



**"WHAT IS ESSENTIAL
IS INVISIBLE TO THE EYE"**

This handbook was produced within the Grundtvig project

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Handbook for professionals involved in the educational relationship
with persons with severe Down Syndrome and other intellectual disabilities

Whom is “the essential is invisible to the eye (INV) for?

INV is addressed to those who live and/or work with people with a (severe) intellectual disability.

What is INV all about?

A pedagogical model, a conceptual framework for the relationship established between the professional and the person with intellectual disabilities.

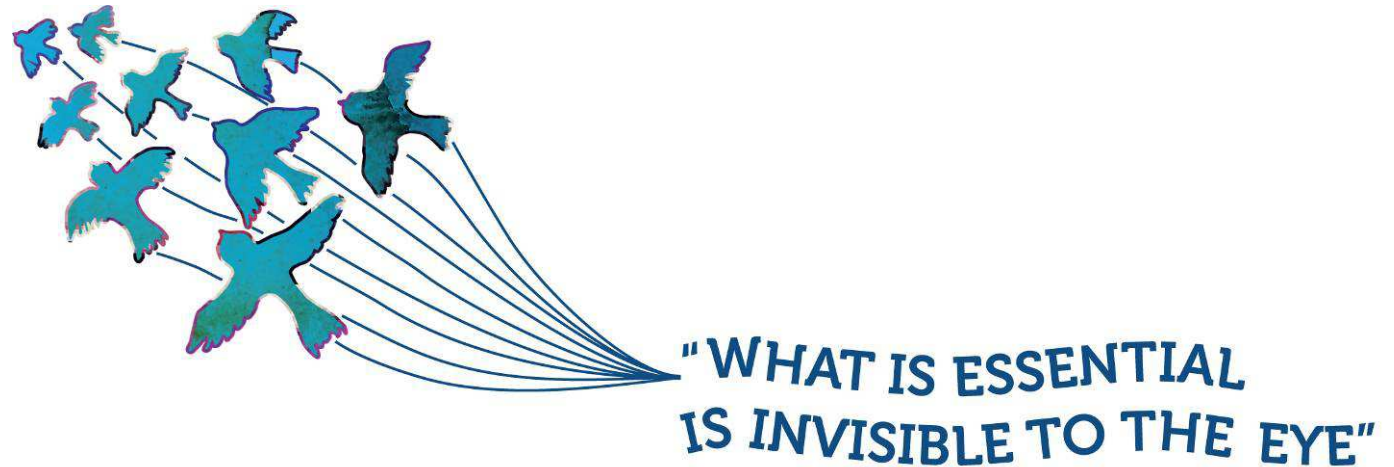
Which are the main tools provided by INV?

1. one handbook, which explains through examples the steps and phases of the relationship as well as its main features and potential enemies,
2. one training itinerary, which foresees 5 training sessions and includes all training resources necessary to transfer the model,
3. one self-observation protocol and a logbook, which should help the professional in enforcing the pedagogical, model in their everyday work,
4. other pedagogical tools.

What is INV’s origin?

The INV project (October 2012- January 2015) has been financed by the European Commission in the framework of the Lifelong Learning process – Grundtvig, for adult education.

This handbook has been written by Gabriella Fabrizi, who has used the results and contents coming from Focus groups undertaken in the first period of the project, training of professionals, in-the-field-testing. Some of the tools proposed are the fruit of the experience of the project team or come from the “cultural heritage” of partner organisations.



What is essential is invisible to the eye: Pedagogical Model

Handbook for professionals involved in the educational relationship
with persons with severe Down Syndrome and other intellectual disabilities



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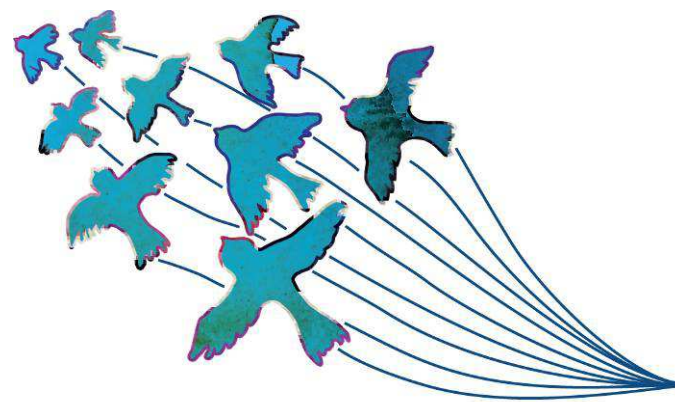
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PRELIMINARY REMARKS

(Anna Contardi)

In Europe in the last few years, the number of adults with Down syndrome and other intellectual disabilities has greatly increased and this has solicited new and adequate answers on the part of the services that provide for them.

If some of these adults grow up and express their autonomy to its full potential, by obtaining regular jobs, others require the presence of employment/occupational services, assistance and residential care that can provide for their needs as people with strong personal needs and a low level of autonomy.

The professionals who work for these services where their relationships are heavily influenced by daily-life events and by an idea of assistance that does not always enhance the complexity of their role, they often suffer from solitude, they fall into a routine and use a training more focused on techniques rather than on relationships.

This project came about following these considerations. On one side, it is aimed at the professionals that work with disabled people in grave situations so that they can improve their capacity to act, think and listen. The project is also aimed at the

people with disabilities to help them regain their identity and dignity as people within a reciprocal relationship where they are seen not just as the object of assistance, but also as the subjects of a relationship.

Too often in the world of services we hear the word “emotion” associated only with “vocation”, “kindness”, “availability” almost as if all these “good” emotions could replace professionalism. However, if education as A. Canevaro says is: “the constant work of negotiating interiority and exteriority”, then a good educator knows that awareness of what one feels is an integral part of their profession.

This manual proposes a process of reflection and some work tools to accompany the educators in this path towards an awareness of “What is essential is invisible to the eye”.

**“L'ESSENZIALE È
INVISIBILE AGLI OCCHI”**

INTRODUCTION

The project “What is essential is invisible to the eye” (INV) is funded by the European Commission, within the Lifelong Learning Programme (LLP) – Grundtvig Adult Learning Programme and promoted by the AIPD (Italian Association for People with Down Syndrome)

This initiative came about following the many years of experience of operators working with people with Down syndrome in difficult situations and major difficulties regarding autonomy on a daily basis. The main idea is based on the fact that the relationship that is created between an operator and a disabled person must be considered an educational one, with phases, characteristics and risks that are peculiar to the job.

Two Foundations for Down syndrome have taken part in this project, which began in November 2012 and ended in January 2015: Down Alapitvany (Hungary) and the Fundació Catalana Síndrome de Down (Spain), and a Spanish institute called Instituto de Formacion Integral as well as the AIPD who led the project.

The model, created on the basis of the experience gleaned from the professionals who took part in the national Focus Groups has been proposed with specific educational activities

and tested on approximately 60 people among the three countries taking part. These people belong to 10 different institutions that work in this sector.

The following manual is therefore the result elaborated by the partner organizations but it also formulates the comments and suggestions of the professionals taking part who experimented the educational model and its instruments in the field.

To “explore” an in depth version of the project, take a look at the messages and impressions of those who have already “experienced” this model and also find all the instruments proposed (such as videos one can use for training purposes), in four languages (English, Italian, Spanish and Hungarian), you can visit the website: (<http://invllp.eu/inv/>).

1. CONTEXTUALIZATION. THE REASONS OF THE PEDAGOGICAL MODEL

The European strategy on disabilities aims at improving social inclusion, well-being and the full exercise of disabled person’s rights by means of complementary action at both European and national levels¹.

¹ “European strategy on disabilities 2010-2020: a renewed effort for a Europe without barriers” COM [2010] 636

This is based on the **United Nations Convention on the rights of the disabled person 2006** and on the **European Charter of Fundamental Rights**.

FOLLOW UP MATERIAL

The Convention seeks to guarantee that disabled people enjoy all their human rights and fundamental freedoms. Among which are: the right to **live independently** and to **social inclusion**; to **education**; to **qualifications** and to work; to **rehabilitation**; to create a family and to reproduction; to the realization of their physical, mental, social and professional potential; to an **adequate standard of living**.

United Nations, "Universal Declaration of Human Rights", 1948
(www.ohchr.org)

One notices, however, that despite new attentiveness and social changes in recent decades, pockets of backwards behaviour and cultural reference models no longer adequate persist towards disabled persons. For example, in a certain school of thought it is still strongly felt that in the functional recovery of the person with respect to his or her "productive capacities", is based on a conception of "proficiency" which corresponds to the idea of performance capacity. This does not allow for approaches focused on the development of the

person's autonomy with a view towards reducing to a minimum their dependence and social.

Moreover, the analyses and reflections of the past years, both regarding the formation of social workers working as educators and care-givers, as well as the activities carried out in socio-educational services addressed to people with serious disability, have observed the following critical points, described below.

1.1 BURN OUT OF PROFESSIONALS

The professional is engaged in an absorbing job that concerns the emotions and the deeper aspects of the person and that often puts him in contact with suffering and pain. They have to work not only with their intelligence, but also with their insight and sensitivity, not only with the mind but also with the body. The exposure is complete and the inevitable attrition becomes a source of frustration and disappointment and frustration due to unattained successes, and results that seem out of reach. What becomes evident over time is not so much what they can do but what they cannot. This leads to a sense of helplessness and worthlessness, giving rise to self-defence and loss of

motivation, conflict with the organization, attributing ones impotence to disability: **in a few words, the burn out syndrome.**

FOLLOW UP MATERIAL

Some definitions of burn out syndrome:

Progressive loss of idealism, energy and aims, lived out by a social worker – professional and otherwise – as a result of working conditions

(J. Edelwich, A. Brodsky “Burn out”, Human Sciences, 1980)

Condition of physical and emotional exhaustion found among those working in helping professions, caused by chronic emotional tension arising from contact and continual and intense engagement with the people, their problems and their suffering

(H. Freudenberger, G. Richelson “Burn out: the high cost of high achievement”, Bantam Books, 1980)

It can be defined as a syndrome: emotional exhaustion, depersonalization, reduction of personal capacities – all of which can be found in subjects who take care of people professionally, as a reaction to the chronic emotional tension created by continual contact with other human beings, in particular when they have problems or sources of suffering

(C.Maslach, S. Jackson, “Maslach Burnout Inventory”, 1981)

The person absents him or herself from their work in response to the excess of stress and dissatisfaction

(C. Cherniss “Staff Burnout: job stress in the Human Services”, 1980)

As is well known, the burnout syndrome concerns not only the individual but can also propagate as a contagion through the rest of a team and can influence the client who benefits from a specific service; it is in fact what causes the so-called “relational damage”, which can undermine an entire service.

FOOD FOR THOUGHT

Do you share the definitions listed above? Did you ever find yourself in a similar condition? What about your colleagues? Did your service suffer the consequences of this problem? Did the relationship have a negative effect on those using the service? Has your service suffered (or is suffering) the consequences of this disease? In which way?

1.2 RESPONSES IN TERMS OF UP-DATING AND TRAINING

Generally, organizations trying to repair the burn out damages through training interventions aimed at professionals. Usually provided contents – as also requested by professionals – are:

- 1) The handing down of techniques and intervention methodologies;
- 2) The Other to be educated, with his or her psychophysical specificity, cognitive processes and context of reference.

The professional risks remaining invisible, when, on the contrary it seems increasingly necessary to focus on the daily-lived experience of the professional, on his or her biographical and professional trajectory, on the motivations behind his or her choosing this line of work and on the motivations, which support them throughout it, as well as on the helping relationship.

The training and education usually revolve around the teaching and learning of techniques concerning the **know-how** toward the person with disabilities in order to have the "recipe" for **how to act** with a person who doesn't speak, who doesn't seem to listen, who ignores the other or attacks him. However, the problem does not regard techniques and there are no methods available: techniques cannot solve the problem as such. They should always be rethought, contextualised and customised. That is to say that **they should be appropriate with both the service and the activity and made effective within the relationship with that specific person (not just thinking to people with disabilities in general)**. Notwithstanding even though realize these techniques are not the solution, the more we use them; their low level of efficiency feeds a vicious circle: "If this technique does not work, you need to learn another".

1.3 THE VISION OF THE DISABLED PERSON

Disability continues to be the subject of stereotypes. Because they are different from the norm, disabled people are considered abnormal and therefore excluded from the social context, trapped within the categories of dependence, normalization and "ability-ism". **Ability-ism** constitutes a set of representations, beliefs, images and myths that lead to a self-image of perfection: in this framework, the disabled person is considered unable to carry out activities considered normal for a human being.

FOLLOW UP MATERIAL

"From the ability-based norm there follows a system of social management of differences that tends towards stratification and exclusion of the more difficult and unproductive members. The ideology of ability-ism produces at least a few pairs of stereotypes: the figure of the disabled person as a child and the figure of the 'super-cripple'. On the basis of these images, disabled people are often seen as superheroes and then admired for their courage and determination".

