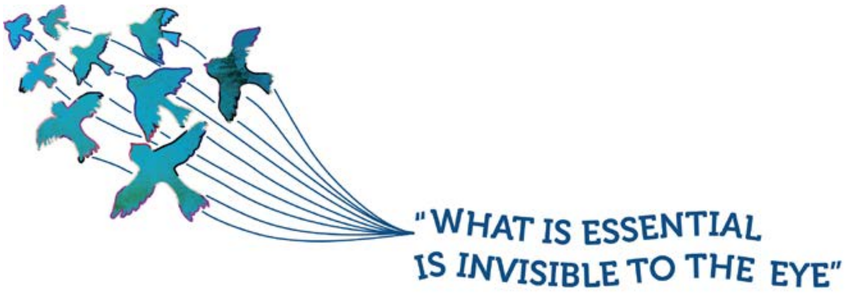

INV

DEFINE THE ESSENTIAL

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1. INTRODUCTION

This report, entitled "Define the Essential", has been developed within the framework of the project "What is Essential is Invisible to the Eye" (INV), as part of the Lifelong Learning Programme of the European Commission. This project is funded by a grant from the sub-programme Grundtvig, which focuses on adult training.

The aim of the INV project is to improve the lives of people with severe Down syndrome (SDS). To that purpose, this project focuses on the personal development of professionals working in educational services for people with disabilities, specifically in services aimed at people with severe Down syndrome, designing new pedagogical and training patterns to improve their competences.

The INV project is coordinated by the Italian organisation Associazione Italiana Persone Down (AIPD), in partnership with the Hungarian Down Alapitvany, and the two Spanish organisations Fundaciò Catalana Síndrome de Down (FCSD) and Instituto de Formación Integral (IFI).

Focus groups involving professionals working with people with severe Down syndrome were organised by all partners, in order to learn about the relationships between people with SDS and professionals, and to provide data to form a foundation for the INV pedagogic and training models, which will be developed and tested at a later stage of the project. The results of these focus groups will enable the pedagogic and training models to be accurately tailored to the real needs of these professionals.

The focus groups represented a good opportunity to discuss topics related to INV with the social professionals who work with people with SDS, and to understand the issues they encounter. In particular focus groups focused on the relationships these professionals established in their daily activities. All the professionals who participated in the focus groups stated that they appreciated the space for debate and exchange of experiences that the groups opened up.

This report compiles the results of the focus groups held by partners of the INV project, attempts to summarise and synthesise the opinions of the participants, and draws out common threads and points of agreement in order to "define what is essential" to best practices with people with Down syndrome. This will enable the project to tailor the development of the pedagogic and training models to the needs of these professionals.

1.a. Methodology

The focus group (FG) is a qualitative research method that facilitates social interaction through group discussions, in order to effectively reproduce the processes through which people form opinions in the wider world.

All discussions were led by a moderator. An observer/assistant to the moderator was in charge of taking notes, making audio recordings of the sessions and observing both the non-verbal behaviours of group participants and the atmosphere generated during the discussions.

The focus groups were organised into two sessions, each with designated topics for discussion, and with a break in between. This was greatly appreciated by participants in general.

The discussion was guided using a question grid in order to generate common discussion topics and later facilitate comparisons across different focus groups and countries. This question grid was adapted to each country's language, and also allowed for a degree of flexibility in following the development of each discussion. The analysis in this report follows the same structure as the question grid.

The following five topics were discussed in the FG:

- People with severe Down syndrome (SDS)
- Relationships between people with SDS and social professionals
- Feelings of limitation in the relationship
- Taking care of people with severe Down syndrome
- Working with people with severe Down syndrome

The non-verbal behaviours of participants were also recorded using an observation grid, in order to account for all the communication that the audio recording could not register, such as gestures, posture and facial expressions.

