



Lifelong  
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Programme

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



"WHAT IS ESSENTIAL  
IS INVISIBLE TO THE EYE"

AIPD -  
ASSOCIAZIONE ITALIANA  
PERSONE  
DOWN

## RESULTS OF FOCUS GROUP IN ITALY

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

**ANNEX 8. Italian report on national Focus Group** – L'essenziale è invisibile agli occhi – INV – 2012-3660/001 001

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## INTRODUCTION

### Methodology

[Explanation about how the group was organized, how many sessions, dates, venues]

Associazione Italiana Persone Down (AIPD) has organised 3 focus groups, each of them has foreseen one session of approximately 4 hours:

- Roma, 2 April 2013, 9 participants
- Bari, 9 March 2013, 11 participants
- Bergamo, 16 March 2013, 7 participants

An email presenting the abstract, the goals, the actions and the role of the project was sent to all the presidents of the sections of the AIPD in Italy to invite participants.

Other participants who were not from AIPD were invited by the AIPD sections who hosted the focus groups, according to previous collaborations or acquaintance, both direct and indirect.

### Participants

[Number and profile of participants, job position, difficulties encountered to meet them, etc.].

The only difficulty encountered during the enrollement phase was the selection of the candidates, whose number was higher than the spaces available. Diversity in the experience working with people with severe disability was the criteria of selection, in order to increase the representativity of the sample.

The richness of the groups consisted in fact in their internal heterogeneity, brought by the difference in:

- age of the professionals

- working or volunteering experience with intellectual disability
- the different projects professionals were involved in.

All participants showed up at the meetings with punctuality and left according to the set times.

Here is the complete list of participants in the focus groups and their working experiences.

## Focus group Rome

- *D.P., section of AIPD in Rome (Lazio):* day center “Casa Arcobaleno”. “Casa Arcobaleno” is open from September to July, from Monday to Friday from 9.30 a.m. to 3.30 p.m. and from morning to evening on weekends. It is organized as a home of communal living. Its activities are designed so that its attenders gain autonomies, both personal and social, in personal or home care, in the streets and in the shops, and for social integration.
- *R.T., Rome (Lazio):* from “Capodarco” community. Day centre
- *S.R., section of AIPD in Castelli Romani (Lazio):* involved in the “Autonomia” project, a training course aimed at autonomy of young people (15 to 25-years-old) with Down syndrome.
- *S.M., section of AIPD in l'Aquila (Abruzzo):* from the day centre collaborating with the project “Casa più”, a short stay residence for young people with intellectual disability in the city of l'Aquila. The apartment has gradually been equipped according to the domotics principles; machineries and tools were designed to increase the apartment's safety and “smartness” in interaction with the kids, offering a useful support for different daily life's activities.
- *G.A., section of AIPD in Rome (Lazio):* coordinator of the project “Agenzia Più”, a training course aimed at autonomy for adults (35 to 60-years-old) with Down syndrome.
- *R.C.B., section of AIPD in Termini Imerese (Sicily):* involved in the experimental project “Autonomamente grandi”, promoted on a national level. The project involves all the recently opened sections with little experience with adolescents with Down syndrome. It foresees the start of

new courses for teaching autonomy with the supervision of expert professionals.

- *M.T.M., section of the AIPD in Termini Imerese (Sicily)*: involved in "Autonomamente grandi" project (see above).
- *M.C.O., section of AIPD in Caserta (Campania)*, involved in:
  - project for semi-residency
  - "Agenzia del Tempo Libero" (ATL), for kids from 18 yrs old and above to organize their free time in an autonomous way. Participants meet once a week.
- *V.C., section of AIPD in Caserta (Campania)*, involved in:
  - project for semi-residency
  - "Agenzia del Tempo Libero" (ATL) (see above).