G. Vadalà, "The DNA of Disability: Dependence, Normalization, Ability as Disabling Categories" in Italian Journal of Disability Studies – Italian Magazine of Studies on the disability, 2011

FOOD FOR THOUGHT

Do you know any texts on these concepts in the literature of your country?
Do they express a similar view?

These representations hinder the construction of empathetic relationships with disabled people, consolidating their exclusion and reinforcing social injustice. All this is truer in case of Down Syndrome (DS) or other intellectual disabilities persons with cognitive and behavioural difficulties serious enough to be defined as “severe”.

FOOD FOR THOUGHT

What social representations towards disabled people do you consider more frequent in your country?

- Child (who will never be considered as an adult),
- Super-cripple (brave, determined),
- Unhappy,
- Angel (without sexual needs)

....

During the Focus Groups that the partners activated within a workshop that involved professionals participating in the project, many professionals reported their difficulties in dealing with the sexuality of people with disabilities. Moreover, they expressed the need for training courses in order to obtain tools to address this issue in their daily working life. Do you share

this need? Do you think that the difficulty to address this issue can originate, at least in part, from your social representation of a disabled person? Your representation, the one of the service, the one of the social context in which your service is located, ...

SUGGESTIONS FROM THE INV PROJECT

During the Focus Groups, the leaders tried to understand if participants had a common vision about people with severe intellectual disabilities. As a premise, participants highlighted that a person with severe syndrome must be considered like any other person and therefore their lives should be fully fulfilled, and they should have the same rights as any other person. The concise definition as it emerged from the FGs is the following one: A person with severe disabilities needs permanent support and care in their daily life and as they do not have the fundamental skills to autonomously manage their personal relationships.

“Define the essential”, Report on the results of Focus Groups

1.4 THE CONCEPTION OF CARE AND INTERVENTION

In many services addressed to people with severe intellectual disabilities, it is often understood that the curative dimension is a set of techniques regarding hands-on care giving: washing, dressing, nourishing, etc. Even if these elements are important (basic) aspects they do not represent **the essential** and they

do not allow the professional to take responsibility for the other as a person who transcends the disability and has – but is not always able to express - the serious existential needs of recognition and relationship. These needs are often "blacked out" from the most immediately obvious features of the syndrome and from the material needs. The danger of this behaviour is mostly in the reinforcement of the unconscious idea that the existential, spiritual and volitional dimension of the disabled person does not exist.

The professional is often trapped in the doing, **substituting him/herself for the other**: bringing to completion the other's actions, **leading the other to understand and imitate**. Conditioned by what does not function well, the professional gives him/herself as a model towards which the other ought to tend, reducing the other in this way to one dimension only: that of the pathology. This "**pedagogy of the model**", still quite common today, is situated within a vision which sees "normality" and "disability" not as relational facts in an unstable balance where the contexts are from time to time defining, but rather as typical, stable personal traits.

1.5 THE NEED TO RE-THINK CONCEPTS AND MODELS

Every individual constructs a model of him or herself born of interaction with society. The social transformations of recent decades have also changed everyone's cultural reference points, their concept of social inclusion and needs.

In modern society, more and more we find a sensibility towards a sense of citizenship understood as a right and obligation of belonging to a precise local, national, European and global community.

Services aimed at people with severe intellectual disabilities must also be placed in harmony with this growing sensibility; on the contrary, they risk avoiding defining disabled people only as passive users and not as citizens with rights.

New pedagogical models need to be defined towards which more adequate educational processes can be oriented, so as to respond in a more appropriate way to new questions directed towards the intervention of educational services, and moreover, of services aimed at people with severe disabilities. Professionals involved in these services need to be capable of understanding the **dimension of citizenship** belonging to everyone and thus also to people with severe problems. They

need to **think beyond the symptoms and pathology and see the person.**

These are the main aims of “L’essenziale è invisibile agli occhi” pedagogical model.

2. THE ESSENTIAL IS INVISIBLE TO THE EYE: THE PEDAGOGICAL MODEL

“Be careful how you interpret the world: it is like that”

Erich Heller

The Pedagogical Model illustrated in this handbook aims to develop a different concept of the work and the relationship with people with severe DS or other intellectual disabilities. A conception that assumes as its central element no longer disability but rather the dignity of each human being, as proclaimed in the Universal Declaration of Human Rights:

“All human beings are born free and equal in dignity and rights ...” (art. 1);
 “Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind ...” (art. 2);
 “Everyone has the right to life, liberty and security of person” (art. 3).

United Nations, “Universal Declaration of Human Rights”, 1948
 (www.ohchr.org)

The Model aims at achieving these goals:

- Taking education as an essential factor for the construction of paths towards autonomy, capacity planning and citizenship of each person,
- Addressing professionals as fundamental tools of the growth paths of people with disabilities, in order to provide them with stimuli and tools for reflection - individual and collective - and a change of perspective (in relation to their vision of the person with severe DS, of the service and its objectives, and of their work),
- Focusing on the centrality of the educational relationship between the person with disability and the professional.

FOLLOW UP

THE CONCEPT OF EDUCATION

Education is the ensemble of the care and activities aimed at **stimulating and orienting the growth processes, of social integration and cultural transmission** by means of individuals. Within specific historical, environmental, familial and genetic situations, this includes the formation and development of all the aspects of their personality: physical, intellectual, emotional, personality “...in a process of development and maturing a balance between the individual and social spheres of the personality”²

The etymological analysis of the term educate shows two possible origins, which seem to be opposites. One from Latin derived from *ex ducere*, which means, “to lead out from inside”, “to draw out of” (the Socratic Method) means “to get grow, to promote”. The other from Greek, is an intensive form of the verb

² A. Curatola, “L’approccio terapeutico ed educativo alla disabilità relazionale”

edere which means “to nourish”, to introduce and then to transmit (transfer)³.

When reflecting on the concept of the Education one should retain both of these etymological derivations. However, because education appears as a rather complex process and any simplification or reduction of the term would render its comprehension excessively limited and thus incomplete.

Education is considered, in light of this, a *constant labour of negotiation between interiority and exteriority, between promotion of the endogenous and the organization of the exogenous*⁴.

“The aim of education is not to give the person an increasing amount of knowledge, but to “develop within them a deep inner condition, a kind of polarity that can orient him for a lifetime”

E. Morin, 2000

³ M. Veronesi, “L’Operatore sociale nei processi relazionali”, ARIS, 2000
G. Pampanini, “Verso una teoria dell’agire educativo”, 1995

⁴ A. Canevaro – J. Goudreau, “L’educazione degli handicappati”, 1998

2.1 THE EDUCATIONAL RELATIONSHIP

The fundamental dimension of education is the relational dimension. The educational process cannot exist if not through interpersonal relationships and communicative processes. Furthermore, the educational processes and the results they obtain (contents, behaviours, capacities) are historically and socially determined and, in their turn, determine change.

The relationship is a process by means of which people influence each other reciprocally, using exchanges of words, thoughts, actions, sentiments, reactions, signs, etc. All these things are the mental space of each person and as such they represent a point of view that passes them off as concrete reality and truth; this partiality is fundamental because it is the experience of any person (subjective, of course) and makes it possible to know, to think, to understand.

FOLLOW UP MATERIAL

Bateson asks *“Is there a line...of which we can say that ‘inside’ that line or interface is ‘me’ and ‘outside’ is the environment or some other person?”* (...) *“The mind contains no things... only ideas... information about ‘things’... Similarly, the mind contains no time and no space, only ideas of ‘time’ and ‘space’.*

“Learning the contexts of life is a matter that has to be discussed, not internally, but as a matter of external relationship between two creatures. And relationship is always a product of double description.”

G. Bateson, “Mind and Nature – A necessary unit”, 1979



The relationship is a fundamental experiential element that is being constantly re-worked and changed, because it is a function of the confluence between personal history, environmental context, emotions, aspirations, needs, etc. Experience understood in this way creates the possibility of carrying out continual changes of perspective, of

presuppositions, of modifying oneself, a task that the educator/professional cannot renounce⁵. What happens within the services, the analysis made by the staff, the reflections of the professionals, the lived experiences of the users, represent a continuum maintained through the reciprocal exchange, that is to say through the relationship that reproduces itself continuously. How many of the things we observe concerning the other person are in fact in our mind? How many of the things we blame the other for, are something we are not able to correct in ourselves? The Model runs as a tool to define the lines, to allow the reading of the mental maps of each individual and allows one to make matches between these individual maps and the “objective” definition. Such a decoding and “stitching” of this information also makes it possible to compare this same information (mental maps).

Relationship is effectively described by the couple/word “I-thou”, which establishes the very world of relationships⁶.

FOLLOW UP MATERIAL

“The relationship is the encounter between two people understood as protagonist systems, significant and observant, who change each other

⁵ M. Veronesi, “The relationship. Handbook of best practices”

⁶ M. Buber, “Il principio dialogico”, Ed. San paolo, 1993

reciprocally by means of feedback. It seems important to understand, therefore, that several elements such as empathy and comprehension are individual points of view and must be made explicit and brought to sharing. We propose once more the term dialog as logos done in two, within a space/time that possesses the meanings constructed together in relationship”.

M. Veronesi, “L’Operatore sociale nei processi relazionali”, 2000

FOOD FOR THOUGHT

It seems very appropriate and interesting to borrow the following reflection: “We are able to recognize the fact to be a person in a person, if we recognize in this individual the possibility to have a dynamic relationship with us over time, or rather a relational dynamism built through our and his/her self-representative modality, built through questions, answers and interactions along a specific lapse in time. Now, we can say that we can easily recognize this relational chance at a “glance” when we are in front of a person with an intellectual disability?”

Stefano Onnis, “Do the policies and the current discourse on disability produce social stigma? The analysis of a paradox through ethnographic research in Rome, Italy” in Italian Journal of Disability Studies – Rivista Italiana di Studi sulla disabilità

Let us try to take an honest look at ourselves, knowing that no one judges us and that recognizing our limits is the first step to finding solutions or at least it will modify our perspective.

The difference between a “simple” relationship among persons and a real educational relationship is given by the **intentionality of the educational action** developed by the professional to achieve precise objectives of development (cognitive, relational, emotional, affective ...).

2.2 THE RECIPIENTS OF THE PEDAGOGICAL MODEL

The Model is aimed at professionals who work in services for people with severe disabilities that **manage significant relationships** with these persons, are their reference point and are **responsible** – within their role - **for the educational project**.

The term “**service**” is used here with reference to distinct typologies (residential communities, group homes, workshops, home care, courses in autonomy), offered specifically to people with severe DS or other severe types of intellectual disabilities.

The Model was developed to allow the professionals to:

- a) **Activate processes of elaboration and organization of one’s own knowing:** *learning to learn* from the relationship and from experience.
- b) **Plan the educational management,** based on experience, and to render it possible within a context

developing therefore both a project-based mind-set (with a mid-to-long term framework) and an operative mind-set (in the here and now); in this way each professional can conscientiously reflect on his or her own role as a social builder promoting forms of emancipation for him or herself and for others;

- c) **Redefine the concept of care** as part of an integrated relationship capable of establishing a reciprocal rapport aimed at the development and growth of both subjects.

SUGGESTIONS FROM THE INV PROJECT

During the Focus Groups, participants defined the concept of care:

Take care and look after are always present in all types of services, regardless of the level of SD. In order that they do not provoke any exclusion from the groups they belong to, and therefore isolate themselves, they should look after their physical appearance including hygiene, clothing, etc.

Look after implies:

- Gets substituting the person
- Be far from the objective to pursue
- Low participation
- More severity need more looking after

Take care implies:

- Speak with the person

- Being able to observe and detect the needs of the person
- Value him/her
- Make him/her grown up.

Both dimensions are overlapped in the organizations, even some educational activities are focused on issues related to look after, aiming to keep these competencies in the life of PSD, in order they can gain autonomy and the “look after” activities with them were reduced.

Take care includes also look after, but is a more participated relation, implies accompany, observe and detect needs of the person with SDS, is more focused on the person, in order they can develop their own personal resources.

It requires teamwork of all professionals working in both dimensions and adapt the intervention with each person.

“Define the essential”, Report on the results of Focus Groups

As shown in the Report concerning the Focus Groups, those working with severely disabled people have diverse expressions of professionalism, different qualifications and different cultural backgrounds: assistants, nurses, psychologists, teachers, trainers, educators, social professionals and social workers⁷. According to their mandate and the type of service, they can work one to one (e.g. in the case of a home health care worker) or with a team of similar professionals, or even with an inter-disciplinary team, with

⁷ “Define the essential”, op.cit.

different roles and functions. In the text, reference is made to the **professional** in a generic sense.

2.3 THE CHARACTERISTICS OF THE PEDAGOGICAL MODEL

II The Pedagogical Model illustrated in this handbook is based on two categories:

a) The ***category of intentionality***

The relationship between the professional and the person with severe disability is deeply asymmetrical, above all at the beginning. This produces a confluence of emotions, desires, resources and competencies that concern both in a dynamic process. In order for this process to be developmental, i.e. that it may **bring about change and development**, it is necessary for the professional to activate *the category of intentionality* in educational activity. This should be understood as cognitive intention, transformative and ameliorative volition, awareness and ability to interpret and construct, capable of allowing a new way of seeing things, a greater consciousness of one’s internal and external conditionings that risk (if not recognized and governed) conditioning one’s care giving and helping relationship..