1.b. Participants

The following focus groups were organised by partners:

PARTNER	GROUPS AND PARTICIPANTS
AIPD (Italy)	1st group in Rome: 9 participants 2nd group in Bari: 11 participants 3rd group in Bergamo: 7 participants **TOTAL: 27 participants**
IFI (Spain)	1st group in Madrid: 7 participants 2nd group in Santiago de Compostela: 7 participants 3rd group in Santiago de Compostela: 8 participants **TOTAL: 22 participants**
DOWN HU (Hungary)	1st group in Budapest: 9 participants 2nd group in Budapest: 9 participants **TOTAL: 18 participants**
FCSD (Spain)	1st group in Barcelona: 8 participants 2nd group in Barcelona: 8 participants **TOTAL: 16 participants**

The profiles of the participants within all focus groups were quite heterogeneous, which improves the results. All participants worked directly with people with severe Down syndrome in some capacity, but in fields as diverse as: education, leisure, independent living, respite care, day care, labour insertion, residences, etc. Participants were carers, nurses, educators, psychologists, staff trainers and social workers, and therefore had experience in carrying out a range of different activities. In the Spanish group held in Madrid, most of the participants were coordinators of different services, but they were either currently developing direct interventions with people with SDS, or had done so in the past.

This heterogeneity allowed for a complementarity in the points of view, and enriched the results and conclusions about what is essential in working with people with SDS from the perspective of the professionals.

In IFI some difficulties were encountered in finding enough focus group participants, and in finding adequate time to organise the group. This was due to professionals having a general lack of time, and also to organisations not permitting the absence of more than two staff members at one time to attend the focus group. In Italy the opposite happened, as more people were interested in participating than was foreseen.

It must be pointed out that in the case of FCSD, the focus groups were formed by professionals working directly with people with Down syndrome with a range of abilities, not exclusively people with more severe forms of the condition. It is important to clarify this so that the results of the FG can be contextualised properly.

2. RESULTS OF THE FOCUS GROUPS

2.a. People with severe Down syndrome

In general, participants all agreed on the premise that all people with severe Down syndrome must be recognised first as people, and therefore should have the same rights and opportunities for personal fulfilment as anyone else.

In general, participants of the focus groups were quite reluctant to create a concrete definition of 'severe' Down syndrome. This was partly because they wanted to avoid labelling individuals, and also because they pointed out that as Down syndrome can present different levels of "severity" throughout the life of an individual, static definitions of "severe" Down syndrome may not be fair or helpful.

With these thoughts in mind, professionals were willing to discuss the concept of "severity" less in terms of an individual label, but more in terms of the level of support needed by an individual, and by the level of autonomy that person could have. Participants also stated that the "severity" of an individual's Down syndrome is strongly correlated with environmental factors and barriers. In general, they discussed the concept of severe Down syndrome according to the level of permanent/regular support that individuals required, particularly with daily basic needs. They also considered the individual's capacity to develop their own potential and to communicate effectively as being important considerations.

So, a person with severe disabilities:

- Needs permanent support and care in his/her daily life and
- Does not have the fundamental skills needed to autonomously manage his/her personal relationships

Participants also framed much of the discussion by emphasising the importance of the individual. Discussions naturally referred to the personal characteristics and defining features of individual people with Down syndrome, and the difficulties and limitations professionals face in identifying unique characteristics and developing strategies to meet them.

In general there was a stress on the importance of assessing the unique needs of each person with Down syndrome, and on the importance of personalising services to honour these unique needs. All working programmes should be adapted and individualised, because it is important to know the person in order to discover his/her strengths and weaknesses, and also is important that professionals can see the potential of each individual and empower them accordingly. Participants identified some current obstacles to this model of personalisation and individual empowerment as the following:

- Institutional background: lack of sufficient human and material resources, lack of time
- Activities designed for groups that:
  - Do not allow for personalisation of the service, and therefore do little to encourage professionals to break away from strict routines
  - Do not allow enough time for alternatives tailored to the needs of specific individuals to be explored and developed
  - Use a rigid behaviour management scheme centred on behavioural guidance
- Outdated models and traditions, together with the resistance of the professional to change
- Difficulty in recognising the potential of people with severe Down syndrome because of their communication difficulties

Keywords

Routine, difficulty, institutionalisation, interests, desires, activity, special needs, autonomy, life environment, communication, limitations. Equality, normalisation, care-giving = teaching = co-operating, over-care and over-control, professionals' own barriers, time requirements, good practice, abilities and strengths, make the work more interesting!, abilities, diversity, social stereotypes, quality rather than quantity, surprise

Non-verbal behaviours during the discussion of this topic

Participants in general were very quiet, and when talking about difficulties, their facial expressions were set and serious.