## Focus Group Bari

- *S.M.G., section AIPD in Bari* involved in:
  - "Club dei Ragazzi", course that teaches autonomy to adolescents with Down syndrome. Participants meet every week for approximately three hours;
  - "Agenzia del Tempo Libero" (ATL)
  - Project "Spazio Libero", that has the goal of keeping in practice the autonomy competences in young people and adults with Down syndrome. Participants meet every morning for three hours and once a week are involved in a handcraft workshop. The group is in charge of running the place (i.e. cleaning, paying the bills) and organizes evening hang-outs.
- *E.L., section of AIPD in Bari (Apulia)*: involved in "Club dei ragazzi".
- *D.G., section of AIPD in Bari (Apulia)*: involved in "Club dei ragazzi" and project "Spazio Libero".
- *A.D.I., section of AIPD in Brindisi (Apulia)*: day centre.
- *M.P., section of AIPD in Campobasso (Molise)*: day centre "Casa Nostra". Participants meet every day from morning to evening and occupational such as ceramic, cooking and theatre workshops.
- *S.D.M., section of AIPD in Campobasso (Molise)*: day centre "Casa Nostra" (see above).

- M.Z., Bari (Apulia): volunteer at a day centre for people with disability and at the Unitalisi. The Unitalisi (Unione Nazionale Italiana Trasporto Ammalati a Lourdes e Santuari Internazionali) organizes pilgrimages and projects aiming to offer concrete responses to the needs of people who are sick, have a disability or are in difficulty.
- *M.T., Bari (Apulia)*: volunteer at a day centre for people with disability and at the Unitalisi (see above).
- S. G., section of AIPD in Lecce (Apulia): is in charge of the activities of the section, that include the administrative office, the recreational activities and the autonomy education.
- D.P., section of AIPD in Lecce (Apulia): see above.
- L.G., Bari (Apulia): consortium working with people with different disabilities; specialized assistant in a school.

### Focus Group Bergamo

- E.M., section of AIPD in Marca Trevigiana (Veneto), involved in:
  - "Club dei ragazzi": course for teaching autonomy to adolescents with Down syndrome
  - "Agenzia del Tempo Libero" (ATL) .
- M.G.S., section of AIPD in Venezia-Mestre (Veneto), involved in:
  - "Club dei ragazzi"
  - "Agenzia del Tempo Libero" (ATL)
  - SIL ("Servizio di Inserimento Lavorativo", service of job placement)
  - professional in a project of semi-residency
- S.A., section of the AIPD in Venezia-Mestre (Veneto): involved in:
  - "Club dei Ragazzi"
  - "Agenzia del Tempo Libero" (ATL)
  - SIL ("Servizio di inserimento Lavorativo", service of job placement)
  - professional in a group of preadolescents (10 to 14-years-old) with intellectual disability
- *D.T., section of AIPD in Pisa (Toscana)*: coordinator of the activity of teaching autonomy.

- *P.B., Bergamo (Lombardy)*: educator in a social cooperative and in a day centre. In the day centre there are people with and without Down syndrome, some in serious conditions, from 18 to 60-years-old.
- *L.C., section of AIPD in Bergamo*, involved in:
  - "Club dei Ragazzi"
  - collaborator in a cooperative for minors removed from their families.
- *S.M., section of AIPD in Bergamo*: is psychologist involved in:
  - "Club dei ragazzi"
  - SIL ("Servizio di inserimento Lavorativo", service of job placement)

Participants of the focus groups expressed different motivations for their attendance:

- To understand how to work with kids with most severe disabilities, especially to look for tools to support the work with people with severe disability.
- To have a discussion with other professionals in the field about what is meant by "severe disability".
- To share experiences on how to overcome the difficulty of some people with intellectual disability considered "severe" in being with other people and being integrated within a group.
- To satisfy the curiosity regarding the target and the topic of the research proposed by the INV project. The project, in fact, meets the needs and especially the difficulties encountered every day by all the sections of the AIPD in working with people with intellectual disability who have major difficulties.
- To grow professionally and meet other professionals coming from other AIPD sections or elsewhere.

