



L'essenziale è invisibile agli occhi
(*The essential is invisible to the eye*)

Final Report

Public Part

Project information

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Executive summary

The situation to be faced and target audience.

“What is essential is invisible to the eye”. The project is primarily addressed to all the people who take care of people with severe intellectual disabilities and who usually cannot see the little improvements behind the objective severity of the situation.

If we cannot change the scenario, we can at least change our perspective. This is what the following cartoon represents:



Outdated cultural models and behaviours towards people with severe intellectual disabilities still exist. It is, therefore, urgent to design new pedagogical patterns, also in order to adequately reply to the expectations and needs of professionals working in educational and care services for people with intellectual disabilities.

The pedagogical model, which is the core output and its tools are directed to these professionals who run the so called “burn out syndrome”, as main professional risk

On the other side, people with intellectual disabilities are the most important indirect target group: if the relationship between them and the professionals who work with them is enhanced, their personal situation gets better and their personal rights are more likely to be respected.

The wider target audience is represented by technical and political decision makers who can affect the political, social and organisational “environment” where the relationship between the professionals and the people with disabilities take place.

Project objectives

Encouraging professionals to get a comprehensive and evolutionary vision of the person with severe DS and to consider the taking care process as addressed to the whole person and not just to her/his "ill part". Supporting professionals in activating empowerment processes.

Facilitating the empowerment process of people with severe intellectual disabilities

Participants involved

Direct target group of the project has been composed by 83 professionals working in residential services, day centres and educational (extra school) services addressed to people with severe Down syndrome.

The Consortium was made up of 3 organisations directly operating in the field of people with Down syndrome. A fourth one, which is specialised in training provision and project development, withdrew at the end of the project due to internal reasons.. The three Ds organisations are among the most experienced in Europe, leaders in their countries and with past experience of collaboration.

Approaches used

- 1) *Focus groups* (3 in Italy, 5 in Spain and 2 in Hungary) have involved 83 professionals and have been managed according to common guidelines. Such events were aimed at detecting strong and weak points of the work with people with severe Down syndrome. Special focus has been devoted to the educational relationship.

One report, entitled "*Define the essential*" illustrates the main results of the focus groups.

- 2) On the basis of the report and of the remarks of the participant organisations, one *pedagogical model* and one *training itinerary* for professionals have been drafted.
- 3) Professionals of the three participating countries have been *trained to the use of the pedagogical model and its tools*, according to the already mentioned *training itinerary*.
- 4) The pedagogical model has been *tested* through the adoption of its main tool (self observation protocol), by 83 professionals operating in the partner (and non) organisations.

The results of such testing have been merged in one *testing report*.

- 5) All participating professionals have taken part in *national final training meetings* where also video-tutorials, specially developed for the project, have been shown.
- 6) Results and outputs of the project have been *disseminated* by the three remaining partners, through the web site, one final workshop per country, distribution of books and CD ROMS or USB devices with the pedagogical model and the video tutorials.
- 7) *Political recommendations*, based on 5 articles and the preamble of the United Nations Convention on the rights of people with disabilities, have been spread

and 5 video interviews to national MPs have been produced by AIPD and posted on You tube and on the website of the project. <http://invllp.eu>

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1. Project Objectives

Overall objective

Contributing to the development and promotion of a new image of the person with severe Down syndrome (Ds). In such a vision the syndrome itself and its hypothetical healing are no more considered as central and deciding elements. The assistive perspective of services concerned should be overcome and education should be considered as an unavoidable factor in order to promote autonomy, planning skill, citizenship rights.

Specific objectives

- Encouraging professionals to get a global and evolutionary vision of the person with severe DS
- Encouraging professionals to consider the taking care process as addressed to the whole person and not just to her/his “ill part”. Such a process should enable the person to mobilize his/her own resources, to develop his/her personal skills and face difficulties. Taking care should also support the person to reorganize her/his relational settings.
- Supporting professionals in activating empowerment processes: helping people with severe DS to increase their potential, to achieve more challenges, to become main actors of their own life.
- Increasing self-awareness and professional consciousness of the care taking professionals to be able to follow the results – even very small steps forward – of the applied pedagogical/training method, to be able to evaluate the progress, satisfy their professional ambitions and prevent burnout.