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2.b. Relationships between people with severe Down syndrome and social professionals

Aspects of the relationship with people with SDS

The relationship between professionals and persons with SDS is defined by guidance and support. The basis of the relationship should be mutuality, which means that the relationship is personal and not hierarchical, and that both individuals are equal. The following are possible elements that can affect this relationship:

- **External factors:**

  - **Regulatory framework**: policies, laws and procedures can all condition how relationships develop between the various roles. Within society, governments establish limitations for people with SDS as well as opportunities (in fields such as employment, formal education, financing of resources). This can affect certain elements of the relationship between the professional and the person, and include what activities can be done, what time can be spent on each activity/person, and what opportunities are available as regards the community, employment, civil status, etc.
  - **Organisational context**: Institutional policies, work philosophy, procedures, leadership style, and available resources all affect relationships. The focus groups developed by FCSD stated that the specific role of the professional had an impact on the relationship. For some professionals, such as those working on labour issues, the professional's relationship with the individual/s they advocate for are not greatly impacted by the fact that the individual/s in question have Down syndrome, although the language or communication methods they use must be adapted according the specific abilities each person has. In other fields such as theatre, independent life and leisure or cultural activities, professionals have a closer relationship due to a strong group component and/or the quantity of time spent together. They all agreed in defining their relationship with the person with Down syndrome in terms of guidance, support and companionship, but they did not want to think of themselves as 'responsible' for them.

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- **Family**: In all groups families appear in the recordings as an important factor to take into account. Sometimes they are supportive of the professional's role and can facilitate the relationship with the person with SDS, but sometimes they can obstruct the development of the relationship, as they are not able to see its potential. If the family is on the same page as the professionals, the relationship will be better and more can be achieved.

- **Internal factors:**

  - **Age:** the quality of the relationship is influenced by the respective ages of the two individuals. Be older is associated with respect, independently of the individual's needs and disabilities. Age and severity of the disability do not influence the educational project, but methods and tools to be applied by the professionals should be adapted.
  - **The relationship itself:**
    - **Emotions**: the relationship is full of emotions, affectivity, special feelings, etc. It is no different from any other relationship with any other person.
    - **Dependence**: a high degree of dependency drives the participants to define the relationship as authoritarian, because professionals feel that they are always telling the individual with Down syndrome what to do and how.
    - **Communication**: professionals try to find alternative communication channels: non-verbal communication, Makaton, PECS, etc. If the professional can find an effective communication method, the relationship is better. A common communication strategy should be established together with other figures around the individual, such as the family, school, etc.
  - **The professional:**
    - **Respect** towards the person with Down syndrome, and respect for his/her pace. Professionals should be able to adapt constantly to the capabilities of the person.
    - The **attitude** and **mood** of the professional. Empathy, fun, motivation, patience, and an environment of respect in the relationship, are needed to generate a good relationship between the person with SDS and the professional.

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- As **provider of new experiences**: If the professional can provide the individual with opportunities to experiment, new activities, new tasks, etc., the relationship will be better.
- **Skills and competences**: In order to adapt the relationship to the potential of the individual, and not to focus on limitations, and also to solve difficulties or conflicts, the professional's competences come into play.

When professionals talk about how the individuals they work with regard them, they think than they are a support to complement their needs, a source of security, and an inexhaustible source of leadership and support. People with SDS are very selective and their behaviour will change depending on the professional they are with. If the relationship is positive the individual will be calmer, while a negative relationship can result in anxiety or even behavioural disorders.

Participants did not agree on the "correct" level of dependency in the relationship and the boundaries that should be established in the relationship. In general, there was not a consensus about how to find the balance between friendship, intimacy and distance.

Time dimension in the relationship

Time plays an important role both in the relationship and in the nature of working with people with severe Down syndrome. Time is important along the following lines:

1. Amount of time available. For example, in residential situations, there is more time available, which facilitates long-term perspectives, and the changes achieved are more visible to the professional. In educational projects and activities, time is often too short to reach specific long-term results, and starting from scratch each time can be frustrating. Participants proposed that the professional work plans could be divided into short and long-term tasks, and should be evaluated according to short and long-term criteria.

Professionals are aware that long-term change is affected by the expectations they have about the person with SDS, and this can affect the relationship. They said that as change can come slowly, it is important to work with simple goals that are not over ambitious, and which are tailored to the pace of the individual. The emphasis should be on future change rather than immediate short-term results.

