals versus referents, accommodating, ask for opinion, good ambience, different rhythms, autonomy, connecting

Non verbal behavior and atmosphere: At this point group 1 achieved more consensus and positively broke the ice. Those members of group 2 who did not speak during question 1, they discussed the issue of how people with sDS saw the social professional a lot. There was a strong and a bit tense debate on the concept of authority by group 2, in which there was no agreement.

2.c The feeling of limit in the relationship

When asked what concept of disability they have, participants consider that everyone have disabilities because nobody can achieve all. Disability is something external to the person, it is something socially and culturally imposed, a 'social category' or label. Each person is unique and has different abilities and limitations. Disability must not be such a strong social label in a sense, it is only a functional difference.

On the other hand, there is not much difference between the work with a person with or without disabilities. Everyone has her/his own roles and dynamics. You take these and start working with them. Failure can come for people with or without disabilities, the main difference is than in the first case it is more apparent or visible, people with sDS exaggerate failure and get more blocked or have more difficulties to overcome it (or a list to verbalize it).

However there is a difference between people with a certification of disability and those who don't, because people with disabilities have a common path: they are accompanied by speech therapists, psychologists, doctors and other professionals through all their lives. They have to live with this.

They discuss about the concept of 'limit'. Having 'limits' and the fact of being 'less' (socially speaking) have a negative cultural impact. We should substitute the stress on the 'less' and the 'limit' with abilities and strengths people have. Participants of the FG say that they get to forget that trainees have sDS when they work with them a lot.

Trainers say that they try to adapt the training to each person's rhythm. They acknowledge this is a difficult thing to do but they try to leave trainees their own space somehow. However they combine this type of intervention with other group dynamics.

A participant stresses that sometimes there are situations in the classroom when people with sDS do not follow you and you are fully aware of it. They find these situations difficult to tackle. Another one stresses the difficulty of working with emotions, because it is a long job and you need to be very experienced.

A key idea here is working towards autonomy. However our intervention is more guided than we desire as we are constantly proposing, guiding and conducting. Participants would like students to sometimes have more autonomy and initiative, but it is a difficult task because often they have not received this kind of education and they are used to be assisted and helped in some things and ways.

They say trainees have the need of accommodating you because for them pleasing you is a personal satisfaction and if they do not please you or have the feeling of failing then they get a big frustration and get sometimes blocked. What trainers do in this situation is to make them see it is not so important and they try again.

Key words: disability as a social category, diversity, limit, adapt, difficulties, autonomy, emotions

Non verbal behavior and atmosphere: Both groups replied to this set of questions with quick replies and it was not possible to generate a deeper debate.

2.d Taking care of people with Severe Down Syndrome

We have to admit that we encountered some difficulties understanding the meaning of this block of questions fully. To avoid any misunderstanding, we first of all want to clarify that we understand the concepts in this way:

- *Looking after* includes contemplating the assistance of basic and primary issues such as hygiene, dress and nutrition, amongst others.
- Professionals tackle the issue of '*taking care*' through a mainstreaming perspective, that is, promoting that people with sDS develop their own personal resources. Professionals stress that the concepts of autonomy and empowerment are basic here.

For FCSD promoting autonomy is one of the basis in its work with people with sDS. However professionals agree that they also tackle the 'looking after' component in a way.

About the 'looking after' element, they say it is important to work it with tactfulness. In some courses, like labour access and integration, they focus on issues such as personal image, hygiene, clothing, manners, etc. because in the professional arena people with sDS have to respect a range of social basic rules.

In other domains it is also important because having the 'taking care' issue under control will help them to have a good relationship with their social environment. Not having their personal image and hygiene resolved, for instance, can provoke exclusion in the groups they belong to.

Also there is the issue of nutrition, some people with sDS have to be on a specific diet because of health needs and trainers see them eating sugar or fat they have to advise them but they cannot oblige them. It is important to tackle this kind of things with a sense of humour.

It is important that families educate people with sDS towards autonomy so that they take care of themselves. Some families do it and others don't. Many families prevent ridicule and mistakes their sons and daughters with sDS can make.