Operational objectives

- Carrying out focus groups in the three countries involved (4 partners), aimed at detecting difficulties of the work with people with severe DS.
- Designing an innovative pedagogical model for residential, semi-residential and extra school educational services addressed to people with severe DS.
- Designing a training model for social professionals working in the services and shaped as a workshop based on experience, practice, in order to support comprehension and acquirement of the pedagogical model
- National training of those who will take part in the testing.
- Testing the model through a training action addressed to professionals
- Disseminating results.

2. Project Approach

INV project is designed on the basis of the innovative methodology called PAAR “Participatory and Appreciative Action and Reflection”. PAAR is based on the principle of appreciative approach, which is not yet very much spread within the in-service training of social professionals, who work in educational and care services. PAAR methodology allows the person to prefigure a better future starting from present positive aspects.

PAAR is based on 4 main shifts:

1) **From the critical to the appreciative perspective**

Such an approach promotes a change of perspective and of attitude: from so called deficit based discourses to strengths based conversations.

2) **From the paradigm of stability to the paradigm of change, innovation**

By the means of PAAR methodology, professionals activate their appreciative intelligence, which means the skill to reshape reality you are immersed in, towards a renewal and positive development perspective.

3) **From “blame culture” to positive appreciation**

The methodology which is based on problems stimulates stories which remain on problems themselves. It refers to emotions (distress, pain, frustration), but just those reactive and defensive, due to a blame culture. On the other side, the appreciative approach is aimed at giving rise to reactions based on positive appreciation.

4) **From the retrospective attention to the future attention.**

PAAR stimulates proactive reflection, which is growth- and change-oriented.

Situational (pragmatic) ethics is promoted as well. It is a sort of teleological or consequential theory, concerned with the outcome or consequences of an action: the end. In the case of situational ethics, the ends can justify the means or rules can be used to justify the means if a situation is not intrinsically bad. This approach should give dignity and legitimacy to choices and decisions taken by professionals in an incertitude and contradiction context, which is usually the case in social practices. The appreciative approach has been used both in the Focus groups (FG) and in the training.

3. Project Outcomes & Results

The specific objective of the project was to increase the awareness of professionals involved in constant/periodical relationships with people with severe intellectual disabilities about new educational strategies which could enhance their working conditions and, at the same time, ensure an increased respect of the rights of people with disabilities.

Thus the main result of the project is the delivery of a pedagogical model which illustrates such relationship, provides a specific itinerary and tools to enforce it.

The model has been created on the basis of the results originated from the focus groups of professionals and on the multi annual experience of the Down associations engaged in the consortium

This model is contained in a handbook which has been put in a number of paper and electronic supports in order to look for the widest diffusion.

List of main outcomes

- 1) "Define the essential" focus group report.
- 2) "What is essential is invisible to the eye" pedagogical model
- 3) INV web site
- 4) INV political recommendations for decision makers (From the UN convention on the rights of people with disabilities)
- 5) INV training itinerary to transfer the pedagogical model
- 6) INV Videos

1) "Define the essential". Report from the Focus Groups.

Description of the outcome

Report on the work and achievements of the national focus groups. Focus groups involving professionals working with people with severe Down syndrome (sDS) 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 pedagogical model and training itinerary. The results of these focus groups have enabled the pedagogical and training models to be accurately tailored to the real needs of these professionals. The report compiles the results of the focus groups, summarises and synthesises 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.

Available formats

Web site: <http://invllp.eu/inv/?q=node/380>

Available language versions

English

2) Pedagogical model “The essential is invisible to the eye”



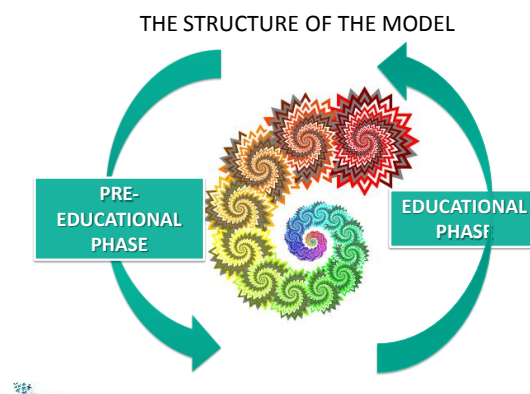
Description of the outcome

The Pedagogical Model aims to develop a different concept of the work and the relationship with people with severe DS or other intellectual disabilities.