With the necessary support, people with severe Down syndrome are able to improve, and so professionals must work to develop their potential. The goal is improvement, no matter what the timeframe. The professionals were all in agreement with the "*slowly but surely*" approach.

It is not only the individual's development that is time dependent, but the relationship between that individual and the professional. It is necessary to consider the effect of time on this process too, to maintain optimal relationships. Time and the continuity of the relationship between one professional and one person with disability is a fundamental element in building a good bond.

2. Individual pace and group pace. Also in relation to time, participants in the focus groups discussed the agenda of group activities established within organisations, where time can play a crucial role. Sometimes the group goes faster than the individual, and a personalisation of the activities to the individual is needed. Individual wishes of the people with SDS should be taken into consideration.

In the organisations where one-to-one work is not routinely undertaken, people with Down syndrome who present with more difficulties can end up isolated from the group, and professionals can end up focusing on those individuals that have greater autonomy and fewer difficulties, because it is easier and more comfortable. They can predict better results and it is more rewarding. If a person with Down syndrome presents with a greater degree of challenging behaviour or difficulty, he/she require more time and support, and professionals have to manage their own frustration and resistance.

Some of the participants are committed to the idea of having better quality activities in the sense of adapting to the needs and interests of the people, but fewer in quantity, so as to avoid a busy day crammed full of different group activities. It is important to listen to each individual, and to allow them space to develop. The key idea here is that everyone should be able to follow their own path at their own pace, and so patience and the ability to wait are important attributes in the professionals.

One of the focus groups in Spain stated that, as time goes on in the relationship, the sense of "slowness" and limitation disappear.

Enjoyment as a dimension in the relationship

Generally professionals enjoy it when an individual improves, attains a milestone, or overcomes a difficulty. It can be concluded that it is more difficult to enjoy working with individuals whose rate of improvement might be very slow or limited, and who require more patience and effort to communicate with and understand. It is important to generate a good atmosphere of respect.

When progress is measured, professionals are more aware of the progress that has been made, and this gives them a sense of satisfaction, fulfilment and enjoyment.

Keywords

Potential, security, families, change, good relationships, acceptance, friendship, honesty, respect, sympathy, parent-child relationships, touch, intimacy, closeness, distance control, aggression treatment, stepwise development, “slowly but surely”, long-term follow-up, satisfaction, “with, not for”, let person with SDS do, diversity of situations, guidance and support, concept of authority, interiorising rules rather than imposing them, equality not hierarchy, accommodating, ask for opinion, good atmosphere, different rhythms, autonomy, connecting, frustration, slowness, patience, respect.

Non-verbal behaviours during the discussion of this topic

Smiles when a positive change in an individual was explained by a participant. Serious faces when difficulties were explained. There was in general much lively attention and active involvement. Expressions of solidarity were observed, and a willingness to question.

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2.c. Feelings of limitation in the relationship

How the concept of disability influences educational projects and the planning of activities

Disability is socially and culturally imposed, a ‘social category’ or label. Also, disability is produced when there are barriers to interaction with society, so disability occurs when there is a gap between the demands of the environment and your competences. Therefore, professionals should both assess the support needed to eliminate these barriers, and work on the competences needed to interact with the environment.

Having ‘limitations’ and being viewed as "lesser" than others both have a negative cultural impact, and professionals find it positive to substitute the stress on limitations and lack with a stress on the abilities and strengths people do have, using competences rather than disability, skills rather than limitations as the starting point.

The individualisation/personalisation of services also arose in the discussions. The nature of an individual's disability defines the activities and support strategies that need to be developed. Professionals try to adapt the support they offer to each person’s rhythm. They acknowledge that this is a difficult task but they try to allow individuals their own space, and adapt teaching tools to the abilities of the person in question by preparing materials that are easy to read and understand, repeating learning opportunities as often as needed, and moving towards practical work instead of theory.

Participants said that the goal was for individuals to work towards autonomy. However, problems can arise if professionals "over-intervene" by constantly making suggestions, guiding and helping. Many individuals with Down syndrome are used to being given a lot of assistance and help, which can become an obstacle to the development of their autonomy. This is another reason to focus more attention on individual needs.

Keywords

Support, environment, competences, trust in the abilities, capabilities and talents, identifying development, preferring independence over dependence, empowerment, encouragement, patience, creativity, accepting the risks of independence, lack of time, tiredness, negligence, stronger link between learning process and its practical outcome, limitation, disability, project, bias, disability as a social category, diversity, adapt, difficulties, autonomy, emotions.