## RESULTS OF THE FOCUS GROUP

### 2.a Person with Severe Down Syndrome

#### 1 page

- **[Concept of person with Severe Down Syndrome: kind of images raised from the metaphors; definition by participants; coherence**

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## level between the metaphors and the experiences recognized by participants.

A person with severe intellectual disabilities " *has an objective severe cognitive retardation but can also be someone with "severe" behaviours like: not be autonomous in basic things ( personal autonomy, going to the bathroom by him/herself, being able to ask for, being able to recognise a basic need)*". Furthermore, someone " *who has got little self awareness*". The concept of "severity" directly recalls that of autonomy: "The "severe" person is not able to get autonomous", or "is a person who, starting from a specific situation, has got fewer possibilities of a complete development, fewer than the average." Someone refers to the Proximal Development Zone<sup>1</sup>: in those people considered as "severe", pdz (that's to say the distance between the starting point and the potential arrival), is reduced, according to participants. The person with severe intellectual disabilities, in addition to having "a cognitive retardation and no autonomy ...is a person who is not able to develop his/her own potentials, also because of an environment (like family, society etc) which doesn't promote him/her. Attention is then turned also to the living environment of the people." We should take into consideration not just the support due to people with severe disabilities but also to all the people- like the family and other contexts- who rotate around that person." It has been said that families should be supported in recognizing potential autonomies of their children.

The concept of autonomy recalls the attention of participants also to the concept of limit: many times the "severe" person presents limits in the expression of his/her primary needs (like eating, personal autonomy etc). Regarding this topic, two main components of the limit should be mentioned: those which are innate, that's to say objective difficulties which are there from

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<sup>1</sup> According to Lev Vygotskij's theory, **proximal development zone** (pdz) is a fundamental concept which can be used in order to explain the way the learning process of the child takes place with the support of the others. Pdz is defined as the distance between the actual and the potential development levels . Potential level can be reached with the support of other people, either adults or peers with a greater level of competence.



the birth; those which belong to society and social context. This means that a person with good competences can be more dependent than someone who has got more evident objective limits: *"the limit is our starting point but it should not stop us. We should go beyond the limit as we do when we use a recipe book with images, for people who are not able to read. It's hard to make the guy saying: "I can do it!"*. Other aspects of severity are unpredictability and communication problems : *"it's harder with more severe people, it happens that one manner can work one day but not the following one"*. It is especially difficult to get a feedback, to measure the outcomes of an intervention and understand the welfare status of one person. It has also been underlined that the condition of severity is very much linked to communication, to the difficulty to express one's own needs , to approach the other with one's own ways , which are often hard to be understood: *"when a normal person slaps you, you tell him/her something, while with a person with a severe disability you try to understand and to work on this gesture, and act in a different way"*. One's action could be the alternative channel, through which the person is trying to communicate, his/her anger towards a specific situation. He/she would not be able to express in a different way this anger, through the verbal channel, for instance, which requires greater and higher abstraction skills , which in persons with intellectual disabilities are usually reduced.

Another element that has been stressed is the lack of sense of danger: *"I need to support them from the point of view of the sense of danger. Sometimes it can happen that they throw themselves in the middle of the road , I find it hard to make them understand the danger they are running"*.

Thus "severity" is referred to personal autonomy of the person, but also to his/her social and relational autonomy, as well as it is related to the struggle and the difficulty of one professional to understand the world of the person who is in front of him/her and what such a person is trying to tell him/her.