In brief, the category of intentionality concerns:

- The **awareness of the educational act**, namely the awareness on the part of the professional with respect to the initiatives, activities and care that stimulate and orientate the process. Doing nothing (at least in the educational setting) is an illusion;
- Awareness regarding the **person of the professional**. The principle working instrument is the professional, who must therefore know him or herself, what he or she wants, what his or her fears are, paradigms, reference values, and must know how to evaluate his or her limits and motivations; **the professional must know how to work with his or her own emotions.**

b) The *category of otherness*

This is activated in the first encounter and recalls the capacity to access and comprehend the other with reciprocity⁸.

The Otherness often frightens insofar as it is identified with unfamiliarity, which arises from a comparison with the characteristics of difference (difficulty, behaviours, etc.). For this reason there arise, causing schematic rigidity, routine action and the loss of achievable **horizons towards which the other can tense.**

⁸ A. Canevaro, "La formazione dell'educatore professionale", 1991

On the contrary, the piece proposed below will bring to mind the value of the category of otherness:

FOLLOW UP MATERIAL

"Just otherness takes possession of my responsibility and no longer requires any appropriation. Yet this subject is far from "perfect", entirely contingent, perceived in its own transience, poverty and insecurity, it must have the strength induce me, simply through mere existence (and not for its particular qualities) to make it available to my person, free from all desire of appropriation."

H. Jonas, "Das Prinzip Verantwortung", 1979

Beginning with the assumption of responsibility, the professional will be able to reflect and construct **by means of caring** (taking care of, caring for) the ethical relationship that unites him or her to the Other, who nonetheless maintains his or her own difference⁹.

FOOD FOR THOUGHT

"During the training course this exercise was proposed, "How do I feel in the relationship?". Trainers arranged on a sheet 3 emoticon representing all the possible emotional states: happy/peaceful, serious and sad. Then they will

⁹ E. Levinas, "Totality and Infinity", 2001

invite the participants to think of a specific person with whom they have a significant relationship, and then choose the image that best represents their emotional state after which they will explain why.

One can do this exercise periodically during the staff meeting or as an individual reflection, in order to achieve awareness of feelings.



Assuming responsibility and constructing an ethical relationship contrast with the “pedagogy of the model” cited in paragraph 1.3 and recall the need of a **“Pedagogy of the occasion”**, in which each professional is at the disposition of the person insofar as he/she accepts it. It implies an educational process understood as the construction of spaces that, through dialog built together, allow for the fulfilment of one’s potential and resources and not merely the simple teaching of ways and means.

Therefore, the Model does not want to advise or prescribe by undertaking certain activities, but of working (in the context of daily life and the normal activities foreseen by the service: personal assistance, work groups,

housekeeping, training activities, workshops, etc.) in a specific way on the goals of the educational relationship as will be explicated below.

Another important feature of the model is within **everyday life**, i.e. the dimension in which professionals and the people they serve are immersed, in which they act and react. Because of its “naturalness and obviousness”, it is the dimension most difficult for professional to consider; the understanding of the mechanisms that support it is not immediately visible because it is hidden by routine. Everyday life is by nature repetitive, always the same, and this, on the one hand permits to reassuring organizational elements, on the other side it can put a brake on change, growth and understanding the possibilities and potential the other in any case possesses.

The need for a design thinking emerges; a thinking that, is a forerunner of what could be, allows one to experiment actions characterized by rupture of the everyday constraints, of the routine, because **the hours of everyday life are the testing grounds for any real inclusion**. A thinking that can integrate the planning of the service with the individual project, the medium-term creative process with the micro-project creation.

Welcome the reflection of the great Italian psychiatrist Franco Basaglia:

FOLLOW UP MATERIAL

“The truth lives in the daily practice, in the rupture of the preconceptions, in the removal of pessimism within our reason and in the strength of an optimistic practice”.

F. Basaglia, “Conferenze brasiliane”, 1979

FOOD FOR THOUGHT

Do you know some texts on these concepts in the literature of your country?
Do they express a similar view or not?

The Model is **descriptive** and **normative** at the same time, namely it offers on the one hand the principle elements and theoretical references, and on the other hand, the implementation phases of the educational process are presented, distinguished in pre-educational phases (or helping relationship) and in the actual educational phases.

We do well to point out that the model does not intend to respond to the widespread need of prediction in the educational field: if I do this action, I can have this reaction, this result. Having “design thinking” does not mean being able to predict.

Education demands a strenuous and constant **work of research and reflection** and this is what the Model demands to professionals: to look at their work through new eyes, to reflect on their actions and assume a new perspective. For this reason, this Handbook also provides food for thought and exercises that can be developed both individually and during staff meetings starting from concrete experiences. Indeed, experience is a wealth to be appreciated and safeguarded against the risk of becoming a rigid mental habit that threatens to hinder the possibility of thinking in alternative ways.

2.4 THE RULES OF THE MODEL: THE AXIOMS OF THE EDUCATIONAL RELATIONSHIP

Because the Model focus the Educational Relationship, it is important to master the functioning of the latter. To do this, we can borrow and assume these as the central six axioms¹⁰, rules given as true although indemonstrable.

Each professional must test the veracity of the proposed axioms through constant reflection in their own work.

¹⁰ M. Veronesi, “Professional in the relational processes”,

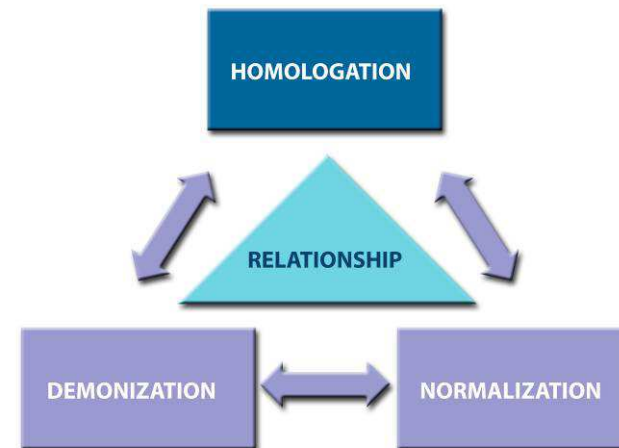
A. FIRST AXIOM

The relationship is a comport-ment space, or rather: every relationship 1) is a behaviour (to comport); 2) every behaviour follows a precise *mental* map. The relationship, in fact, is a pragmatic, operative process whose subjects can never assume a neutral, indifferent role: every attitude, every behaviour defines the very relationship. Every message is not only content but also indication, request, command. A phrase such as “I don’t feel well today” is not merely a description of the subjective state of the one speaking, but also means “Do something!” or “Consider me a person who doesn’t feel well.” Every message exchanged between two people tends to define the type of exchange that can take place between them. Even if one tries not to influence the other by keeping silent, the silence becomes a conditioning factor of the interaction¹¹. Furthermore, we organize our knowing and our being through mental maps¹² based on several reference points that are given socially (by culture and by meanings that every specific culture offers and imposes). We bind and connect elements and functions (meanings and relationships) elaborated personally depending

¹¹John. Haley "Strategies of Psychotherapy" 1963

¹² Cfr. Gregory Bateson: "Mind and Nature", 1980

on how we are constituted, our genetic patrimony, the environment, personal experience, etc. The relational space determined by the map, culturally given and individually interpreted, hangs between *homologation* (homologate the other to one’s own idea, e.g. to the idea one has of disabled people), *demonization* (the other is too different and incomprehensible and therefore dangerous or “contagious”) and the *normalization*¹³ (the strict application of the rules hinders the listening). **The educational relationship is in the middle, equidistant among these three elements.** We can find comprehension of the other only through listening, attention and respect.



¹³ In sociology, “normalization” refers to social processes through ideas and actions come to be seen as “normal” and become taken for granted or “natural” in everyday life; it can produce social control forms

The following short story was used to better explain this axiom, during the training course addressed to professionals involved in INV project:

THE TRAVELLING CAT

Once upon a time, a cat boarded the train from Rome to Bologna. This was nothing new to the train for many had ridden it, mostly inside baskets or boxes with a hole or two to breathe from but this cat was a travelling cat and travelled on his own.

He had a black bag under his arm, like a lawyer, but he wasn't one: he was a cat. He had eyeglasses like a near-sighted accountant, but he wasn't one and his sight was fine. He had an overcoat and a hat on like a smartly dressed man, but he wasn't one: he was a cat.

He entered a compartment in first class, spotted a vacant seat near the window and sat down. There were three people already seated in the compartment: a woman going to Arezzo to see her sister, a high-ranking officer going to Bologna on official business and a young man going who knows where. The cat's entrance aroused a few comments:

The woman said: What a cute kitty. Here kitty, kitty, kitty... are you travelling alone like a little man, eh?

The officer said: Let's hope he doesn't have fleas.

But don't you see how clean he is? said the woman.

Let's hope.... I mean, well, I am allergic to cats. Let's hope he doesn't give me a cold.

But he doesn't have a cold so how could he give you one?

But I catch colds from everyone, even from people who don't even have one.

Kitty, kitty, kitty... Have you come along to keep a seat for your owner, eh?

Meow!

What a pretty little voice. I wonder what he said.

For the first time, the young man spoke up: He said he doesn't have owners. He is a free and sovereign cat.

How interesting!

A stray cat, let's say then, the officer observed suspiciously, let's hope he doesn't give me the measles.

The measles? The woman exclaimed. But cats don't catch the measles and anyway it's a illness that you get as a child.

My dear woman, I didn't have it as a child. Do you know that it is far more dangerous if you get it as an adult?

The train departed and shortly after the conductor passed by.

Tickets, please.

The woman opened her purse: Here you are.

Thank you, Ma'am. And the cat's ticket?

But he's certainly not my cat.

Is he yours, sir?

I wouldn't have it, burst out the officer, I can't stand cats. They make my blood pressure go up.

He's not even mine, said the young man. He is a cat that is travelling alone.

But he has to have a ticket.

Don't wake him up, he's sleeping... He's so sweet, look at his little nose.

Little nose or not, I have to punch a ticket.

Kitty, kitty, kitty, said the woman, pussums... come now, be a good puss, look who's here...

The cat opened one eye and then the other and meowed: Meow, meow.

And the nerve to protest! Criticized the officer. How dare he.

But he didn't protest, explained the young man. He said: I beg your pardon; I was just dozing off...

Dozing off, eh?

I see. Seems he likes to choose his words.

Meow, meow, said the cat again.

Now what did he say? The woman asked.

He said: Please, here is my ticket, The young man translated.

Check it properly; the officer said to the train conductor, there are people who would travel in first with a ticket for second.

The ticket is in order, sir.

Meow, meow, meow, purred the cat energetically.

He says, the young man explained fellow, that he ought to be offended by your insinuations, but he will respect you thanks to your grey hair.

The woman sighed: You're so good at understanding the language of cats. How do you do it?

It's easy, just pay close attention.

Meow? Meow?

This cat's a chatterbox, blurted the officer. He won't shut up even for a moment.

What did he say? What did he say?

He asked if smoking bothers you.

Of course not, kitty, not at all... Heh, look, he's offering me a cigarette... He lights it so well! Could it be! I mean, he actually seems to be a smoker.¹⁴

¹⁴G. Rodari, "Il gatto viaggiatore e altre storie", Editori Riuniti 1990

The explanation of the story

The cat in the story is the other, the marginalized, the other-than-me, and the one who by egocentric definition is different.

The other characters represent not merely a communication style, but a fundamental attitude that makes us reflect, a symbol/meaning that defines the behavioural space.

The woman seems to want to establish a good relationship with the cat: “What a pretty kitty (...) Don’t you see how clean he is? (...) What a sweet little voice...” etc. Nevertheless, in this apparent sweetness, the woman denies the specific reality of the cat “he seems like a little man”, she denies him an autonomous existence, “You’ve come along to keep a seat for your owner, eh?” The life of the cat as such is useless and unthinkable if not in function of something else, if not for the presumed purposes of the woman and at any rate outside of him. Furthermore, the kind woman carries out a very subtle operation in relation to the cat: she conforms it to an idea of cat that she possesses, cataloguing it according to her image and does not make the least effort to get to know it, i.e. to allow it to be itself. Acting in this way, she cannot understand it; she is not able to understand what it says. It is inaccessible to her. In the end, when the conductor arrives, she does not even take it under her care. Despite her apparent tenderness, she denies

the bond and leaves it to fend for itself. On the other hand, given the presuppositions of the relationship, she cannot do otherwise: they do not belong to each other. They are in two different worlds that have nothing in common. The apparent acceptance turns out to be rejection.