Non-verbal behaviours during the discussion of this topic

Nods, noises of confirmation, open statements. Intensive reflection in some groups, quick replies in others. Some groups showed excitement at discoveries, creative attitudes and planning. Some showed impatience and urgency in commenting.

Other participants during this phase of the debate were more tentative; some expressed sadness and anger about their work, while many were silent and thoughtful. Feelings of shame were expressed.

A veiled annoyance hovered among the younger professionals, linked with their frustration in working with people with severe disabilities. There was greater equanimity among more experienced professionals. Sometimes there was a sort of resignation in accepting the limitations of people with severe disabilities.

2.d. Taking care of people with severe Down syndrome

“Taking care” and “looking after”

Taking care and looking after are always present in all types of services, regardless of the level of disability the person with Down syndrome has. Looking after individuals (regarding personal image, hygiene, clothing, etc.) is important in order to not provoke exclusion in the groups they belong to. If these basics are not attended to, individuals can experience social isolation.

Looking after can imply:

- Doing the work for the individual
- Little focus on achieving individual autonomy as a goal
- Low participation of the individual
- That the individual has a more severe form of Down syndrome that means he/she 'need' looking after

Taking care can imply:

- Communicating with the person
- Being able to observe and detect the needs of the person
- Valuing the individual
- Helping the individual discover greater autonomy

Both types of care overlap to a degree in the organisations. For example, some educational activities are focused on the basic issues related to 'looking after' yourself, aiming to develop these competencies in the life of the individual in question, to promote autonomy and help individuals to look after themselves with less intervention.

Taking care also includes looking after, but is a more participatory relationship. It implies that the professional accompanies, observes and detects the needs of the person with severe Down syndrome, is more focused on the person and is more concerned with helping individuals to develop their own personal resources.

Educational activities needs to take health, posture and hygiene needs into account, and should be fitted to the individual's needs in all cases. This requires teamwork

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from all the professionals involved in adapting the interventions undertaken with each person.

Keywords

Needs, important, adapt, look after, take care, autonomy, empowerment, tactfulness, adults, to substitute, wholeness, overprotection, wellbeing, care, integrated care, rising/education and supervision, fatigue = look after instead of caring, prevent burnout, unsuitableness, unfitness, not proper preparedness, burnout indicators, early warning of burnout, supervision, honest discussion, diverse tasks, more rest, professional competence should be increased.

Non-verbal behaviours during the discussion of this topic

In one group participants in general were very quiet and serious talking about this topic, and showed a strong consensus. In other groups more positive gestures, open gaze, smiling together and so on were observed.

2.e. Working with people with severe Down syndrome

The concerns, aspirations, desires, suffering and dreams of a person with severe Down syndrome

Addressing this part of the discussion was hard in all the focus groups. Participants were first asked to select a person with SDS with whom they have a good relationship in order to answer the questions. One participant found it hard to select a particular person with SDS with whom she have a good relationship, because her expectations about professionalism were that she needed to have good relationships with all the users. Some of the professionals said that they did have a "favourite" person, and that this was natural, as with other relationships in your life.

Other groups found it difficult to detect emotions because of the difficulties that people with severe Down syndrome have in verbally expressing them. In general, none of the groups were able to calculate how many times a week these emotions emerged in the individuals they worked with.

For one of the groups, the feelings that emerged more frequently were those of sadness, apathy, and negativity. Sadness was often related to death, being alone, and also because people with severe Down syndrome can struggle to achieve their dreams or get what they desire: either because the opportunity is not provided or is not viable within the institution.

Another group said that desires and dreams appear much more often than suffering and anxiety, and that the main desires expressed are to have a relationship, get married, and to have sexual intercourse. Aspirations generally involve being happy whilst seeking autonomy and having a high degree of participation in everyday life.

Anxiety is often related to a break in routine, whether current or future, actual or hypothetical. Overreliance on a routine is a form of dependency and to break it can pose a challenge for people with SDS. It is necessary to work towards autonomy but with realistic expectations based on a realistic understanding of the possibilities.