- **A person with Severe Down Syndrome must be considered as persons as anyone else and therefore they should completely fulfill themselves.**

After the reading of the “glass of water” metaphor, many causes for reflections about how to define a person with severe intellectual disabilities emerge:

- some people state with determination equality of people with intellectual disability, in the sense of “considering them and act with them as with anyone else”,
- others accept this definition, giving it a different meaning and stressing the fact that equality is a mental “building”: *“I force myself to understand how to answer to certain questions treating hm as anyone else”. Or: “It is not the fact that I don’t consider her as the others, I consider her as a person whom I don’t understand, [...], in fact though she has got duties and rights as the others, if one person wets herself, I don’t treat her exactly as all the others but I succeed in understanding such a situation more than it would have happened to an able bodied person”.*
- According to others, the person with a severe intellectual disability *“is not equal to the others; her/his need are equal to those of the others!”.*
- Others get another hint: rather than thinking in terms of “same needs” *it is appropriate to think in terms of “special needs” which not all the people have got. If I want to go out of my place I can do it! If we deny that there are people with special needs, we deny that there are differences*
- *As if we put them at our starting point. Furthermore, as far as legislation is concerned, the State would say that no benefits are needed!”.*
- Again about persons with severe intellectual disabilities: *“ they cannot be considered.... Equal to the others, everyone has one’s own potentials and it’s necessary to work on those”, even if “we should consider not just potentials but also limits; the person has to get aware of personal limits; there are things which he/she will never be able to do as, for instance, driving a car”.*

- **Main agreements, disagreements and final solutions adopted by the group (if possible).**

1) Considering one person with intellectual disability as equal to the others is equivalent to ignore the real conditions of that person and not consider the individual needs of each one.

2) In order to define "severity" it's necessary to take into consideration a number of variables at the same time. Condition of "severity" can be caused by the presence of: severe cognitive retardation, severe mobility problems, a social and family context not appropriate (facilitating) for the development of the potentials of the person, degree of autonomy of the person him/herself.

It seems to be hard to define "the conditions for severity" tout court, because a definition takes inevitably to generalisation of some aspects. All participants agree on the importance to globally know the person in order to discover his/her strong and weak points.

- **Recurrent key words:** special needs, autonomy, life environment, communication, limits.
- **Atmosphere: did participants reach a group solidarity?**
- **Non verbal behaviors during the discussion of this topic]**

**Roma:** the group appears very lively since the beginning, communication trend during the focus group is relentless, sometimes interventions overlap and take a provocative tone, many times conflicting positions emerge with the purpose of eviscerating the subject under all points of view and not declining to a generalisation of such a complex and hard to define phenomenon.

**Bari:** the discussion goes on slowly, there are many silent moments, many times off which oblige the conductor to push for and facilitate the debate, through rephrasing what has already been said and asking questions about individual cases. There is a substantial agreement among participants on the

definition of severely disabled person, at the same time, participants are not that active in such a discussion.

**Bergamo:** the group looks like collaborative and respectful of one's own paces.

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

1-2 pages

- **[Kind of relations: The most important aspects of the relation for people with Severe Down Syndrome. What is the basis of the relationship between participants and people with DSs? Points of view by participants – Points of view by people with DSs (according to participants)].**

Participants in all the three groups don't answer immediately to this question and take a time off in order to think about their own professional experience. By time passing a series of reports comes out about substantial relations with people with severe DS.

Different opinions come out of the discussion. The relation with the person with severe Down syndrome (sDs) presents some elements:

affective bond (presence of emotionality): *"a special feeling, not explicable, there has been a sort of activation of the emotional part of both of us through the channel we had found, eye contact got deeper and deeper(...)"*

- Non verbal communication which helps in the comprehension of the point of view and of thought, in absence of verbal communication of the other one ;
- Dependence, which is the basis of the relation between the professional and the person with sDs, as reported in this example: *" I feel not recognised, frustrated; the first thing you give is yourself but my fear is that this myself doesn't reach him. This fact makes me feeling bad. The only way to "manage" such a person is to tell him what he has to do , by giving him one order at a time. I feel like I treat him as a machine and it*

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*seems to me that the rest doesn't reach him. He follows me as he would follow anyone. If he is with another professional the situation remains the same".*