The Model is articulated into **2 fundamental phases**, each of which calls for several sub-phases:

- a. Pre-educational Phase, in which the helping relationship predominates;
- b. Educational Phase, in which the educational relationship predominates.

Each phase has some sub-phases. The timelines of the phases and sub-phases cannot be determined in advance; they are often long and demanding.



The model takes into account some rules, which have been called the **6 axioms** of the educational relationship. They are:

- 1) The relationship is a *comport-ment* space
- 2) The relationship depends on me
- 3) The relationship implies a unilateral risk
- 4) The relationship has enemies, who are fear, lucidity, power and old age.
- 5) The relationship demands a metamorphosis
- 6) The relationship implies the tragic as an existential category: taking on responsibility.

Main tools proposed in order to implement the model are:

□ *The Self-observation protocol.*

It is an instrument of self-observation and monitoring for the professional. It is useful for keeping one's emotions under control, understanding them in order to reflect, to learn from one's errors as well as from one's unexpected successes, to foster awareness of possible conditioning by past experiences. It is to be used whenever events occur which the professional considers significant or in any case on a weekly basis.

There are two issues of this protocol, the second one being developed following the testing of tool and has some changes proposed by professionals. The two versions can be adopted jointly or separately.

□ *The Logbook*

The so-called Service Log is a tool usually employed in all service sectors. However, it is generally used to transmit information that is useful for workers on the next shift, but is ignored as an instrument for collective reflection and training.

The Model assumes, however, that one uses the log as a particular tool of participative observation and shared elaboration.

□ *The protocol of the minutes of staff meetings*

The protocol is a list of noticeable topics to consider for the draft of the minutes of the meeting. Such items are helpful for sharp and synthetic minutes:

- detection of unresolved critical points and training needs;
- evaluation of the internal climate.

The pedagogical model, together with the logbook ,the self-observation protocol and the protocol for the minutes are all included within the "Handbook for professionals involved in the educational relationship with persons with severe Down syndrome and other intellectual disabilities"

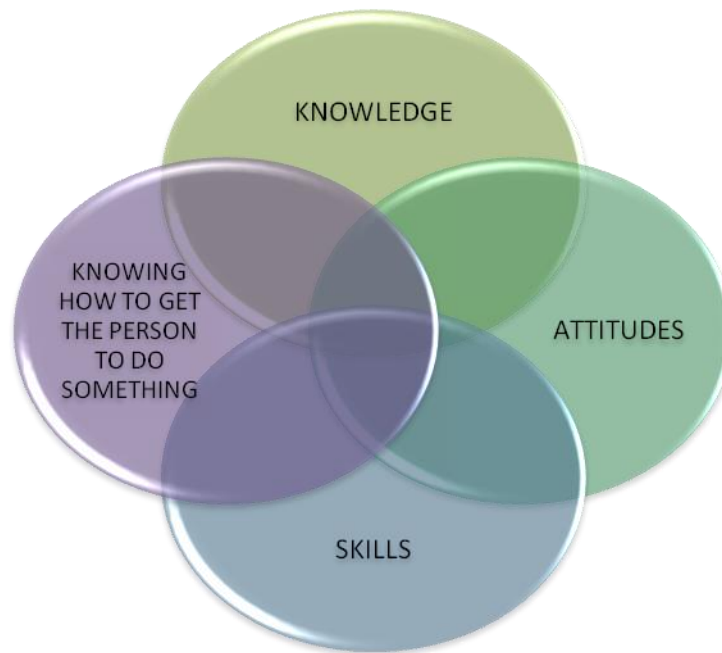
Available formats

Web site. <http://invllp.eu/inv/?q=node/232> CD. USB. Paper copy

Available language versions

English, Spanish, Italian, Hungarian.