One of the fears of participants is whether the people with SDS they work with have assimilated rationales for doing things, and if they do them because they want to or because this is something being imposed by outside influences (professionals, families). In other words, professionals have doubts about whether people with SDS really ‘connect’ with their desires. Is he/she doing this because we are telling her/him to do it or because she/he understands and interiorises that it is important to do it, acknowledging the pros and cons, etc.?

In Hungary, one of the groups stated that it is easier to work with more seriously disabled people, because she or he has a contented personality and can live peacefully in the moment, than with less disabled people who could be more frustrated and unsatisfied due to perceiving their own limitations more clearly. Participants in this group also came to the conclusion that the quality of relationship is influenced by the respective ages of the two individuals. Age is associated with respect, independently of the individual's needs and disability. Age and severity of the disability do not influence the pedagogical model, but the methods and tools to be applied by the professionals.

Individual plans developed with people with severe Down syndrome to realise their potentials

A mentor scheme was used in Hungary to work with people with serious disabilities, which organises individual programmes and takes care of this people in the widest sense by facilitating close relationships with the person with SDS.

In the rest of the groups, individual plans try to manage these feelings individually, to the extent that the institution permits. Activities always are developed in a group context, which means catering to individual needs and desires is often a matter of compromise.

Professionals work with general programmes, and they try to make individual adaptations according to the abilities of the users, in order to help maximise the quantity and quality of each individual's participation. It is important to regard the group as a sum of individuals with specific needs and abilities and avoid notions of homogeneity about the group.

It is important to draw attention to achievements and to celebrate them through positive reinforcement. Recording each person strengths, abilities, fears and so on in a personal document of some form allows professionals to see what interventions and actions work best with each person.

Keywords

Suffering, death, routines, sexuality and love, diversity of people with SDS, connection with and purpose behind acts, autonomy, sexuality, limitation, omnipotence, adult life, individual care, close relationship, mutual selection of each other, person-specific solutions, additional tasks.

Non-verbal behaviours during the discussion of this topic

In general, a more relaxed atmosphere was reached in this moment of the discussion. Participants' body language was much more relaxed, they spoke much faster, many of them wanted to speak at the same time, etc.

3. CONCLUSIONS

The focus groups held were useful in analysing current best practice of intervention with people with SDS, and reflected not only the knowledge and attitudes of the professionals, but the interpersonal relationships, the strengths and weaknesses of the existing internal support system, and the differences and similarities between different contexts of intervention.

The keywords that prevailed at the focus groups give a useful overview of the most important considerations and concerns of professionals working with people with severe Down syndrome. Words like autonomy, independence, care, disability, diversity and limitation all express the nature of their relationships and their daily work. Words such as patience, respect, frustration and communication express personal issues related to this work.

In spite of some differences, people with SDS are people like anybody else, meaning that they have the right to personal fulfilment, and to move towards independence and autonomy. Given that they encounter difficulties in their daily lives, they need permanent/regular support in their education, employment, living and decision-making.

In general there is a strong agreement about the importance of empowering individuals and promoting autonomy within a realistic framework; that is without creating expectations and goals that are difficult to achieve.

Professionals state their intervention is more intensive than they believe is ideal, as their work constantly implies making suggestions, guiding and helping. Furthermore, working towards autonomy is a difficult task because many people with SDS often have not received this kind of education and because they are more accustomed to constant help and assistance and reluctant to move beyond this, which can make it difficult to work for their autonomy.

Concerning the weaknesses of professionals working with people with SDS, one group stated that that direct care staff often come from a geriatric care or nursing background, rather than having worked with people with Down syndrome or other disabilities. These fields are concerned solely with care rather than education, and so many direct care staff do not have much knowledge about the educational dimension of caring for people with disabilities, and how to construct activities in this area. Participants stated that most of them struggled to understand the professional terminology used and often do not have enough knowledge about how to work with people with SDS.

Carers and educators function by instinct and emotion, and they learn by working experience. Less qualified professionals do not act at the pace of people with SDS to make things easier, do not allow them time to process, and are dissatisfied with less than perfect results. In general, educators cannot find appropriate teaching tools for the capabilities and talents of people with severe Down syndrome, and they do not use to have time to rely on the already existing assessment results.