- tuning, that's to say one "special code to get in relation with the other person, based on reciprocal trust, in order to find one communication channel with that person;
- physical contact;
- faith: *"the relation is more importantly based on reciprocal faith, intended as an expectation of positive reactions to the relation itself"*;
- mutual understanding with the person with whom one interacts;
- transparency, which is the answer to the question: "Are we always aware of why we are making a certain activity? Is the other person aware as well? It is a way of working which always and anyway rests on a principle of truth;
- respect for what one person is and his/her pace.
- 
- **Time dimensions in the relation.**

The discussion focuses on timing foreseen for due activities, which changes according to different projects. Both respect of the pace of the other and the time dimension in general, greatly affect the work and the relation with the person. Furthermore they are good indicators to detect which objectives could be reached with that specific person. As far as residential situations are concerned (people living in residential units), available time is longer ; it facilitates the work because it allows to respect "longer times" (slower pace) people with sDs require and also changes obtained appear more visible. Short term projects (like education courses to autonomous life, whose activities take place three hours a week) are considered as a too tight container to reach specific expected results. Even, for some participants the idea to start from zero, each time (each meeting) is frustrating.

For this reason, it is worthwhile to report the intervention of one professional about the concept of reality: *"the words "fidelity" and "honesty" in the relation occur to me as a matter of fact. It means "to be there", to be constant in the attitude and the presence even through antisocial behaviours. For instance , with an autistic youngster who presents inadequate and provocative*

*behaviours, it is important to agree in some way, with non verbal channels, a constant behaviour and "to be there".* The concept of fidelity, which has been mentioned, relates with the establishment of some rules, which must be shared and create a sort of container for that person, also respecting his/her spaces of freedom and pace.

But: *"Is it possible to establish such a relation in three hours per week?"*

It comes out the need to contextualize (from both time and space points of view) the educational objectives which constitute the basis of each activity, in order to value both working time (devoted to individual activities) and the time the person needs to perform the activity itself.

Many professionals stress the positive aspect of *"having learnt from the youngsters"* to slow their own pace, to be able to wait , to be patient.

A slow time is not necessarily dead time. So, participants agree that to be able to wait is a fundamental competency in order to observe with care and detect even the smallest changes, which remain often unobserved and are key indicators of an ongoing development process.

Speaking about "pace" reminds also the time needed to get in relation with the person and the continuity of the relation between one professional and one person with disability, which is a fundamental element for the building up of a good bond.

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

This topic raises different emotions, which are expressed by the group. There is who:

- is happy when he/she stops frightening of the reactions of the person he/she works with (who, may act some aggressive attitudes);
- is happy when he/she feels competent or when he/she feels to have reached an objective, even if *"sometimes happiness can originate not so much from the attainment of objectives which I had established but because he/she succeeded in achieving an objective which had not been envisaged"*;
- Compares joyfulness , within the relation with the person with sDs, with a *"love story which gets stronger with time passing and, on the other side, who*

*expresses a sense of dissatisfaction caused by the routine of his/her work:" Every day always the same things, always the same people..."*;

- Is happy in the moments when the person with sDs is successful in expressing his/her "being adult".

Within the Bergamo group , the main and shared emotion is frustration, due to the hard effort to establish the right goals for those youngsters who look like having no leeway. Thus , *"one should pass through frustration to feel happy"*. It often happens that the person with disability gets in relation with other educational figures , who employ a language which differs from that which is used within the educational projects aimed at autonomy (Overprotection vs autonomy). As a consequence of this consideration, a common language should be established together with the other figures who rotate around the person with disabilities, in order to improve the work and give continuity to the educational project also within the family, at school, with home assistance and in all the contexts where the person lives.

- **Main agreements, disagreements and final solutions adopted by the group (if possible).**

There is a common trend among participants aimed at looking for the bright side in the worse situations. Centrality of the person and his/her needs are fundamental to set specific goals aimed at the attainment of a possible (feasible) - and specific for each individual person -autonomy.