3) Training itinerary



Description of the outcome

Goals of the itinerary

- Encourage the exploitation of the Pedagogical Model by the professionals working in services for people with severe disability,
- Enhance the professional experiences;
- Encourage the change of perspective and a different vision about people with severe intellectual disabilities, “free” from the schemes by organizational elements and routine;
- Promote a different vision of oneself as a professional who is able to work from the viewpoint of a “Pedagogy of Opportunity”.

Contents of the itinerary

The contents of the Itinerary have been organized based on at least five meetings approximately 7 hours each. Each meeting can / must be re-designed with flexibility based on the relevant information relating to the context, such as:

- The composition of the group (homogeneity / non-uniformity of training and qualifications, number of years of experience in the field),
- Level of knowledge / appropriation of Pedagogical Model.

The training itinerary contains:

- Training modules

- Guidelines
- Story-telling (examples)
 - Exercises
- Specific tools

Available formats

Web site. <http://invllp.eu/inv/?q=node/264>

Available language versions

English, Italian, Hungarian, Spanish.

4) Political recommendations

Description of the outcome.

The successful empowerment of ID persons and their development toward an independent and autonomous life is not only a model to be followed by professionals and social service providers, but, at the same time, a message to decision makers and legislators not to disempower intellectually disabled persons and to accept and commonly practice the new attitude.

Recommendations are addressed to political and technical decision makers and get inspiration from the United Nations Convention of the Rights of People with disabilities (2006).

More in details:

Preamble. (...) J. Recognizing the need to promote and protect the human rights of all persons with disabilities, *including those who require more intensive support*.

Article 12 - Equal recognition before the law

Article 19 - Living independently and being included in the community

Article 22 - Respect for privacy

Article 24 – Education

AIPD has used such recommendations to interview Italian MPs belonging to the whole range of political groups.

Available formats

Web site. <http://invllp.eu/inv/?q=node/218> Both recommendations and interviews to Italian MPs. (In Italian). These latter are also on YouTube:

Palmieri <https://www.youtube.com/watch?v=6qv5x6Thhxl>

Guerra https://www.youtube.com/watch?v=4PAHOgPq_cE

Di Vita https://www.youtube.com/watch?v=PGtilmJ_3pl

Biondelli <https://www.youtube.com/watch?v=YFw3JNyeuXQ>

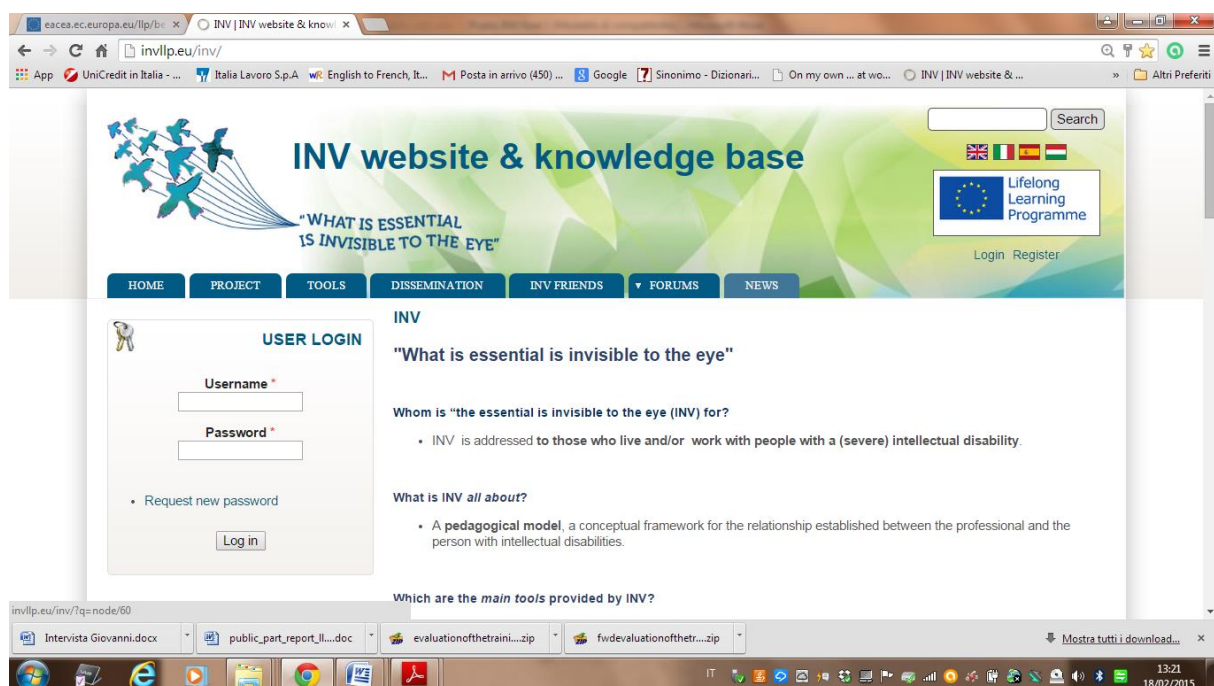
Roccella <http://youtu.be/cevzF-PkMY8>

Available language versions (political recommendations)
English, Italian, Spanish, Hungarian.

Aiming at dissemination

5) The web site (<http://invllp.eu>)

It has been designed for the dissemination of the outcomes and results of the project. Very great care has been devoted to the presentation of partners, project steps, outcomes and results in 4 languages. It has required a big effort of coordination. It has even been hacked by Jihadists (!) and rebuilt again.



Description of the outcome.

The menu is multilingual: English, Italian; Hungarian and Spanish. It consists in 8 categories:

- ☐ Home;
- ☐ Project. Submenus: Partners and Project steps;
- ☐ Tools. Submenus: Focus group tools; Pedagogical model tools; Training tools; Videos; Evaluation tools.
- ☐ Dissemination
- ☐ INV friends
- ☐ Forums;
- ☐ News.

Available language versions

English, Italian; Hungarian and Spanish

6) Videos

Description of the outcome

Three videos have been produced. The three of them show typical attitudes in different situations. They can be used as educational resource materials for holding the trainings to transfer the INV model.

1) Spain: the model and the relationship

In this Spanish video the professional illustrates three attitudes in a stalemate situation with an intellectually disabled person in a public cafe. In addition to the best solution for the concrete situation, the professional explains the essence of the INV model, so the video can be used as an introductory lecture for the description of the INV model and the relationship between the professional and the intellectually disabled person.

Available formats

Web site; <http://invllp.eu/inv/?q=node/219> CD or USB device;

Youtube: <https://www.youtube.com/watch?v=GHXs6KQbUXU>

Languages available: Spanish (original); subtitles in Italian, English and Hungarian.

2) Italy: Whose decision? "Un week end con gli amici"

The Italian video illustrates a situation, where the father of a person with DS would like him to join a group organised by the association, but the sister, patronizing the person with DS, says NO, without asking the person concerned. The relationship between the professional and the youngster with DS is friendly, so it is natural, that the professional does not discuss the question just with the father, with the sister, but the person herself and will make arrangements according to his will.

Available formats

Web site; CD or USB device; Youtube.

Youtube: <https://www.youtube.com/watch?v= XMXK8d6pcY>

Available languages: Italian (original version), subtitles in English, Spanish and Hungarian.

3) *Hungary: The right attitude*

The video was prepared to demonstrate three different attitudes of the care takers working with intellectually disabled persons.

The scene of this video is a sheltered workplace where the intellectually disabled persons have dinner together at the same time

One person does not want to join the others and eat together with them

The professional in the video plays three situations, mirroring three different attitudes

1. *"If he does not eat now, he will not have the chance later. I am sure he will be hungry later, because he usually eats a lot..."*
2. *"I cannot believe he can ever adapt to the others. He always pretends to do it his own way. He should do what I ask for once and obey."*
3. *"He is clearly not hungry yet. He is a grown up person who can decide when and how much he eats"*

Available formats

Web site; CDs and USB format, upon request to partner associations.