Training needs regarding knowledge, skills and abilities for the educational process of people with severe Down syndrome

Training needs of professionals working in the educational process of people with severe Down syndrome can be defined along three axes:

1. Educational principles and tools

- Specific training in dealing with people with intellectual disabilities, particularly severe Down syndrome
- General characteristics of SDS
- Management of educational projects, educational intervention, latest intervention strategies
- Educational tools for normalisation, integration, inclusion, person-specific solutions in care, tools for empowerment, methods for monitoring and identifying slow development, treating intimacy and aggression properly
- Specific work with families

2. *Attitudes, behaviour and ethics where working with people with severe Down syndrome*

- Social skills: empathy, assertiveness, communication skills (active listening, interpretation)

- Management of stress and frustration and prevention of burnout
- Emotional intelligence, accepting limitations, motivation, self-confidence, creativity. Accepting the risks of independence (of people with SDS), accepting and adopting the long-term perspective, having a good professional overview, finding balance in relationships with people with SDS

3. *Adopting and adapting good practice*

- Meeting to explore existing good practices and adapting good practices to local conditions and individual needs
- Conducting trials, verifying and disseminating the results
- Applying positive findings to long-term intervention planning

One of the groups were keen that this training should be also addressed to **managers** of the centres, as they think that there is a need of challenge existing leadership models, to humanise them, and to make managers more aware and more flexible so as to improve the development of educational interventions. Therefore managers also need training on new intervention models and changing beliefs, and to be up to date in order to best organise work.

Development of the INV pedagogical model

For the development of the pedagogical model in the INV project, it is important to highlight that participants need practical training, with an everyday support structure implemented at the workplace, as working with people with severe disability means daily confrontation with a professional praxis which proceeds by trial and error.

Training on concrete and innovative techniques to use is also necessary, as a facilitating tool that can be adapted to each person with SDS and each new context, one which recognises that this work is highly changeable.

The development of a targeted pedagogical model based on assessed needs drawn from the results of these focus groups is possible.

The training model should include:

1. Theoretical training in an interactive form including up-to-date social models and practices, as well as suitable care tools and training tools for working with people with SDS.
2. Personal development training for the professionals, which could include most of the important competences, such as:
   - Design and execution of personal development plans
   - Social skills: empathy, assertiveness, communication skills (active listening, interpretation)
   - Management of stress and frustration and prevention of burnout
   - Emotional intelligence, accepting limitations, motivation, self-confidence, creativity. Accepting the risks of independence (of people with SDS), accepting the time requirements, having a good professional overview, increased professional competence, finding balance in relationships with people with SDS
   - Improving self-awareness, self-knowledge, identifying or improving potential, developing strengths, improving wealth.
3. Meeting to explore good practice and to prepare a plan for how to integrate good practice within each organisation's daily work. This could take the form of:
   - looking at professional practice in other services (inside and outside of the foundation)
   - professional visits to other service-providing organisations, both within and outside of the project, or in other countries
   - making a plan for the adaptation of the good practice of others
   - finding ways to harmoniously integrate new good practice with existing services
   - finding methods and indicators for assessing its efficiency
   - preparing a study on the selected good practice and its applicability

The main objective of INV is to respond to the stated needs of professionals, after having listened to them, through the development of a pedagogical and training model which takes into consideration not so much the theoretical aspects of the relationship between the professional and the person with SDS, but the practical. INV aims to contribute to the discussion and reflection that is already happening among these professionals, through the suggestion of activities, praxes to be implemented, relevant subjects to consider and working methods.

The pedagogical model that the INV project is to develop should have in mind the time dimension, phases of the educational care, and the relationship between people with SDS and professionals.

An innovative pedagogical model would not only contribute to the personal and educational development of the service users, but also the development of the professionals who work with them, and to a greater efficiency and quality of the services providing by them. In addition it could help facilitate positive changes in the attitude of professionals and thence in the attitudes of the family, residential community, mainstream service providers and wider community of people with severe Down syndrome.