- **Recurrent key words:** frustration, slowness, patience, respect.
- **Non verbal behaviors during the discussion of this topic]**

Most of the participants have shown an active involvement and willingness to call into question . Often, when one participant was telling his/her "story", he/she looked away, as if he/she wanted to focus the image of the person he/she was speaking about, in order to describe him/her in details.

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

1-2 pages

- **[How one's concept of disability influence the educational relationship with people with severe Down syndrome.**

The answer to these two questions creates two sub groups , according to age and professional experience within this sector.

1) According to younger professionals, the presence of disability originates a preconception within the relation with the person . Such a prejudice *"conditions the professional, because , he/she has to play his/her role and set the goals for that guy, taking into consideration his/her disability"*.

2) Older professionals propose to replace the term "conditions" with "takes into consideration" in this specific question. Such a substitution could facilitate the point of view of the question and thus the perspective of the action: you can start from the competences of that person, instead of his/her disability, from his/her residual skills rather than his/her limits.

- **How the concept of disability influences the educational projects and the planning of activities.**

This question is not immediately clear to everybody. At the beginning it looks like a non sense, somehow predicted. Then it is interpreted, with provocative statements: *" Perhaps I don't understand but the project is focused on the person with disabilities, thus the project itself should be based on this!"*. Also: *" But I have a person in front of me , I see the disability just in a second moment"*, and *"my relation goes beyond disability but when I have to plan the educational project I have to think about the difficulties this person has to face "*.

Disability turns out to be the "starting point" but it is not the only feature to be taken into consideration. For instance, those who are more experienced



state:" *Family, person, social context,...everything is affected by the project. But this is something I've understood just after many years of experience*".

Thus it comes out the need to take into account the disability of the person in the moment when the professional is planning the educational project but at the same time , he/she must not forget the whole person with his/her needs and peculiar features. Sometimes it may happen to be obliged to make a backward step , when one realises , for instance, to have considered some phases as granted.

Such questions make participants face the concept of limit, which is correctly summarised in this intervention: *"Very often I feel frustrated when I realise that I've got too high expectations and so the limit is quite present [...]there is the risk to put the limit too in high or too downwards. I think that both things are not right"*.

- **Main agreements, disagreements and final solutions adopted by the group (if possible).**

In all cases , it is an inescapable fact that disability conditions the relation with that specific person. Even if *"sometimes the image of one person we got at the beginning, then turns out as wrong. How much of what I imagine about that person can condition me? More than speaking about how much disability conditions the relation , I would talk about the person him/herself, because this relation goes beyond " [...]*

The fact to take into account disability hasn't always got a negative meaning. The word" conditions" is used as it gives sense to the educational planning work focused on a person with intellectual disabilities. Details are very much looked after: *"we try to look after details. For instance, during staff meetings, we take into consideration all the steps of our going out with youngsters with sDs, rather than considering any other activity"*.

- **Recurrent key words:** limit, disability, project, bias.
- **Non verbal behaviors during the discussion of this topic]**

Group climate during this phase of the debate gets more nervous; someone expresses sadness and anger in his/her work, while many people keep silent, thoughtful.

A veiled annoyance hovers among young professionals. It is linked with their frustration in working with people with severe disabilities.

There is more tranquillity among more experienced professionals. Sometimes there is a sort of resignation in accepting the limits of people with severe disabilities.

In general, at this point, all groups look like tired and ask for a pause.

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

### 1-2 pages

- **[Concept of Taking care.**
- **Differences and connections between taking care and looking after in the daily work of professionals and between taking care and relationship.**
- **How professionals take care of the people with Severe Down Syndrome.**

All attendants agree that taking care of someone includes also looking after him/her.

Looking after *"recalls more the MATERNAGE concept, that's to say maternal care. Thus taking care cannot be separated from looking after, but it must be carefully avoided that looking after gets substituting the person with disabilities"*. Looking after should include actions like physical care, personal hygiene, etc. These actions, according to many professionals, can be very tiring from the physical point of view and far from an objective to aim at : *"looking after one person gives me the idea that all the charge is up to me", "you know when looking after starts but not when it will finish"*.