Tolerance, though less “distasteful” than explicit rejection, if it stops there and never arrives at understanding the other through dia-logos, if it does not transform into construction of a common space in which to abide, although with difficulty, to seek out the words with which to relate, is analogous to rejection. The officer, though hard, is quite clear. He has no love for cats, wants no relationship with them, and fears their ... CONTAGION. Fleas, colds, measles; the cat infects, spreads the viruses of his cat being to those around him.

We shall call the grand officer’s behaviour demonization: the other is completely different, unknowable and dangerous. The other does not exist: he is hidden from my eyes by my fear.

The conductor in our metaphor represents that which is: the institution, bureaucracy, formal service uninterested in reality as long as it complies with the rules: cat or no cat “I have to punch a ticket”. In the end, there is the young fellow: he understands the meowing and speaks with the cat. The first sentence he pronounces is what the cat affirms about himself: “He said he

doesn't have owners. He's a free and sovereign cat." Moreover, when the woman states with a sigh, "You're so good at understanding the language of cats, he responds with full composure, "It's easy. Just pay close attention."

FOOD FOR THOUGHT

At the end of the story, the participants were invited to take part in an exercise.

The trainer presented the framework of the Behavioural Space (with power point, on a sheet affixed on the board, distributing individual sheets) and asked the participants:

- a) To place the characters of the story within the triangle
- b) To reflect upon several types of clients
 - Drug addicts,
 - ROMA people,
 - People with severe DS

And decide which side of the triangle they should be placed.

This is a useful exercise and each professional should do it periodically: How do I place myself among people with whom I have an educational relationship? Where do I place the service where I work?

B. SECOND AXIOM

The relationship depends on me. The other, as a binding principle, is always an autonomous, free subject. Due to this

principle, in the systemic logic of the dyadic relationship, in order to activate a change in the I -Thou system, I may not do otherwise than intervene upon myself and... change me. One of the basic principles of education concerns the freedom to accept to participate in an educational process or not. Therefore, it is implicit and basic to education to take into account the other needing education as a unique subject and – as far as possible – free to decide. Thus, the relationship depends on me; I am the only variable of the relationship; I, as builder of reality and meaning, must initiate to work to promote and encourage the participation of the person.

To better explain this axiom, during the training course, addressed to professionals involved in INV project, the following story was used - the Fedro story "The frog and the ox" and two different versions by Gianni Rodari:

- 1) Fedro: *Once upon a time, a frog, in order to become as large as the ox (because her envy), bloats himself to the point of bursting and death.*
- 2) Rodari a: *A frog wanted to become as large as an ox. She started to bloat and got to the point where he burst. The ox cried, touched by the event: it is not my fault I am so big.*
- 3) Rodari b: *A frog wants to become as large as an ox. She starts to bloat. The ox is scared that he might burst and so becomes little, little to make him happy.*

The explanation of the story (of the different versions):

- 1) First version not only is the indifference of the ox highlighted but also the incompatibility between the two animals: either the relationship stays how it is, or they die. Indeed, the frog dies. Two worlds that take on meaning through the prohibition of contact.
- 2) The ox lets himself be moved by the failed attempt of the frog. He would even have accepted it. The fact is, you cannot go against the established order of things and he was not the one who determined the difference of sizes and the frog's desire. So many who reflect it daily, though more sensitive, are not open to taking responsibility if the matter does not directly involve them. Compared to the ancient text, in this first version, the ox shows a certain awareness that, nevertheless, does not bring about a change in the situation, but only leads him to breaking down in tears.
- 3) In this version, something appears that goes beyond an empathetic attitude: the ox realizes what the toad wants to do and what will happen, and so intervenes. The way he intervenes is certainly very meaningful, and beyond the classical framework of possible responses. The ox does not

judge. He does not judge the frog's desire. He does not look for the causes of that perverse desire.



FOOD FOR THOUGHT

Can you remember an episode – personal or professional – in which your attitude, your behaviour, your vision changed something?

C. TIRD AXIOM

The relationship implies a unilateral risk. Risk is the only possibility/occasion for encounter with the other. It is the possibility for one's own change that, as such, can also make

possible...change in the other. In the approach with the Other, one must accept to “expose oneself”, to come across unarmed and defenceless in order to invite the Other to do the same.

To explain this axiom a story was used during the training course addressed to professionals involved in INV project. The story was “The Frog and the Scorpion”.

A scorpion has to cross a pond and asks a frog if she can carry him on her back, given that she knows how to swim and he does not. The frog says she does not trust him: what assurance does she have that the scorpion will not sting her with his mortal poison? The scorpion tries to convince her saying that if he uses his poison, the frog will sink and so he will die as well for he cannot swim. The frog accepts, but in the middle of the pond, the scorpion strikes the frog with his stinger. The frog asks the scorpion as it is sinking, “Now you’re going to die, too. Why did you do this?” The scorpion responds, “You ask me why? Because it’s in my nature.”



The explanation of the story

The frog is not purely and simply good: it represents the heroism to play against the inevitability of things, the moral choice that clash with the law of the nature of the Other. Without “frogs” that risk, no one scorpion will ever change.

FOOD FOR THOUGHT

Do you think the frog has a reason to do this or do you think that defeat is inevitable, and that the risk is too big and useless?

Have you ever felt that your actions are useless? If yes, how did you cope with this feeling? Have you been able to confront yourself with your colleagues?

On the contrary, do you feel satisfied in taking a “risky” action that you experimented by changing the situation? If yes, have you been able to reflect and systematize your action, assuming it as concrete operational capability? Have you compared notes with your colleagues?

D. FOURTH AXIOM

The relationship has enemies, who are Fear, Lucidity, Power and Old Age.

- **Fear** is always present at the beginning of a relationship and can come alive in very specific moments of the same

relationship. It can constitute an obstacle to knowing the other, to give development of growth and change a chance; it can become a source of renunciation to relationship. However, when recognized and checked, fear can constitute an occasion and a resource: instead of escaping, the professional can approach the other with discretion and gradualness, he/she can change his/her attitude, attentive to the other's situation, using prudence in requests that expose or confront. Fear that leads to these "cautious" behaviour must be recognized as a precious emotion, without fear of appearing weak: it is important to consent to fear, accept it and respect it.

- **Lucidity.** One who knows, analyses, correlates, labels and defines is often identified as a lucid person. For a social professional lucidity can mean capacity of interpretation, adequacy of behaviour, pragmatism. However, it can become an enemy of the relationship because it can result in excessive self-assuredness and excessively organized interventions; one deceives oneself by being immersed in the knowledge of the Other and one risks distancing oneself from knowing the other by means of homologation: the other must correspond to the idea I have made of him. In this sense, lucidity/knowledge does damage, it cancels doubt and cancels the desire to remain in

the mystery of the relationship, transforming it into an enigma to be solved. Knowledge is obviously necessary, but not for using as a mediating instrument in the relationship with the other; on the contrary, it is an important occasion for self-knowledge on the part of the professional: in this way and through the listening and the effort of the dialogue built together it is possible to comprehend the reality of the person.

- There are two paths to defeating the feeling of **Power**, both of which must be followed. According to the first one, power must be distributed in order to be checked and eliminated, placing it in circulation, passing it around continuously. Each must "place one's own head in the hands of another": supervision, teamwork, coordination. Power is always given away, shared with others.

The second path wants power is also to be placed in question within the relational structure, which must be governed by reciprocity; a symmetrical relationship must be established, even if the roles, experiences and knowledge are different for each. The other is a subject and should be recognized and considered as such.

- **Old Age**, for a professional, is ascribable to being bored with a situation: it is *being tired* that makes one lose interest in being in

a relationship with the other; the end of enthusiasm and courage in starting over every time. On the other hand, Old Age is also *awareness* that doing the activities of social services (although necessary) is not sufficient in and of itself; the “old” professional knows that a good educational itinerary does not depend solely on his or her actions. The “old” professional is systemic and as such no longer believes much in theories and techniques in doing activities that, for the most part, correspond to a linear trajectory “do this, get that result”. The “old” professional has more experience; cultivates the awareness that there are limits and failures, that there will be “fatigue”: the relationship is a process and not a given, not an element; it is the confluence of elements over a period of time, in which things happen one after another, interfering with each other, creating con-fusion. The relationship is “being”, for as long as the other requests.

FOOD FOR THOUGHT

Periodically professionals are required to consider the following thought: “In my professional history, how have the enemies acted?” In my educational relationship with each specific person, what are the events, the circumstances, the behaviours that can make me anxious? The following exercise of self-evaluation is suggested with regard to “power”¹⁵

	TRUE	FALSE	
MY WAY OF WORKING IS MORE EFFICIENT THAN THAT OF OTHERS			
I TEND TO MAKE OTHERS DO WHAT I THINK IS BEST			
I GET ANGRY WHEN OTHERS DON'T WANT TO DO WHAT I SUGGEST			
I AVOID IMPOSING MY WAY OF SEEING THINGS			
I LIKE TO LET MY COLLEAGUES DO WHAT THEY WANT TO WITHOUT PUTTING MY IDEAS AND OPINIONS IN THE WAY			

¹⁵ The exercise is based on P. F. Scilligo, “Io e Tu. Parlare, Capire e Farsi capire”, 1991

E. FIFTH AXIOM

The relationship demands a metamorphosis. In the relationship with the Other, one must take into account one's own experience, in order to get beyond it, improve it, and free oneself from it if necessary, though without annulling it. The professional must assume the attitude of a child who starts over every time. He or she must "become a camel" so as to take responsibility for and bear the weight of the containment of his or her omnipotence, who is an always-present risk. Michel Serres expresses this in terms of "*discretion*": leaving space for the other, making room for him or her to exist. How much space does the professional leave to the Other? In the relationship, the other should not be controlled based on an implicit social mandate or contained in order to tranquilize "society"; the other is helped in fulfilling himself as an individual, as a bearer of rights. The professional is not a soft social controller but an agent of the other's promotion.

FOOD FOR THOUGHT

Periodically professionals are required to consider the following reflection: "What have I changed since working with people with severe DS?" and to

identify at least 3 elements of change.

We do not take for granted that the answer can be valid once and for all: in fact, it can change depending on the length of time and the professional's feelings about his/her work. Taking notes on the different answers in time can help the professional to achieve a greater self-awareness.

F. SIXTH AXIOM

The relationship implies the tragic as an existential category: taking on responsibility. Reality is always contradictory, and conflicting. Humans are exposed and immersed in total uncertainty in the face of the success or failure of their projects and actions. Greek tragedy, as a theatrical event, is the symbolic image of the human condition. It is forced to yield to a mysterious violence of the real, but which, if it is an authentic human condition, it is traversed and animated by the awareness of being human, in every moment and claims the supreme value of assuming responsibility of the dignity that resides in the fundamental core of tragedy. The structural analogy with social professionalism appears immediately. The other, the person living in a condition of social

disadvantage, has the same human dignity, which must be respected despite their fate.

Existentialist philosophy in our time has asked the pressing question about *being thrown into the world*. “Everything must always be done over”¹⁶, there are no standard formulas for any conduct, and there are no norms from which one may not exempt himself. Liberty and responsibility are such that nicely delineated itineraries cannot be found because all depends on us who are *alone in the night*.

Marked paths do not exist; despite the precepts and “commandments”, we are totally and gratuitously free.

FOLLOW UP MATERIAL

“Man shall be saved from falling by no guarantee; it is up to him to take the step that will bring him out of the abyss. The strength to take this step cannot come from any security regarding the future, but only from the depths of uncertainty in which man responds with his decision about the question regarding being man”.

M. Buber, “What is man?” in Carla Levi Coen: “Martin Buber”, 1991

“Existence (...) is the absolute and consequently perfect gratuity” and it falls to man to create a sense of himself and his existence.

J. P. Sartre, Nausea

Loneliness, responsibility, awareness, the other I am relating to, seem to be the catalogue of the senses of life. For Sartre, restlessness is born from the tension between solitude and responsibility.

The solution is found in committing **to accepting one’s own task of giving meaning and acting in the concrete, making oneself personally responsible for one’s own actions**. That is only mixing with other persons, entering into their problems, expressing one’s solidarity with them and changing the historical conditions that render this impossible: choosing and acting, taking on responsibility.

FOLLOW UP MATERIAL

The philosopher Emmanuel Levinas said that the human being exists because he is in a relationship with others, and the relationship of each person with another is based on responsibility without reciprocity.

¹⁶George Bernanos, *Sous le soleil de Satan*, 1926

FOOD FOR THOUGHT

A film was used during the training course to obtain a better understanding of the axiom,: “The Butterfly Circus” by Joshua Weigel (2009). This film is perfect for going in depth into the concept of Martin Buber. “No guarantee will save man from falling; it’s up to him to take the step that will bring him out of the abyss...”, The concept lies namely in the necessity of creating the conditions for “activating the desire” for fulfilment (insofar as is possible), of overcoming the state of need, for “walking in the world”.

The vision of this film can be useful during a staff meeting (it is available on YouTube) and motivate a common reflection. The film is really powerful and moving but it shows “the greater the struggle, the more glorious the triumph” and that we must not lose the ability to wonder and look for the meaning of our existence and our actions.