Youtube: <https://www.youtube.com/watch?v=RiX77mdGMuk>

Languages versions available

Hungarian (original version); subtitles in Italian, English and Spanish.

4. Partnerships

- *Describe the added value of the multi-country partnership in executing the project (specifically, European added value). Where appropriate, refer to the added value related to the geographical coverage;
Emphasise the experience of working together in a European partnership;*

The multi-country partnership has provided the consortium with an added value thanks to the different experience and background of the partners. People have usually their own national cultural referral points. The collaboration among three different countries has helped in losing some national parts and gaining a more international vision. For instance the first version of the handbook explaining the pedagogical model contained a lot of citations from Italian authors, then, thanks to the cooperation with the other partners, a more European cultural reference framework has been adopted.

The geographical coverage has also been important because in addition to English , official language of the project, most important outputs have been translated into Italian, Spanish and Hungarian.

- **The transnational collaboration (OUTPUTS , OUTCOMES AND IMPACT).**

In order to get a pedagogical model for people with severe Down syndrome and a correspondent training itinerary, which allows their carers to learn how to implement it, requires some “must” in order to be disseminated Europe wide. It’s necessary to take into account of and to adapt to different national frameworks (the practical organization of the services, professional background of the staff engaged, service delivery modalities, funding opportunities and constraints, social policy orientations). It must be translated in as many languages as possible, in order to be adopted by people directly working in the field and not necessary speaking foreign languages.

- **The interest and collaboration with EDSA (DISSEMINATION)**

The three “Down partners” are active members of the European Down Syndrome Association. AIPD actually holds the presidency. EDSA members have been informed of all most important steps of the project, also through the EDSA monthly newsletter, edited by AIPD.

Benefits of partnerships established with GROUPS OUTSIDE OF THE DIRECT PROJECT/ CONSORTIUM e.g. with target users.

The initial period, until the beginning of 2014, has involved professionals from many local services, belonging to the two nationwide organisations and also people working in other institutions. This merging has been quite positive because it has allowed to reach conclusions not originated by just one organisation per country and so too much affected by its internal conditions.

But the core moment of the project was the so called TESTING period, between March and September 2014. It has been the time when professionals have tried to apply the pedagogical model and use its related instruments focusing on their

relationship with specific (one-to-one relationship) people with intellectual disabilities. An evaluation tool of the evolution of such relationships after the introduction of the pedagogical model has been adopted but the time lapse was too short to give meaningful results.

The Hungarian foundation has organised a specific session to explain in an easy language the main features of the model to final users.

5. Plans for the Future

: emphasise the exploitation of results beyond the project's lifetime. For example, this may concern aspects on commercialisation, intellectual property rights, copyrights, etc. as far as they are not confidential. Sustainability of the project's outcomes is a key element of this section

AIPD

AIPD distributed paper copies of the handbook to the general assembly of its local presidents at the end of March 2015 and it's planning to adopt it as a natural development of its own practical experience and theoretical principles. Some local sections have already started.

Since it has got EDSA's presidency at the moment will disseminate it through its monthly newsletter and make paper and electronic output available for all EDSA's members, which are all over Europe and cover the most part of Down syndrome associations.

As it has already happened, INV project will be mentioned in public speeches and uploaded on AIPD's web site.

Political recommendations have been used to make 5 interviews to as many Italian MPs, who engaged themselves in some operational objectives to be pursued. AIPD will monitor their engagement and publish news about.

FCSD

FCSD has distributed the handbook to all the services of the organization and studies the adoption of the INV model and its tools in some of them. Besides this, FCSD will offer training and coaching to those organizations interested in adopting the INV methodology. The information about the project will stay available through FCSD's website

Down Alapitvany

1. to introduce the INV model in 16 services of the Hungarian Down Foundation:

- 2 respite care homes
- 3 day care centres
- 3 group homes
- 5 supported living facilities
- 3 sheltered workplaces.

It covers minimum 130 professionals and 220 ID clients. And to exercise it on the daily basis we have to change the work schedule of the care takers and we have to employ one or two more trainers (we have already two), and held regular trainings, case-discussions, and group-supervisions. We will have a meeting on Wednesday for the leaders of the 16 services to plan the consorted action within all the services.