Taking care aims at keeping those competencies which support the extension of the average life of people with severe disabilities. Under this perspective, it

*"is more important to take care than to look after", because it takes account of the wellbeing of the person and his/her needs. It can be implemented in different ways: to be there, care of the needs of the other, of his/her wellbeing. In a few words, the difference is between "looking after, as a very little participated activity and taking care as a more participated relation".*

*In the most "severe" situations, it seems that looking after is more present: "the more severity is present the more the person needs looking after. There is a right way and a wrong way to look after...". You can help one person in his/her personal hygiene, by protecting his/her dignity and making a leap in quality, making the difference: "taking care of one person may also include physically looking after him/her, but it doesn't necessarily mean that you have to do it mechanically. You can speak with this person, consider him/her as a person that you are helping for his/her toilet. It is different in this way, it is important to treat him/her with dignity".*

*"Taking care is perhaps more adult relationship, because it means also to pay attention to someone". Thus it entails being able to observe and detect the needs of the person and re-cognise him/her: "listening to the other means taking care of him/her".*

*"If we take care of one person is in order to value him/her and to make him/her grow up".*

In general, most of the participants, reassessing their professional experience, affirm that their work is founded on taking, as it can be deduced from the following statement: *"I am re evaluating the fact of taking care as: I am close to you, I cook with you, I walk with you for .... Not in order to you with me but as walking together" .*

*"Taking care is also putting trust in someone".*

Taking care comprehends, in this discussion, many different meanings with a common denominator: a focused- on- the- person approach, where trust is important , which is built upon mutual acquaintance , with active involvement of the care giver but, above all, of the person who is receiving the care, as far as he/she can arrive.

- **Main agreements, disagreements and final solutions adopted by the group (if possible).**

All agree on the fact that "*taking care includes also looking after*".

It is immediately highlighted the difference between:

- 1) **Looking after**, which is more linked to a sort of physical and assistive situation,
- 2) **Taking care**, which comprehends the whole interest towards the person, paying attention to small things, to the needs and the manners to activate taking care. "*taking care is contained within the "I care" concept, while looking after is assistance, caring for*".

- **Recurrent key words:** to substitute, wholeness, overprotection, wellbeing, care.
- **Non verbal behaviours during the discussion of this topic].**  
No remarks on this point.

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

1-2 pages

- **[Description of persons whom the participants have a good and keep relationship. Positive characteristic and potentialities.**
- **How many times a week can emerge doubts, aspirations, desires, suffering, dreams from a PDS person.**
- **Description of the individual plans developed with people with Severe Down Syndrome: how doubts, aspirations, desires, suffering, dreams tackle in the plans.**
- **How much time the professionals can devote to the realization of PDS potentialities.**

All groups found very hard to detect dreams, aspirations, desires of the people with severe disabilities. This is often due to the fact that that these

people are not able to verbally express them but it doesn't mean that they have not such feelings.

Some professionals underline the difference between desires and aspirations. *"According to me desire is something practical; aspirations are higher from a cognitive point of view, potentialities.... Discovering them is an important part of our work ..."*

The concept of limit in the people with sDs reappears here. Such situation is often caused by the hard effort to find a comprehensible channel through which one's own desires can be expressed: *"we proceed by trial and error, in the sense of exploring a little bit their world"*.

Aspirations and desires of people with severe intellectual disabilities, many times they emerge, thanks to the acquaintance with the person, then one goes through mutual knowledge, in order to understand which could be the aspirations of that person. Desires are usually detected from behaviours acted by the person.

Furthermore, in all the groups the debate diverts to the difficulty professionals encounter in facing subjects related to adult life and which often belong to the sphere of desires and dreams of people with severe disabilities (when supported in expressing them); sexuality, getting driving licence, to have children, couple relationship. A wide individual diversity emerges on how to face such subjects. Many times it depends on the limits of the professional to get a point of view which is different from his/her own.