4. ANNEX

Lists of participants and contacted organisations:

AIPD (Roma):

Nº	Name of the participant	Organisation
1	D.P.	section of AIPD in Rome (Lazio): day centre "Casa Arcobaleno"
2	R.T.	Rome (Lazio): from "Capodarco"community. Day centre
3	S.R.	section of AIPD in Castelli Romani (Lazio)
4	S.M.	section of AIPD in l'Aquila (Abruzzo)
5	G.A.	section of AIPD in Rome (Lazio)
6	R.C.B.	section of AIPD in Termini Imerese (Sicily)
7	M.T.M.	section of the AIPD in Termini Imerese (Sicily)
8	V.C	section of AIPD in Caserta (Campania),

AIPD (Bari):

Nº	Name of the participant	Organisation
1	S.M.G.	section AIPD in Bari
2	E.L.	section of AIPD in Bari (Apulia)
3	D.G.	section of AIPD in Bari (Apulia)
4	A.D.I.	section of AIPD in Brindisi (Apulia)
5	M.P.	section of AIPD in Campobasso (Molise)
6	S.D.M.	section of AIPD in Campobasso (Molise)
7	M.Z.	Bari (Apulia)
8	M.T.	Bari (Apulia)
9	S. G.	section of AIPD in Lecce (Apulia)
10	D.P.	section of AIPD in Lecce (Apulia):
11	L.G.	Bari (Apulia):

AIPD (Bergamo):

Nº	Name of the participant	Organisation
1	E.M.	section of AIPD in Marca Trevigiana (Veneto),
2	M.G.S.	section of AIPD in Venezia-Mestre (Veneto),
3	S.A.	section of the AIPD in Venezia-Mestre (Veneto):
4	D.T.	section of AIPD in Pisa (Toscana):
5	P.B.	Bergamo (Lombardy):
6	L.C.	section of AIPD in Bergamo
7	S.M.	section of AIPD in Bergamo

IFI Madrid:

Nº	Name of the participant	Organisation
1	Mª R R L	Apanid
2	C.J.M.	Apanid
3	E.S.R.	Fundación Síndrome de Down Madrid
4	M.P.Q.	Fundación Síndrome de Down Madrid
5	D.C.B.	Apanid
6	A.V.S.	APADEMA
7	I.R.A.	APADEMA

IFI Santiago de Compostela group 1:

Nº	Name of the participant	Organisation
1	B.T.P.	Down Compostela
2	B.P.M.	Down Coruña
3	B.M.D.	Down Ferrol- Teima
4	S.P.V.	Down Ferrol- Teima
5	MC.R.S.	Down Lugo
6	S.A.F.	Down Orense
7	S.P.D.	Down Pontevedra- Xuntos
8	AM.T.V.	Down Vigo

IFI Santiago de Compostela group 2:

Nº	Name of the participant	Organisation
1	MG.R.L.	Down Compostela
2	MJ.E.A.	Down Coruña
3	M.M.F.	Down Ferrol- Teima
4	L.C.V.	Down Ferrol- Teima
5	E.V.S.	Down Ourense
6	L.E.F.	Down Vigo
7	A.M.C.	Down Galicia

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DOWN FOUNDATION :

Group 1

Nº	Name of the participant	Organisation
1	A.N.	Respite care home, Zágrábi
2	A.J.	Day care centre, Zágrábi
3	T.T.	Day care centre, Zágrábi
4	S.M.	Care-centre, Zágrábi
5	E.C.	Respite care home, Szalóki
6	G.E.	Day care centre, Szalóki
7	I.K.	Respite care home, Szalóki
8	M.M.	Andor group-home
9	O.B.	Márga supported living

Group 2:

Nº	Name of the participant	Organisation
1	V.S.	Respite care home, Szalóki
2	M.S.	Respite care home, Szalóki
3	P.K.	Andor group-home
4	B.L.	Márga supported living
5	H.K.	Márga supported living
6	K.H.	Andor group-home
7	M.I.	Andor group-home
8	B.H.	Andor group-home
9	J.S.	Petőfi supported living home

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FCSD:

Group 1:

Nº	Name of the participant	Organisation
1	M.L.S.	FCSD – Theater cine forum
2	C.B.P.	FCSD – Modern dance
3	J.R.M.	FCSD – Theater
4	A.R.	FSCD – Training
5	I.C.U.	FCSD - Painting
6	N.A.	FCSD - Trainer
7	L.G.	FCSD – Painting
8	L.V.	FCSD – Trainer

Group 2:

Nº	Name of the participant	Organisation
1	M.M.	FCSD – Employment
2	N.LL.	FCSD – Employment
3	A.F.	FCSD – Employment
4	E.A.	FCSD – Employment
5	C.R.	FCSD – Employment
6	E.B.	FCSD – Leisure activities
7	I.R.	FCSD – Leisure activities
8	R.C.	FCSD - Inclusive education

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