The Butterfly Circus

3. THE STRUCTURE OF THE MODEL AND THE OPERATIONAL PHASES

3.1 THE STRUCTURE OF THE MODEL

The proposed model is developed in two fundamental phases. However these should not be considered sequential (interpretive strand of causality which takes inspiration from the stimulus/response mechanism) insofar as they are related to a process of development, in and of itself dynamic, which concerns people (in this case people with severe DS or other intellectual disability) placing them in the centre of the action.

The relationship is a process of co-evolution whose result lies in a dynamic, emergent reality in continuous modification. It is a co-production in the shape of a spiral, which stratifies, adapts and modifies the new to the old and the old to the new.



In fact, given that it is directed towards work with people with severe intellectual disability, it takes into account the frequent necessity of recalling phases, sub-phases and actions already carried out: this does not mean “going backwards”, or even “we have to start over, what’s been done up to this point has been lost”. Nothing is lost; rather, everything simply must be adapted to the timeline and developmental path of the individual person.

3.2 THE OPERATIONAL PHASES

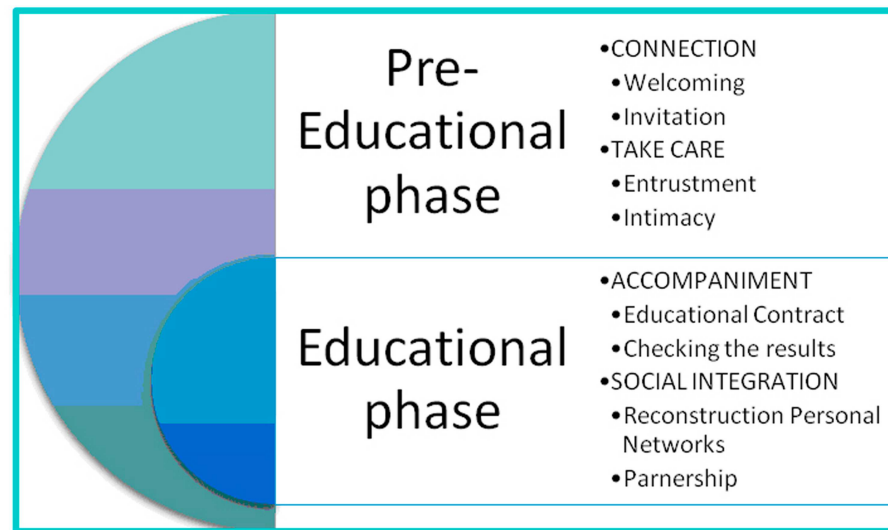
As mentioned, the Model is articulated into two fundamental phases, each of which calls for several sub-phases:

- a. Pre-educational Phase, in which the helping relationship predominates;
- b. Educational Phase, in which the educational relationship predominates¹⁷.

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.

As already highlighted, the Model creates a distinction between the Helping relationship and the Educational Relationship as such. The former is characterized by a profound asymmetry

between the two subjects: the professional and the person with severe disability. The intervention ought to establish the goal of reducing this asymmetry in order to construct the Educational Relationship characterized by the greatest possible awareness (constantly sought out and nourished) of the itinerary underway. In working with people with severe intellectual disability, the two aspects of the relationship continually intersect in a spiral fashion. Presumably, it will never be possible completely to overcome the phase of the helping relationship. As explained above, it will often be necessary to relate the new to the old and the old to the new, to plan, construct, consolidate and to plan again: planning over and over the helping relationship so as to promote and maintain the educational relationship.



¹⁷ M. Veronesi, “The professional in relational processes”, op. cit.

PRE-EDUCATIONAL PHASE

This phase concerns:

- The launch of the intervention, when the person makes use of the service for the first time.
- The need to reconsider the intervention an **“adaptation of the new to the old and the old to the new”** in a spiral fashion: crisis moments of the person that disrupt / hinder the process started; contingent change of the reference professional; the very traits of the person. All of this can necessitate the retracing (even contemporaneous) of the various operative moments in the constant recognition of the sense and meaning (and value) of the itinerary, retracing one’s steps in order to grow and enrich oneself every time.

1ST SUB-PHASE: THE CONNECTION

(or the **“Hook up”** or **“Getting to know you”**)

1. THE WELCOMING

Aimed at facilitating the encounter between persons, its reference context (usually the family) and the service.

A service is represented by various elements: the physical structure, the typology (residential, day centre, training, home health care, etc.) and the operative objectives; furthermore, it is represented by the staff and by the roles covered by each of them as well as, obviously, the people to whom it is directed and who “inhabit” it. Although all of this might seem a given, it is important to take into account the fact that “the first time” in service has a real impact. For this reason, the professional who welcomes the person must:

- First of all, consider the fact that the person usually, though not always, accesses the service not of his or her own volition but rather because brought there by someone else (family, other services) and is therefore less aware;
- Provide for a **clear and reassuring presentation** of the service in its entirety and for a first **illustration of the aims and activities**;
- Assume immediately a **listening stance** (to the family, to the person) in the awareness that **acquaintance is a specific action** and that every person enters the service with his or her own individuality, their own story, with problems and gifts, with

dreams and fears, with experiences from other services and with their own reference context.

2. THE INVITATION

It is a move aimed at taking the first steps towards constructing the reciprocal trust that characterizes the second phase: the person must be placed in the condition of gradually integrating into the service and entering into the following phases, upon invitation. Inviting solicits collaboration.

FOLLOW UP MATERIAL

Inviting is *“that way of intervening in the lives of others that is good to follow because it not only does not suffocate their freedom, but seeks to promote it as well as possible”*

P. Bonagura, “The art of inviting. Dialog as an educational style”, ARES, 1995”

FOOD FOR THOUGHT

Do you know some texts on these concepts in the literature of your country?
Do they express a similar view or not?

Invitation must be maintained as an operating mode involving the whole path.

The professional will have to:

- Act on the awareness of dealing with not simply any disabled person (a conception that identifies the person with the condition of the disability) but rather **that specific person** with his or her characteristics, who like any other human being is by nature unique and incomparable¹⁸ and therefore cannot be generalized (“the disabled people”);
- **Analyse their knowledge of the person**, not only through personal data that arises from the predisposed instruments but above all by establishing a relationship of trust and **through exploring the project potential** the person nevertheless carries within. The professional, indeed, will have to understand **using listening and observation**. They should understand the needs of the person, his or her intimate experience, attitudes, desires and resources, their way of communicating. They must **go beyond a mere diagnosis**: this, is indeed fundamental although (it should be said) it cannot and

¹⁸ S. Mazzei, “I see you, I hear you, I accompany you. In search of answers in being empathetic”

must not build a “cage” to crystallize the person within, also because the diagnosis is not always able to take into account the actual potential and ability of the person.

- The professional must nonetheless consider the diagnosis as one of the initial cognitive elements to work from when planning and adjusting the next intervention, in a dynamic perspective, setting goals to attain and identifying results to reach;

- **Support the person in their integration** into a service, in the setting of a group, fostering the gradual acquisition of feelings of **familiarity** (being “at home” in the case of a residential service or at any rate “in their own space”) **security** and **respect** (in the dimension of reciprocity);

- **Act as a bridge between the service and the family**, placing them in the condition of comprehending the meaning of the service, stimulating agreement on the operative objectives and seeking their collaboration. Indeed, unless the family is completely absent, it is important to promote their participation and above all the aspect of affective reference point, even in the case of a permanent residential service.

SUGGESTIONS FROM INP PROJECT

All the groups of professionals that took part in the Focus Groups in different countries highlighted the importance that the family must be taken into account: *“sometimes the family facilitates the work and the relationship with the person, and sometimes they create obstacles in their development as they are not able to see the potentialities. If the family works with the same goals as the professionals, the relationship improves and there are far more achievements”*.

The “connection” will always have different times and modalities in being carried out. The duration of this sub-phase and of the entire intervention, as well as the success or failure of the relationship, depend on how well this sub-phase is carried out. During the “connection” professional can act in a precipitous manner, in the hope of making it work. In this way; taken by anxiety and fear, can introduce him or herself in an improper manner, perhaps putting oneself on a false level of behavioural, lexical, or value equality; he or she can run the risk of being seductive in order to connect, or to allow oneself to be seduced¹⁹ by the other or to be collusive²⁰. In this way, could risk

¹⁹ Seduction: when the professional try to fascinate the person to be accepted

²⁰ Collusion: when the professional accepts misbehaviours by the person, always to be accepted

not coming to know the person as he or she truly is and to understand his or her needs and ways of relating.

To the contrary, this concerns planning and taking time to create an **empathetic connection** with the person. The professional and the person with severe DS get to know and understand each other, setting off on a path to be constructed together.

Reflecting on your relationship with each person with whom you have an educational responsibility, do you feel you made yourself available to build the path together with him / her? Do you think this is possible?

During moments in which the connection will have to be repeated and consolidated, the objective to be set is to “get to know each other once again”, or rather to discover previously unexplored elements. There will no longer be the experience and the fears of the first impact, and the acquired feelings of familiarity will constitute a precious support enabling the person to pick up once more the thread of the discussion underway.

FOOD FOR THOUGHT

For the connection phase, the following simple self-evaluation tool “I am ...” can prove useful (it can be used individually).

During the connection with this specific person, you were

Seductive:

Collusive:

Direct:

In your current state, in the light of your experience, do you feel you are usually at risk of behaviour that is

/_/ seductive or

/_/ collusive or do you feel you are always /_/ direct?

For further reflection:

SUMMARIZING

The “Critical points” of this sub-phase are:

- getting to know the other as a specific, conscious action
- knowing how to perceive the emotions of the person with severe disability from the moment of entering the service
- going beyond the diagnosis
- knowing how to listen, knowing how to observe.

2ND SUB-PHASE TAKE CARE

As emphasized above in the pre-educational phase, in this sub-phase there is a pronounced asymmetry between the professional and the person who is dominated due to their poverty, of which they are aware to a greater or lesser degree. Such situations of dependence can derive not only from the disability but also from other reasons. The fear caused by the moment of the first access to the service, the fear of being abandoned, the search for affective reference points, the fear of failing, the need to be accepted, the search for self-esteem, the fear of and desire to open oneself to other worlds, to other relationships.. are all reasons that should be identified in order to better direct the intervention. In this situation, the professional assumes unconditional responsibility for the person in difficulty.

The goal of the sub-phase is to **reduce the asymmetry** this can be done by carrying out two operative steps:

1ST STEP: THE ENTRUSTMENT

The primary task of the professional is to succeed **in activating in the person the desire to face his/her own needs**, to allow

another to assume responsibility for him or her and **to entrust** him or herself to the professional, to undertake a path that will allow the actual Educational Relationship to be initiated.

In fact, the Model urgently brings up another element: **the will to participate or not in the educational process** on the part of the person with severe DS. Every person is bound by his/her contingent situation, nevertheless they can also go beyond it, even if in different ways and only for limited periods, in developmental processes.

FOLLOW UP MATERIAL

"If ... there is a clear will for encounter, then the I-thou communicative dance becomes creative and the possibilities of accessing the wealth of reciprocal self-giving are multiplied".

P. F. Scilligo, "Io e Tu. Parlare Capire e Farsi Capire", IFREP, 1991

A passage from "The Little Prince" can effectively express the value of the encounter and the reciprocal self-sacrifice:

"My life is very monotonous," the fox said. "I hunt chickens: men hunt me. All the chickens are alike, and all the men are just alike. And, in consequence, I am a little bored. But if you tame me, it will be as if the sun came to shine on my life." I shall know the sound of a step that will be

different from all the others. Other steps send me hurrying back underneath the ground. Yours will call me, like music, out of my burrow.

A. de Saint Exupery, "The little Prince"

FOOD FOR THOUGHT

In the cited I-thou communicative dance, both the actors of the relationship can come out of the burrow. The person with disability (for which the burrow is represented by his/her own contingent situation) but also for professional, often hampered a multiplicity of "burrows" (e.g. homologation, normalization, "lucidity"...). What do you think are your burrows / obstacles?

Entrustment happens gradually; it is a slow, progressive approximation that leaves behind, at every step, a foundational solidity to rest upon.

2ND STEP: THE INTIMACY

Professional must do so to establish a relationship based on the mutual intimacy with the person.

To be able to create the conditions, one must act in daily life, creating *rituals* that accompany the entire shared itinerary. Even little, simple rituals but commensurate with the person's

characteristics and constantly proposed and carried out (e.g. establish a ritual greeting in the morning, specifically dedicated to the person and whose structure remains the same over time).

This might seem to contradict what was affirmed in paragraph 3.2, but it is one thing to take refuge uncritically in routine, often dictated by organizational needs, because it reassures. It is another thing to work consciously to discover and construct together with the person appropriate rituals of recognition.

FOLLOW UP MATERIAL

At this point it seems "compulsory" to quote another passage from the Little Prince:

"What is a rite?" asked the little prince. "Those also are actions too often neglected," said the fox. "They are what make one day different from other days, one hour from other hours. There is a rite, for example, among my hunters. Every Thursday they dance with the village girls. So Thursday is a wonderful day for me! I can take a walk as far as the vineyards. But if the hunters danced at just any time, every day would be like every other day, and I should never have any vacation at all."