- **Main agreements, disagreements and final solutions adopted by the group (if possible).**

When professionals speak about desires, they refer to the person, when they speak about aspirations, they look at the disability.

Many participants, at this point of the focus group, agree on some "must", which have to go along their work, their professional action:

- Recognising limits in one's own job vs feeling almighty;
- Constantly keeping in touch with reality;
- Being able to elaborate frustration;

- Giving value to staff supervision and sharing of one's own experience.
- **Recurrent key words:** sexuality, limit, omnipotence, adult life.

- **Non verbal behaviors during the discussion of this topic]**

Groups get to work, questions encourage the discussion among participants, there is a continuous exchange of ideas and opinions. The climate is peaceful, attendants ask many questions about subjects concerned with adult life (specially sexuality).

It's important to say that younger professionals express more frustration and sense of helplessness towards those subjects which question potentialities and possibilities that even people with severe disabilities can make their *desires come true, once they have been expressed and/or understood* by the person who is with them.

## CONCLUSIONS

### 1-2 pages

[Conclusions from the focus group regarding:

- **Recurrent key words during the FG:**
- special needs, autonomy, life environment, communication, limits, frustration, slowness, patience, respect, limit, disability, project, bias, to substitute, wholeness, overprotection, wellbeing, care, sexuality, omnipotence, adult life.
- **kind of concept on the people with Severe Down Syndrome** (See paragraph nr 2a)
- **kind of concept on the work with PSDS** (See paragraph nr 2d)
- **Lessons learned**

This first focus group has taught to its participants that , though coming from different professional experiences, in different contexts, their needs can be the same. From another point of view, though coming from the same working sector, participants together have been able to get some undertones which have made discussion full of meaning and respectful of subject complexity.

Just the debate about a number of subjects has allowed participants to exchange ideas, opinions, and professional praxes to spend (implement) from now. Furthermore the discussion has promoted a shared reflection and made strong expectations emerge vis a vis of the pedagogical model.

- **Training needs on knowledge, skills and abilities for the educational process of people with Severe Down Syndrome.**

From the answers to the question" which dimension would you like to improve?":

- Empathy
- Communication within severe disability, that's to say proper communication, employing an easy-to - understand language with a person with reduced cognitive skills.
- Management of an educational project.
- Being able to understand the other in order to get the immediate solution and act with him/her.
- Interpretating needs and changes
- Being able to make dreams, wishes come out and help the person to express them.
- Accepting the limits of the person.
- Calling myself into question , not stopping at the first difficulty.
- Supporting the other to overcome his/her own fears.
- Greater self-confidence in facing subjects like sexuality.
- Art of listening to.
- Creativity
- To take into consideration the other's point of view.

- **The elaboration of a Pedagogical model in the next WP.**

All attendants have firmly expressed the need of a practical support in their daily work.

Working with people considered as “severe” means daily confrontation with a professional praxis which proceeds by trial and error.

It is clearly and often expressed within the report that such a work is many times susceptible to changes and hitches, due to difficulty in perceiving change/improvement by the person who is in front of us. Often a proper training on appropriate techniques to employ is missing. Participants identify these techniques as a safe haven , as a guarantee to attain a specific objective , through a facilitating tool , in a work which requires great adaptation skills to always new situations.

- **General goals of the INV project]**

Main INV’s objective is to answer to the needs of the workers, after having listened to them, through the editing of a handbook which takes into consideration not so much theoretical aspects of the relation between the professional and the person with sDs, but which could give a contribution to the already started reflection, through the suggestion of activities, praxes to be implemented, relevant subjects to deal with and the way to do it (sexuality, for instance).



## **ANNEXES**

### **Attendance lists**

(See above)

### **Photos of focus groups**

(We have no photos)