They are adults and it is important to treat them and make them feel as adults. We can do this by giving them responsibilities to the extent that they realize that, if

they do not do something, nobody will do it for them. Making them accountable for their own acts is a great way to treat them as adults.

Key words: look after, take care, autonomy, empowerment, tactfulness, adults

Non verbal behavior and atmosphere: There is a strong consensus amongst professionals in this topic.

2.e Work with people with Severe Down Syndrome

In the beginning of the discussion, a participant stresses that she does not like this question because for professionals it is not easy nor fair trying to be the other person and guessing what he/she feels or thinks. Some participants share her standpoint, while for others it seems easier to reply to the question.

They agree that the main suffering is the fear of losing the ones their love: death. It is difficult to speak about this topic with them, professionals treat it because they do not want it to be a taboo.

A specific example of this is a woman who lives independently and who thinks of her life without her family as separation and rupture and a forthcoming death. In this case, the feeling is rather nourished by a bad accompaniment of the family in the process of her independence. Her main suffering is to be alone, she does not interact much with the social environment, only with her family.

They can also suffer from sticking to things they cannot achieve. For example, they can fall in love or get an attraction about a man or woman who doesn't have sDS and is very smart and good looking, thus not affordable for them. They explain an example of a specific case of a person with sDS who is very good in his workplace but who is attracted to her female colleagues with no sDS.

Sufferings and doubts emerge a lot in the context of people looking for a job taking into account the recession of the Spanish economy. If it is difficult for everyone to find a job, for people with sDS is a difficult goal to achieve. However when they have a job, they do not think a lot about the possibility of it ending, sometimes they are not even aware of how much they earn. They are more concentrated on

the personal relations in the workplace, getting there and leaving on time, the coffebreak rather than on other more relevant labour conditions. Regarding the labour market, people with sDS tend to know much more their responsibilities than their rights.

Doubts can emerge when their routines or schemes are broken for some reason. Routine and rigidity gives them more security, however when this routine it is broken they can foresee problems. For instance, a public transport strike can be a big problem for people with sDS. Professionals stress that they try to tackle this by working on the issue that they should not rely on routines that much because they can be broken for different reasons.

They say desires and dreams appear much more often than sufferings and doubts.

The main desire and aspiration they identify is clearly having a relationship and getting married, both men and women. Participants of both FG discuss a lot about people with sDS's sexuality and their desire to have sexual intercourse. Often families fear this topic and they don't leave their sons and daughters to explore their sexualities freely. Some families say their daughters are not ready for sexuality yet even if they are in their 40s. Participants put examples of sDS adult couples in their 40s who cannot have sexual intercourse because their parents do not let them. This can provoke a high frustration to them, especially if they compare themselves with other people with sDS who are more independent in this sense. This is a generational issue, hopefully younger families will be more open about their children's sexuality.

FCSD has identified this topic as an issue that has to be tackled deeper. For this reason they have started up a course on Sexuality for people with sDS and another one for professionals.

They say the desire of getting married and having children could a reproduction of a social convention of a life in 'normality'. So they could simply be willing to do what everyone else does, regardless of their disability.

Participants say that their aspirations are similar to people without sDS: being happy whilst seeking for their autonomy and participation in everyday life. They would like to be treated as people without disabilities.

Another important idea is that there is more permissivity with people with sDS than with other people. Sometimes people with sDS 'use' their disabilities in order to get more from specific situations, such as to avoid some responsibilities or in order not to do something. There are also social advantages for people with sDS that they use: people who let them sit in the underground, not queuing, discounts in tickets... Society treats them differently and indulges them. This is not positive for them, professionals have to identify this and focus on it.

There is some positive discrimination with people with sDS regarding people with other disabilities. There is the element that some companies want to 'show off' that they have a person with sDS, they are very visible. Also, companies prefer sDS because socially there exist some stereotypes such as that they are seen as docile, kind and happy. But they agree these stereotypes are not true.

Professionals say issues explained above do get into the individualized plan. As trainers, it is important not to create too many expectations and goals that are difficult to achieve. Each person should reach and use the maximum of their possibilities and abilities. Therefore we should take the training group as a sum of individuals with specific needs and abilities each of them, thus avoiding the homogenization of the group.