A. de Saint Exupery, "The little Prince"

This assumption of responsibility demands two fundamental behaviors: constancy and fidelity, which must obviously be maintained afterwards²¹.

- *Constancy* means giving to the other as much time as is needed, overcoming the moments of testing, having the endurance to last even when the relation seems useless or regressive. It means having continuity, steady cadence, real presence, closeness.

- *Fidelity* means maintaining trust in the other despite the difficult or negative situations that may arise. It means always being available for another encounter; knowing how to maintain and recognize the other's effort in fighting against his or her neediness. The professional must refrain from judgment: the evaluation must always be of the act and quite circumscribed, never of the person, for whom one should preserve the maximum respect.

FOLLOW UP MATERIAL

"Fidelity is the bond that unites man with man, it is an interior bond, started from free choice".

J. Tischner, "The Polish Mill", 1991

INFORMATION DATA AND TOOLS NECESSARY IN THIS PHASE

In this phase, one begins to reflect upon the educational project, formulating initial hypotheses that will be able to be verified only in the following phases.

First of all, some **basic information** needs to be acquired, such as:

- Personal data and general information
- Personal history
- Diagnosis
- Case history

Such information can be collected using an **entrance sheet**. It will also be helpful to acquire the **dynamic-functional profile** elaborated in previous situations (e.g. school, other services, etc.) and which will then be verified and further elaborated.

All of these elements constitute, as has been said, the point of departure for the elaboration of the Individual Educational Project.

Furthermore, it will be necessary to prepare some **observation sheets** to be used during the entire intervention, fundamental in

²¹ M. Veronesi, "The professional in relational processes", op. cit

getting to know the person better, evaluating any changes and constructing a well-aimed educational project.

The sheets shall explore several dimensions: cognitive functions, thought processes, basic autonomy, the relational sphere, working ability, the abilities inherent in tasks and jobs, the level of autonomy and continuity. This information shall always be discussed with the person.

Both entrance and observation sheets must be created *ad hoc*, based on the aims of the service as well as of the characteristics and needs of the persons to whom the service is addressed.

SUMMARIZING

The “Critical points” of this sub-phase are:

- knowing how to identify the personal reasons for dependence
- assuming responsibility
 - knowing how to activate in the person the desire to confront his or her need
- knowing how to establish a familiar relationship
- knowing how to distinguish between routine and ritual.

EDUCATIONAL PHASE

La fase è finalizzata alla promozione della crescita, dello sviluppo e dell'integrazione sociale della persona in una prospettiva di cittadinanza e si compone a sua volta di due sotto-fasi.

1ST SUB-PHASE: ACCOMPANIMENT

If, in the preceding phase, one was able to activate and establish the desire to confront the neediness and entrustment, thus placing the bases for overcoming the initial asymmetry between the person and the professional, the latter must begin to consider the other as a subject on the same level. Only by establishing this presupposition can one begin to construct the educational relationship. The person with a severe disability **is and must be an active subject**: a presupposition for this is that the professional considers the other as capable of being an active subject and **this does not concern the level of severity of the person's disability but rather the concept the professional has of the person with severe DS.**

The professional in this sub-phase must thoroughly balance his or her action: accompanying and guiding the person by walking next to him or her, giving him or her the security of the professional's presence, both understanding when to intervene in a more direct way as well as identify the right moment for applying the so-called "**interrupted gesture**", an important element.

FOLLOW UP MATERIAL

The interrupted gesture is an important element of "*an education capable of waiting for the other to complete an action of ours. Our interrupted gesture implies waiting for an original completion by another; it implies a choice that intertwines with that of another, that can be very different from what we had in mind*".

A. Canevaro, "La formazione dell'educatore professionale", NIS, 1991

This implies the capacity to accept the limits of our own actions.

At this point we can take the suggestion of E. Morin concerning the Ecology of the Action:

"We sometimes have the impression that action makes things simple because, faced with an alternative, we decide, we make a choice. Action is decision. But it is also a wager, and in notion of betting there is awareness of risk and uncertainty. Action enters into a sphere of interactions and is finally grasped by the environment in a way that may be contrary to the initial intention. Ecology of the action means taking into account the

complexity it posits, meaning random incidents, chance, initiative, decision, the unexpected, the unforeseen and awareness of deviations and transformations".

E. Morin, "Seven complex lessons in Education for the Future", 1999

FOOD FOR THOUGHT

The interrupted gesture calls to mind the fifth axiom and the "restraint" of M. Serres, necessary to leave enough space to the Other: Pedagogy of Occasion wants take place to other, wants permit and enhance his/her existence. Was there a circumstance in which you were consciously able to interrupt your action to permit the other person to express his/her-self, to "do" autonomously? If yes, are you satisfied with the results? In what terms?

The professional have to pay attention to stimulating in the person his or her being an active subject even if only for little segments of an activity and that in some cases can become awareness (within the context of the event).

The professional must facilitate the opening of a **space for dialogue** through the search for even a non-conventional way of communicating, paying attention to the tone of voice, movement, muscle tone (tension/relaxation), facial expression, gestures, etc. The accompaniment is articulated in two steps:

1ST STEP: THE EDUCATIONAL CONTRACT. THE PERSONAL EDUCATIONAL PROJECT

At this point, the relationship is well formed and is meaningful both for the professional as well as for the person with disability. The professional is now entitled and has the cognitive instruments necessary, to launch the elaboration of the **Personal Educational Project** involving the person who by this time is sufficiently aware. The project thus assumes the form of an **educational contract** stipulated with the person. Namely an agreement – to be steadily monitored and calibrated – between the service (represented by the professional) and the person, aimed to agree objectives and activities and above all to bring again the person to the meaning and the sense of the intervention and to promote the awareness (always to the extent possible) about the path. It is very important to involve the family, above all with regard to the goals and the results expected. The Educational Project is a working instrument to be formulated by professionals based on educational needs and the development of each person. Given that it is oriented towards processes, that is, to itineraries of cognitive, training and experiential development, it has a **particular dynamic character and may not be considered as given for the last time, but rather must be continuously monitored and**

calibrated. As foreseen by ICF, the educational project is based on the principle that every person has a developmental potential that needs:

- Recognition of the environmental factors that can act as a limitation or support,
- Mediating actions with the same environmental factors with the aim of fostering the person's participation.

The goals, actions, methodologies, forms of verification and schedules must be clearly established²².

FOLLOW UP MATERIAL

The methodology adopted by AIPD for the promotion of autonomy courses are certainly explanatory: "After the first two months of activity, each person will have their itinerary explained to them by means of the proposal of 5 concrete goals to be reached in order to become "Cool dudes" shown in the five points of a star (cf. chart chap. 4), goals such as taking their group someplace, buying something, etc. By means of these goals they advance towards the attainment of the competencies mentioned within the educational area, and at the same time, having the person participate in a conscious way in his or her own "learn by doing" their self-esteem is reinforced."

A. Contardi, "Towards autonomy", 2004

²²International Classification of Functioning, Disability and Health, 2001, World Health Organization

FOOD FOR THOUGHT

Thinking of your group, of the people you follow, would you make an exception that certain goals cannot be proposed to those people with particular serious disabilities. Could you also reflect on the possibility and the educational needs of each person for whom you are responsible? Do not stop at his/her severity level, change the perspective, and let your eyes turn to a wider vision and try to redefine their goals and those that are quite simply unachievable on a daily basis. Is not this person able to set the table? Do not let him/her wait sitting for someone else who does it: he/she can work alongside those who do it and help; even only one spoon put on the table – even if a bit wrong – is better than passivity. Is the other person absolutely not able to move? Help him/her physically to do something useful for the group, by explaining the meaning and objectives: he/she may not acquire certain skill but feel “inside” the group ...

The project/contract is aimed at the goals of growth and profit for the person, while binding both protagonists: one is bound to realizing it and the other to facilitating and sustain its realization. This concerns **inviting the other to participate in applying the dia-logos, a discussion built together** in the perspective of the “**Pedagogy of the Occasion**”.

2ND STEP: CHECKING THE RESULTS

As emphasized, the educational project must foresee the means of checking its progress and the attainment of its goals,

as well as the schedule for these checks. This should be carried out involving the person in order to promote their possible participation and awareness of it, seeking together the ways to adjust and re-establish the educational pact. To this effect, the goals are to be explained in a way that is comprehensible and verifiable to a disabled person too, translating them into concrete actions and thus promoting a process of self-learning. Equally important is the involvement of the family.

FOOD FOR THOUGHT

It seems important to suggest one should focus on listening and not just restricted to the moment in which one is checking the results obtained, but above all to glean the level of satisfaction and pleasure of each person and he or she’s sense of well- being.

SUMMARIZING

The Critical points of this sub-phase are:

- “Drawing up” an educational contract;
- the shared elaboration of the Educational Project;
- knowing how to accompany;
- knowing how to identify the moment when “not to act”, when to interrupt one’s action;
- knowing how to identify the elements of the checking.

2ND SUB-PHASE: GROWTH AND SOCIAL INTEGRATION

The goal of this sub-phase is to foster the exercise of the right to citizenship of the person with severe DS. This too is composed of two operative steps:

1ST STEP: THE RECONSTRUCTION OR REINFORCING OF THEIR PERSONAL NETWORK

The aim of all personal educational projects and of all educational relationships is that the other might be able to “walk in the world” on his or her own two feet as much as possible, that the other might be a citizen among citizens. To reach this goal, it is necessary that the entire intervention include working to insert the person into a relational network, to be understood as time, space, relationships of the life of every person. The professional, then, is considered as a network point, one of the resources/relationships of the person now capable of placing trust in an adult, of knowing how to be in relationship even with his or her neediness without being overwhelmed by it and knowing how to enter into dialogue with others. One might think that in all likelihood people with severe DS will not “walk in the world” and even less “on their own two feet”, (e.g. the guests in a residential community will probably live out their entire lives

there). **It all depends on the point of view** one uses, and it would be well to overturn it more often. Rather than conceive the person as “placed” in a static way within an isolated structure, one should understand that the service is certainly and necessarily placed within a context, a territory, and interacts, necessarily, with it. Thus, rendering the service open towards the territory, letting the territory enter and at the same time enabling the people within make use of the territory are actions to be made in order to promote the construction and enrichment of their personal network.

FOLLOW UP MATERIAL

"Inclusion does not mean hoarding through assimilation. Rather, inclusion of the other means that the community's borders (the surrounding community is understood here) are open to all because it builds bridges between people, situations, competencies: real integration gives birth to full human relationships, it concretizes in actions and opportunities, in human rights lived out, in new possibilities yet to emerge".

J. Habermas, “The inclusion of the other”, 1998

2ND STEP: PARTNERSHIP

As we have seen, between the professional and the person an adult relationship has been established in this phase, in which

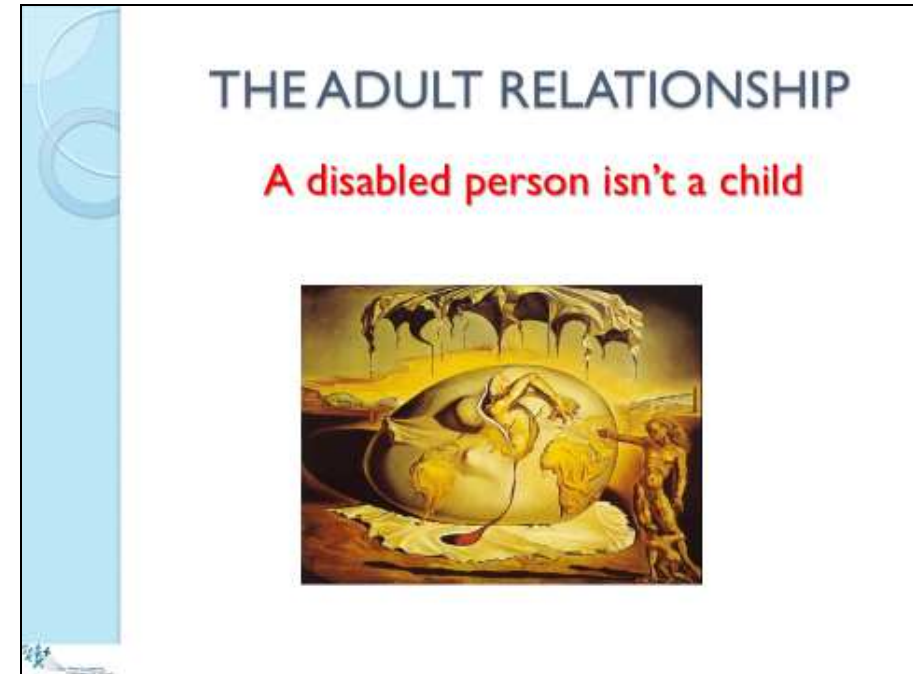
the professional remains the important guide with precise educational tasks but who knows how to keep his or her role as stimulus and facilitator of other equally significant relationships. Two adults (each with his or her limits and gifts) who have to work together now handle the relationship. In this perspective, the professional accompanies the person through the change, helping him / her to enhance himself / herself, to move in the social, family, of community environment in order to find an existential well-being and the greatest achievable autonomy. **The relational network of a person is the instrument for the analysis and intervention about the chances of the person.**

The professional must therefore support the birth or maintenance of constant relationships with several privileged stakeholders established naturally based on “elective affinities,” and who in turn can enter into a partnership with the person.