2. It has been incorporated into the curriculum of two different accredited (officially acknowledged) training courses:

Supported living - course for care-takers and assistants

Supported living - course for managers and lead professionals

These training courses are advertised and held twice a year, for cca. 25-25 professionals.

3. It has been incorporated into the supported living programme for autistic persons - a large nationwide developmental project, including training courses and testing first in 3-6 supported living facilities for 30 professionals and 50 autistic persons. If the outcome is positive it will be introduced in all services covered by the project.

4. Down Alapitvany is planning to integrate the model into the curriculum of the training courses for parents. Both for parents of babies, who participate in early intervention, and the parents of teenagers/young adults after school. The attitude of the parents should be changed in the direction, that INV designates.

5. A 3-volumes book will be published, practically a manual, on independent living and autonomous life of intellectually disabled persons: both on basic knowledge and practical solutions and tools. In this book-series, one of the volumes is dealing with the methods and tools as well as with the relationship between professionals and ID clients: this is based on the INV model. So this book-series will contain all the fundamental principles and practical tools needed by the professionals supporting independent life of ID persons (learning, housing, working, social relations, etc). It will be the first comprehensive practical/methodological writing in Hungarian in this topic.

6. The University's special pedagogy faculty indicated its interest toward the model and is ready to incorporate into the education of the special teachers.

6. Contribution to EU policies

Summarise how this project contributes or has contributed to key EU policies, objectives and priorities (Lisbon, Bologna, Bergen, etc). This relates to the section of the application form about Lifelong Learning Programme Objectives and Priorities addressed.

Objectives of the lifelong learning programme

The INV project is aimed at:

- reinforcing the contribution of lifelong learning to the active citizenship and personal fulfilment of the person with severe Down syndrome. The basic idea is to shift services dedicated to this target group from an assistive perspective to an educational one;
- providing professional carers of people with severe Down syndrome with pathways to improving their knowledge and competences. These professionals are engaged in an absorbing work that concerns the emotions and the deeper aspects of the person and that often puts them in contact with suffering and pain. Such a work causes frustration and disappointment because it is focused more on what has not been achieved than on what has been reached. INV proposes an innovative pathway which values their past experience and develops competencies they are not aware of.

Grundtvig's operational objectives

INV project facilitates the development of innovative practices in education of people with severe Down syndrome, through a pedagogical model focused on this target group and a training itinerary for their professionals, in order to learn how to implement the model. Main innovative aspects of the pedagogical model are: promotion of appreciative intelligence and change of the image of both the person with severe Down syndrome and the role played by his/her carer. To improve pedagogical approaches and the management of associations of people with Down syndrome and their families. If the focus is on empowerment and no more on assistance and limitation, concerned organizations have to start up an evolutionary process of their vision, their mission and their staff policy.

Priority

Quality assurance of the professional development of staff who is engaged with people with severe Down syndrome. INV has tested a non formal approach to the in-service training through reflexive learning and observation of one's own working conditions.

Lifelong learning horizontal policy

Combating all forms of discrimination based on disability. The pedagogical model is aimed at promoting a positive vision of and approach to the person with severe Down syndrome, who has got citizenship rights as anyone else.

Complementarities with other policies Education and Training 2020 Work Programme.

The project is based on the assumption that learning process contributes “significantly to fostering social cohesion, active citizenship and personal fulfilment in European societies”(Council conclusions of 11 May 2010 on the social dimension of education and training 2010/C 135/02).

UN Convention on the Rights of Persons with Disabilities

With a decision adopted in 2009, the European Union ratified the United Nations Convention of the rights of people with disabilities.

Making direct reference to the preamble and to some of its articles (12, 19, 22 and 24) in the political recommendations, the INV project contributes to one of the political actions of the European Union.

7. Extra Heading/Section

This section is optional and can be deleted if not required. If you delete it, please be sure not to delete the section break that immediately follows it as this section break is required to maintain the integrity of the report's back cover.

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