In the case of trainers of cultural activities, they stress that they do not do therapy or psychological intervention, they only 'accompany' them.

One of the fears of participants is whether people with sDS they work with, have assimilated why they do things and do them because they want to or whether this is something being imposed by the outside (professionals, families). In other words, whether they 'connect' with their desires and will of doing things in life. Is he/she doing this because we are telling her/him to do it or because she/he understands and interiorizes that it is important to do it, acknowledging the pros and cons?

In the same line, they think some people with SDS sometimes do things as if they were in a movie. For example: they want to be independent, get married and having children. Is this something that reflects their own will or is it something 'imposed' culturally? Our work as professionals is to accompany them to stick more to reality. This way we could help them to avoid some of their frustration. The key is working towards autonomy but with a realistic perspective.

Key words: death, routines, sexuality and love, diversity within people with sDS, connection and purpose of their acts, autonomy

Non verbal behavior and atmosphere: This point of the FG had the biggest participation and discussion of all. They opened up a lot and tackled the topics with a critic perspective. Their body language was much more relaxed, they spoke much faster, many of them wanted to speak at the same time, etc.

3. CONCLUSIONS

It can be said that the most recurrent word and concept of the Focus Groups has been 'autonomy'. In opposition to the socially- stereotyped tendency to treat people with sDS like children regardless of their age, participants show a strong agreement about the importance of treating them and making them feel as adults in all senses, empowering them and promoting autonomy with a realistic perspective. That is without creating too many expectations and goals that are difficult to achieve.

However professionals stress that their intervention is more guided than desired as their work constantly implies proposing, guiding and conducting. Furthermore, working towards autonomy is a difficult task because many people with sDS often have not received this kind of education and they are more used to be assisted and helped all the time.

They stress the importance of people with sDS's right to choose. Some sectors of society in general, and some families in particular, potentiate the contrary (choosing for them). Professionals want to help breaking this tendency, making them feel accountable and responsible for their own acts and as much autonomous as possible. In this sense, one of the agreements of the groups is that society's education and information about people with sDS is much needed.

Regarding the concept of disability they have, participants consider that everyone has disabilities because nobody can achieve all. Disability is something external to the person, it is something socially and culturally imposed, a 'social category' or label. Everybody has limitations and disabilities, and everyone is different to the rest. The first step is to get to know which abilities and limitations everyone has, and base the intervention on these.

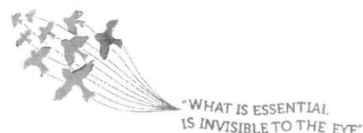
Thus another key concept is the fact of trying to treat the training group with sDS as a sum of individuals with diverse and specific needs thus avoiding the homogenization of the group. The metaphors in the beginning of the FG helped to identify this and the idea has been present throughout all the discussion. It is important to listen to each individual and leave them space to develop themselves. A key idea is that everyone should follow their own path.

Participants agreed that the main desire of people with sDS has to do with having a relationship and sexuality. On the other hand, the main suffering they identified is death.

An issue professionals have raised is whether people with sDS assimilate why they do things and do them because they want to or whether this is something being imposed by the outside (professionals, families). The fact of questioning this issue is something important as the ideal scenario would be that they could 'connect' with their desires and will of doing things in life. Professionals should take this into account and accompany them towards this purpose.

4. ANNEXES

Attendance lists



Focus Group Projecte Grundtvig 'L'essencial és invisible als ulls'.

Dissabte 2/03/2013, de 10 a 12 hores

Fundació Catalana Síndrome de Down

Nom i cognoms	càrrec	signatura
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Focus Group Projecte Grundtvig 'L'essencial és invisible als ulls'.

Dijous 14/03/2013, de 10 a 12 hores

Fundació Catalana Síndrome de Down

Nom i cognoms	càrrec	signatura
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Photos of focus groups

Focus group one (02/03/2013)



This project has been funded with support from the European Commission. This publication reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the information contained therein. Project N° 527382-LLP-2012-1-IT-GRUNDTVIG-GMP.

Focus group two (14/03/2013)