SUMMARIZING

The Critical points of this sub-phase are:

- knowing how to expedite the integration into the network;
- accepting the adulthood of the person.



a) The educational personal project

As it has been previously explained, the Individual Educational Project must be formulated based on the fact-finding data (diagnosis, dynamic-functional profile, results from the entrance file) and has to be constantly integrated with the information/evaluations carried out over time through listening and observation. It must include purpose, objectives, actions, methodologies, forms of evaluation, timelines, and must be oriented as much as possible to adult life and in the direction of development.

FOLLOW UP MATERIAL

The ICF provides valuable indications by drawing attention to the interactions among the different factors that influence each person's identity, giving importance to the factors of the context.

The general framework can be outlined as follows:



a) The maps of stakeholder

In order to facilitate the Planning and identify with more intentionality the Strategic Lines to develop in specific relationship between the service and the social and the territorial contest in which the service works or which is the personal network of each person, it seems appropriate to propose to use two **maps of stakeholders**.

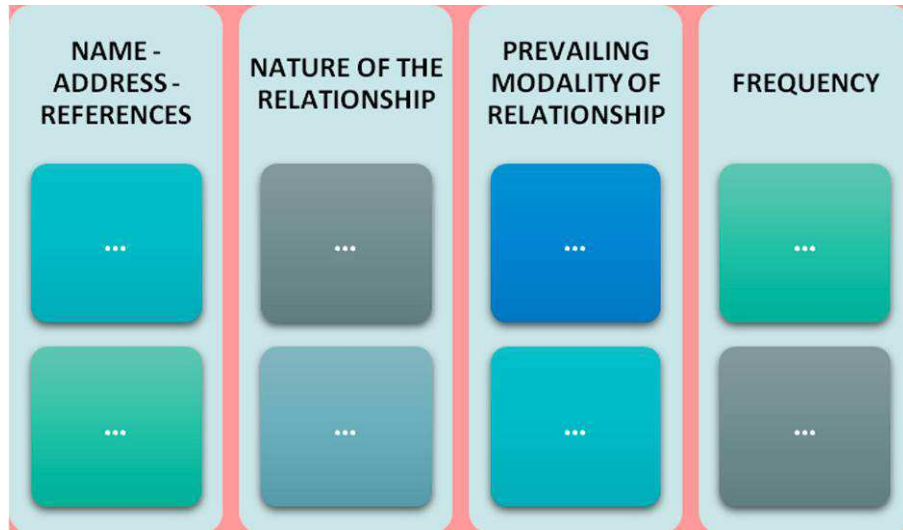
Either must be used separately, both for the service and for each individual. Initially, this work could appear redundant, with overlying and coincident data. Indeed, the separate use permits one to think on specific needs and concrete opportunities.

The first map provides an easy framework of the relationships with each participant. The column "NATURE OF THE RELATIONSHIP" provides information about the typology of the relationship built between the service and each subject (e.g. of membership, of management, regulatory, of operational cooperation) and between each participant and each person with disability.

The column "PREVAILING MODALITY OF RELATIONSHIP" shows if the contacts take place through face-to-face or collective meetings, formal mail, telephone, etc. The column FREQUENCY

Objectives	Activities	Expected results	Methodology	Timing and checking procedures

shows the frequency of the contacts: *daily, weekly, periodically,* etc.



The compilation of the first map permits one to report graphically, in the second map the level of proximity / distance / cooperation / solidarity, etc. of all participants.

The daily contact allows one to place the participant near the **NAME OF THE SERVICE** or the **NAME OF THE PERSON**. This facilitates the work of planning the networking.



Planning the networking can be developed based on the scheme already known:

Objective	Activities	Expected Results	Timing and checking procedures

4. THE MAIN INSTRUMENTS OF THE MODEL AND OF THE EDUCATIONAL ACTION: THE PROFESSIONAL

It has already been pointed out, that the Model is addressed to the professionals of the services for people with severe SD, as the main tool of the educational work is ... the professional.

By remaining constantly with the person during the day, the professional creates a relationship so significant as to make it

part of the sense of identity of the person, which in this finds resources for its own development.

Using himself / herself in the relationship as a significant point in the network of the person in trouble, the operator must elaborate individual and group projects aimed at increasing the quality of life, the maintenance of socio / relational / cultural aspects, and the development of the process of social growth.

His / her mandate is based on the protection of the rights of the person, on the recognition and on respect for his/her diversity, on the development of his/her potentialities, on the recognition of his/her desires and aspirations, and become operative through the educational relationship and inclusion in the network social.

FOLLOW UP MATERIAL

"So, the teacher and the person to be educated, equally free and critical men, learn while they work together and together they become aware of the situation in which they live. This builds a pedagogy that eliminates the authoritarian relationships ... "

P. Freire, "The Education as practice of freedom", 1977

The professional is therefore closely involved in the relationship with the person with the severe SD and although he/she is protected by his/her role, he/she is emotionally involved in it. For these reasons, the Model wants to "invite" the professional to work on himself/herself, to test his/her level of awareness in the educational action, to stimulate the project skills.

The professional have to know how to put him/herself in the educational relationship with:

- Authenticity,
- Consistency,
- Respect for the others and for his/her time,
- Suspension of judgment²³.

Above all, the professional must act with **emotional intelligence** and handle their emotions knowing that they are inevitably activated on a daily basis.

The Model requires great commitment from each professional in terms of time and attention, in the belief that such efforts will be rewarded by the results. These can be defined in terms of:

- increase of awareness,
- more care of himself/herself.

²³ C. Rogers, "The therapy centered on the client"

In fact, it is very important to devote time to himself/herself: this is usually identified with those moments in life different that are outside of work (relax, holidays, family care, sport, etc.), forgetting that the time dedicated to work is a life time, which must constantly be relocated within the existential dimension.

Devoting time to personal reflection, to seek and re-discovering the meaning of ones work and the existential dimension within it is good for oneself and therefore reflects in a good way on the relationship with the people for whose education they are responsible.

In order to support the reflection and self-evaluation process, the Model proposes two self-observation tools, which, asking the registration of meaningful events, permit the analysis of their personal emotions and of the educational acts developed. Each professional can choose the one that he/she feels as more appropriate to his/her own form of expression.

In fact, in any social service and/or educational work, numerous events can occur every day beyond the programmed activities and routine interventions, involving all protagonists (clients, professionals, people in charge, relatives) active or involved in the work. The ordinary or extraordinary character of an event can be determined either by the nature of the event itself or by

the system of interpretation and response that the service adopts, from the quality of the routine, the formal and informal rules.

In a service directed towards severely disabled persons the events could be very numerous. They can concern the unexpected and/or unintelligible actions of the users as:

- **the unexpected disappearance of an assisted person from the scene, with the consequent need to go looking for him or her;**
- **the refusal to participate in an activity;**
- **the precise execution of a task beyond the expectations;**
- **the refusal to eat;**
- **the intense expression of an emotion;**
- **a manifestation of solidarity...**

But also, some organizational aspects, which may influenced the behaviour of the users:

- **the proposal by professional of a new activity with a change in the plan,**
- **the decision not to carry out a planned activity.**

What might seem exceptional and incomprehensible in one context, can be considered routine in the service of people in

difficulty. At times, even too routine, in that we run the risk of “no longer noticing” these things, no longer trying to decipher them, ascribing them as “normal” attitudes of the person or as generic “crisis” situations or even as random behaviour. Here, more than in any other service activity, how one reads, interprets and confronts the various events depends unavoidably on the system of fundamental values and the framework of theoretical and methodological reference points that one gives to that specific activity of service. Equally important are the personal experiences of the professionals, their values and their level of awareness of their being in relationship with the service activity and with the persons to whom the service is directed.

THE 1ST SELF-OBSERVATION PROTOCOL

This Protocol seeks to offer 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.

A Professional is asked to accurately describe both the story of the event and the analysis. This "exercise" of accurate writing can bode well for the correct use of the instrument and the achievement of objectives:

- To reflect on the operational objectives and the action taken,
- To acquire knowledge about their vision of specific people with whom they have an active educational relationship (How do I see this person? What do I actually think about his/her skills, limitations, resources, feelings and emotions? Am I ready to accept the possibility of surprise - and then to change my vision - or am I too conditioned by the diagnosis?)
- To reflect on the quality of the educational relationship.

Sometimes he/she will start processing the protocol with a clear idea, with a certain view of what happened and, in the course of writing, this vision may change. As already mentioned the writing process encourages reflection. Therefore, a professional is asked to check the consistency rather than report, thus enhancing the process of thought: first, I was convinced of ... now I think...

Register used by the professional

Date _____

1. What happened?

Please describe in narrative form the event you consider particularly meaningful and interesting to analyse. Kindly describe the bare facts, reporting the actions of the various protagonists involved, including the professional as well, taking care to avoid every form of interpretation and personal judgment.

2. What did I feel? What do I feel?

Please describe the emotions aroused by the facts above (seeking to distinguish between the emotions felt at the time of the event and those it continues to arouse). Please try to

visualize and describe the eventual images the event provoked. [Please note that this distinction is very important when reflecting on their actions. The emotions you feel when a major event happens inevitably affect the means of intervention that is implemented. For example, if I were afraid that the person could get hurt, it is likely that my speech was focused on trying to avoid this possibility and perhaps I lost sight of other possibilities for intervention. If I felt irritated because the person had not complied with an established rule, I may have lost sight of the possibility of seeking - together with the same person - the reason for this behaviour, and so I did not considered the possibility or opportunity to make an exception, etc.

3. Which experiential reference points come to mind?

Does the event recall previous experiences? In what context? What emotions did it arouse then? Are there similarities? [The experiences that the event evokes can be both professional

and personal. If professional, they may include contexts and types of users completely different from today. Striving to make mental associations with different experiential situations is particularly useful as it allows you to get out of the mental cage determined by the daily routine of the service and to reflect on the inevitable stereotypes that it causes. Please describe briefly the emotions caused by a past experience and make a correlation with the emotion of the current event].

4. How do I evaluate this?

At this point, please make an evaluation of the event, of the motives that caused it, of the manner of action/reaction carried out by the professional and by the others involved. Please do not limit yourself to "explaining" the event with the characteristics of the person, for example with levels of

severity. You need to make a more extensive evaluation, including:

- If the event is a person's unusual behaviour: the reasons that may have caused it; personal reasons (his/her emotions, his/her feelings) or related to the context of the service (change of a program, the arrival of a new person)
- If it concerns a positive but unexpected result obtained by that person: ask yourself if this can be a demonstration of a previously undiscovered competence and why you had yet to discover it.

With regard to your intervention, try to understand if it was a matter of routine or if it was a new way of expressing your own manner of confronting reality. Try now to decipher in the same way the intervention of your colleagues.

5. What determines my evaluation?

The professional is asked to reflect on the theoretical reference points and the fundamental values considered to be guiding his or her judgment and to try to describe them. This is certainly the most complex part of the register and risks being neglected and resolved using standard responses or slogans (e.g. “the centrality of the person” as a value). Because the professional is being asked to make some reflections, this is to be elaborated: e.g. if he or she chooses C. Rogers as their theoretical reference regarding the “centrality of the person”, one then asks the professional to try and explain what this means, or how it might apply to the situation.

6. What have I learnt?

Please try to identify the lesson learnt from the event and from the analysis carried out.

THE 2ND SELF-OBSERVATION PROTOCOL

This tool has been developed following the testing of tool during the training itinerary and has some changes proposed by professionals. The protocol seeks to offer an instrument of self-observation and monitoring for the professional, useful for keeping under control one’s emotions, understanding them in order to reflect, learn from one’s errors as well as from one’s unexpected successes, fostering the 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. It is composed of two parts.

1ST PART: REGISTRATION OF MOMENTS OF EMOTIONAL INTENSITY

Protocol drafted by:

Record nr _____ Date: ___ / _____ / 20__

This form must be completed as soon as possible after a moment you consider of special emotional intensity in your

pedagogical relationship with the person with severe intellectual disabilities, for time can erase or modify nuances that may be important for the later analysis. When filling it in, let yourself lead by intuition, try not to seek justifications or arguments, you will do that when you analyse a sufficient number of records.

In the first question, try to describe briefly what happened, without forgetting important background information (what happened just before). Do not forget the facts - where it happened, what day of the week, what time, whether it was or was not a common activity for that day and time, who was involved, what were you doing, how did it start, develop and end. With regard to the rest of the questions, mark with an 'X' the answers that best fit what happened and what you felt.

1. What happened?

2. Which emotions/feelings did you identify in yourself

- Anger / Annoyance / Rage
- Fear

- Sadness
- Repugnance
- Joy
- Envy
- Guilt
- Shame
- Affection / Tenderness / Love
- Confusion
- Others:
.....

3. Do you think this feeling is particularly yours, because of the way you are, your character, or do you think it would generally happen to anyone in this situation?

- My own
- General

4. How do you value your reaction?

- Positively

Negatively

Neutrally

5. Your reaction has been, from a pedagogical point of view

...

Helpful

Harmful

Irrelevant

6. How have your feelings influenced on the usefulness or harmfulness of your reaction?

A lot

A little bit

Not at all, they have not influenced my reaction.

7. Which of these concepts best explain your feelings and reactions? (you may choose more than one option)

Homologation: conforming and matching the other to the idea that you already have, for example, the idea you have of people with disabilities.

Demonization: the other is very different and incomprehensible

Normalization: Strict enforcement of the rules that may hinder listening

Equidistance

8. What has influenced the situation and how?

My fear for professional failure (to feel questioned as a professional or in my work methods)

My fear for personal failure (to avoid rejection, to seek the approval of the other)

My lucidity (alleged assumption that 'I' am the one who knows)

The power and my ability to distribute it (to recognize a space for decision to the other)

My fatigue, discouragement and loss of confidence regarding the success of the educational or relational approach

My stiffness (resistance to change)

My concept of people with disabilities (in what measure does my performance reflect that I consider them equal in dignity and rights)

9. What do you think you should do with your feelings in this situation?

Express them

Suppress them

Something else:
.....

10. How did you feel as a professional?

Competent

Incompetent

Indifferent

11. How did you feel as a person?

Good

Bad

Indifferent

2ND PART: ANALYSIS OF THE EMOTIONS/FEELINGS IDENTIFIED IN THE PEDAGOGICAL RELATIONSHIP

Self-analysis of the recorded information on the forms nr.1 to nr. ___ of the “**Registration of moments of emotional intensity**” in the pedagogical relationship

Protocol drafted by: _____

During the period between

___ / ___ / 20__ and ___ / ___ / 20__

1. Which emotions/feelings repeat themselves in the recorded situations?

2. Did you consider them mainly because of your own personality or as emotions/feelings that arise logically to most people in that kind of circumstance?

3. Do you prefer to express or to repress your emotions/feelings? What does this tell you about yourself?

4. In general, how did you value your reactions? Positively, negatively or neutrally?

5. In general, how did you consider your reactions from a pedagogical point of view: as helpful, harmful or irrelevant?

6. Do you think that your feelings have had any influence on the helpfulness or harmfulness of your reactions?

7. Which concepts do you think explain better your feelings and reactions: Homologation, Demonization, Normalization or Equidistance?

8. Analyze your responses to the question 5 of the "Registration of Moments of Emotional Intensity". What elements are having more influence on your feelings? Should you work on any of them?

9. Does this analysis help you to identify aspects of your personality and to identify how it affects your competence as an "educator" of people with disabilities? If so, what aspects of your professional performance do you think you should change or improve?

10. Did you record more events that eventually gave you a good feeling or more events that gave you a bad feeling as a professional? And as a person? What does this tell you about what you are giving more importance to - perhaps arising situations of 'conflict' are more 'emotional' for you than 'celebration' or vice versa. Think about it. How do you live conflicts and celebrations in your professional and extra-professional life?

11. Which aspects of the personal relationship that involves the educational relationship, identified in this analysis do you think you should share with your own team?

5. THE APPLICATION OF THE PEDAGOGICAL MODEL INTO THE SERVICE

As explained in par 2.3, the main feasibility factors of the pedagogical model deal with the professional: he/she should have a meaningful relationship with the person and the responsibility of the educational project. It has been stressed in the same paragraph that the handbook is addressed to “the professional”, by also including in such a concept the whole team who works in the service.

Each professional can use this model for their personal growth, to improve their work and their relationship with people with severe disabilities.

However, it would be better if the Model were adopted by the organization / the service: one would then be certain that the intervention with people with a disability would be more incisive.

SUGGESTIONS FROM THE INV PROJECT

During the focus groups, it has come up that professionals share the importance of customize work programmes, as it is important to know the person in order to find out their strengths and weaknesses, and detect and promote their potential.

Some obstacles make it difficult, and these obstacles are the following:

- Institutional background: lack of enough human and material resources, and lack of time.
- Activities designed for groups that:
 - Do not allow personalizing the service and do let the professionals fall into the programmed routine.
 - Lack of time because of these activities for groups cover all the available time.
 - Mark and conduct their behaviour.
 - Outdated models and traditions, together with the resistance of the professional to change.

The remarks reported above do express the real difficulties daily experienced by professionals in their job and which can stymie both the effectiveness of the intervention and the educational relationship itself.

During a transnational meeting, the partners considered it opportune to point out that even the above mentioned services ought to respect at least three several fundamental elements that represent the minimal conditions for applying and sustaining the Model:

- The **continuity of the intervention** (thus, it can't be an episodic intervention a san information centre),
- Its placement in **non-marginalizing contexts**,

- Which allow for the **personalization** of the intervention (e.g. very large institutions are considered too big for this).

So that services for people with severe DS might carry out an educational, rather than assistance-based function, they must be characterized by several elements:

- the tasks are to be shared not divided,
- the knowledge and abilities of each person are not separate but integrated,
- one must act on a daily basis without losing sight of the temporal and evolutive dimension of the other,
- situations and occurrences are unforeseeable and so require a high level of improvisation.

The Pedagogical Model “The Essential is Invisible to the Eye” is aimed at providing responses to these needs, but it is fundamental that the professionals in service be adequately formed to assume it and make it their own and are supported in handling their emotions.

FOOD FOR THOUGHT

The testing of the self-observation protocol, within the INV project has highlighted problems faced by many professionals in recognizing and analysing their own emotions. Which, as shown in several recorded moments, have played an important role in the management of that event.

Surprise, fear, anger, astonishment: they are all emotions that - if acknowledged as belonging to them and possible - can be used positively, not only to manage a specific event or a specific situation, but also to provide everybody with their own "interior manual". The support (by the team, the supervisor or the trainer) regarding this "task" is important.

Another critical element has been the difficulty in distinguishing between "routine events" and meaningful events. A single meaningful event is not necessarily exceptional: its meaningfulness is given by the emotions related by the person, the professional or the team.

What has been said above recalls the feasibility factors of the model into the services:

- Real teamwork, with periodical meetings - on a regular basis - which allow debate and joint rethinking, planning work and verification of the results. Teamwork is also important in order to provide individuals with necessary support to face difficulties and to motivate them in the work of re-thinking and self-observation.

- Methodological supervision should detect and analyse professionals' emotions and thinking and lead them towards a shared and joint educational work, which should pursue objectives like the development and the promotion of the person with severe intellectual disabilities.

FOOD FOR THOUGHT

Here, more than in any other service activity, how one reads, interprets and confronts the various events depends unavoidably on the system of fundamental values and the framework of theoretical and methodological reference points that one gives to that specific activity of service. Equally important are the personal experiences of the professionals, their values and their level of awareness of their being in a relationship with the service activity and with the people to whom the service is directed.

- Training and updating should also be implemented on a regular basis in order to promote professionalization processes thanks to the sharing of educational issues, of languages and methods. Educational paths are crucial to motivate professionals to look for research and the deepening of their input.

- It is quite usual that organisations, which deal with services to the person, have financial difficulties. This fact often implies that neither team meetings nor supervision and (further) training are reimbursed or organised. Nevertheless, a yearlong planning could be useful in order to organise a schedule of the activities mentioned above at relatively low costs. They are fundamental working tools indeed, given the high involvement level, this kind of services require from professionals.

TEAM WORK

As far as teamwork is concerned, two main tools are proposed: a logbook and a record protocol of staff meetings.

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.**

It shares some similarities with the self-observation protocol - it asks for a description of significant events and to carry out a close examination of them. However, while the former is an individual tool whose essential contents can be put up for collegial reflection by the team, only if the individual professional so chooses, the Log is a collective instrument that has to remain available to all parties.

It ought to be compiled at the end of each shift, at least as far as the description of events is concerned; analysis can be carried out at other times without exceeding a week's lapse between entries.

Date __/__/____

1st part: Description. *Please describe in a thorough manner the events that occurred during the shift that you consider significant, taking care to indicate all the people involved. The account of "events" should not be only the unexpected or particular facts about the work of those who benefit from the service but also the launching of new projects/activities, changes in organization and routine, communications, etc.*

1. First significant event

2. second significant event

3. third significant event

2nd part: Analysis. Please describe for each event: the reactions of those involved, the results (or the consequences) of the event, the important elements to be discussed in the team meeting and the motives.

PROTOCOL OF THE MINUTES OF STAFF MEETINGS

For the meetings, the staff would have to use the Logbook as a basis for discussion.

It is important to keep track of staff meetings. What follows 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.

Kind of meeting
Date, start and final time
List of participants

List of absentees
Agenda
Issues dealt with
Decisions taken
Unsolved critical points
Open points and related
Data or information to be looked for
Agenda of the next meeting
Training needs which came up
Description of the climate of the working team and its cohesion level

All the minutes should be kept available for reference.

THE METHODOLOGICAL SUPERVISION

Supervision is aimed at providing support for a deepening process of the meaning of professional engagement, within a

specific context. It also represents a valuable tool for the homogeneous growth of professionals.

Taking into consideration the fundamental elements of the model proposed it is advisable to follow an itinerary that includes three dimensions: listening, careful collective consideration and training. It should also focus on the supervision which is mainly based on methods and contents, and supports new proposals as well as the improvement of operational actions and daily projects. However, in such an “environment”, disagreements might arise spontaneously but they would be contained within a guided itinerary.

The supervisor must be very familiar with the Model in order to ensure the role of “guide” to the same.

TRAINING

As has been done with the training course tested within the INV project, the proposal is to design paths coherent with a self-autopoietic conception of knowing that fosters namely the emergence of learning based on the knowledge already present in the subject.

Training, is therefore understood as a restructuring of ways of thinking and behaving, centred on the processes and contents

of experience by means of recourse to concrete situations. This takes into account that experience is a wealth but also entails a certain rigidity of mental attitudes and prejudices that create a resistance to learning and to the possibility of thinking in alternative ways.

Training paths should make the most of the professionals' competences understood as the mixture of **knowledge, skills, attitudes and **knowing how to get the person to do something**.**

Professionals involved in the services to the person should develop and strengthen solid relational skills, since their work requires:

- To be able to communicate and cooperate with one's own colleagues and with the organisation,
- To get into a relationship also with subjects which are external to the service (e.g. stakeholders).
- To be able to manage a significant educational relationship.

This is the reason why , regardless of the “content” of (further) training , the communication item , specially related to “be able to be” should play a central role.

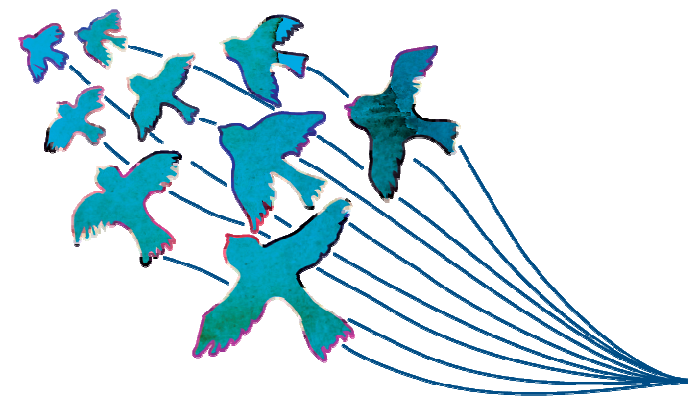
Of course, it is essential that the educators have the mastery of the Pedagogical Model.

From the methodological point of view, it is advisable to adopt the “*Participatory and Appreciative Action and Reflection*” (PAAR), which is based on the concept of appreciative approach. This perspective allows one to foresee a better future, starting from present positive aspects²⁴. It consists in a sort of reflective apprenticeship, which encourages a change of perspective and mental attitude: from a concern on what does not work (*deficit based discourses*) to one based on positive factors and potential (*strengths based conversations*). PAAR does activate appreciative intelligence of involved professionals, that is to say the ability to reshape the reality in which they are immersed towards a perspective of renewal and positive transformation of the meaning of the situations: consideration is a meta-competence that resides in anybody.

The methodology that starts from problems incites one to distinguish which remain closed within the problems themselves; from one side it refers to emotions like discomfort, suffering, frustration from the other side these are just of reactive, justifying and defensive kind. The appreciative

²⁴ Thatchenkery, Metzker “Appreciative Intelligence: seeing the Mighty in the Acorn”, Berrett- Koehler, San Francisco, 2006

methodology is aimed instead at incite reactions based on the perception of positive factors and inspires proactive consideration to growth and change. The ethical dimension intended here as the so called situational ethics, that's to say pragmatic, implies the design of guidelines linked to the outcomes of the actions. Thus, they are able to give dignity and legitimacy to choices and decisions taken in uncertain and contradictory situations, as it always happens in social practice.



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