Peer Counselling

From victims of history to protagonists of life

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From victims of history to protagonists of life

Defend the propriety of
your existence,
the only creative
propriety

Roberto Grimaldi

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Painting by Roberto Grimaldi

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PREFACE

WE ARE ALL IN THE SAME BOAT

Jerome Liss M. D.[1]

"We are all in the same boat". This sentence summarises the basic attitude in the world *of the "self-help" experiences.* When we share a problem with others because we have the same difficulties, we feel a warm reception, an understanding, and a support that goes beyond words. "The same boat" represents the difficulty we have in common and at the same time a communal way to solve it: *Sharing the injury and the pain with other people that know the same situation.*

The Self-Help Movement is vast. This book focalises on the problem of "Disability", and the authors, members of the *D.P.I. (Disabled Peoples' International) Italy Association,* have years of experience and competence in this field.
Here is a book that is worth your attention and, even your trust.

What are the components of this real international movement called the Self-Help Movement? In certain groups, for example, the shared problem emerges from recurrent situations of difficulty and discomfort, sometimes even of desperation: alcoholism, abuse of women, marginalized immigrants, elderly people in a condition of prolonged solitude, anorexia or bulimia patients, etc. Several groups face themes regarding death and illness: the parents of a child with leukaemia, women who underwent an operation for breast cancer, diabetes or *multiple* sclerosis patients, men that suffered their first stroke, etc. Also the social dilemma of unemployment, of "drop outs", of scholastic *mortality* or of the homeless can be a

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[1] Jerome Liss, psychiatrist and psychotherapist, Psychology professor at the Westdeutsche Akademie (Düsseldorf); founder and didactic director of the Italian Association of Biosystem; manager of the training of psychologists, counsellors and facilitators. He is also counsellor and trainer for the World Food Programme of the United Nations and WWF; he often teaches communication training courses for social change groups (Ecology, Peace, Non violence groups, etc.). He also wrote "La Comunicazione Ecologica" - Ed. La Meridiana - and "Insieme per Vincere L'Infelicità" - Ed. Franco Angeli.

starting point for a self-help group. In some other countries the traumatic experience of war, of violence, rape and the loss of an entire family can be the starting point.

The group experience does not eliminate the problem. But all emotions caused by a lacerating situation - shame, fear, confusion, anger and the loss of reference points - can be expressed in profundity and, what is more, receive a *deep* comprehension. And this is the point! Sharing cannot be *accomplished* in emptiness. Sharing, which heals wounds or at least diminishes the feeling of incapacity and impotence, *occurs* when the listening is empathic for a real reason: "They suffered the same thing". This attention is no charity. Every person who has suffered the same situation identifies himself with the others.
During this kind of listening to the others, the person who listens re-elaborates everything inside himself and produces reactions such as "I'm not the only one". "What a brave person". "The problem is real! But not everything is lost!" "I can find my dignity again, even if I don't fit in the stereotype of normality".

Peer Counselling opens the doors for people with disability. The individual shares his/her deep emotions. "*I feel ashamed when people see me in the street." "I can't go to the toilet alone". "How can I accept someone's help when I want to do things independently, but I can't?"* Also the dilemma of intimacy: "*Can I have a sex life?" "Is there anyone who wants to love me or even marry me?"* or *"Could I go to university and find a dignified job and consequently take on the responsibilities?"* I know some people with disability who were able to attend university thanks to a peer-counselling group, and their lives have achieved a noteworthy quality.

In conclusion, this book is not only for people who would like to exercise "Peer counselling," but for all the different Institutions that want to help people with disabilities: hospitals, clinics, rehabilitation centres, associations and schools. The politician who is interested in these issues will find the book an objective guide and a personal encouragement in order to support the independent living of people with *disability* with funds and projects.

And, last but not least, the individual himself who, by simply reading this book, will realise that there is no need to sink in solitude and depression. There is a way out. The same for his family and personal assistant, they will realise, by just reading some pages, that destiny is not something fixed. The human potential can rise again when there is a community that offers support and when dialogue embraces all *those involved*.

PREFACE

RIGHTS AND PROTAGONISTS, DISABLES AND ACTIVE CITIZENSHIP

Andrea Canevaro[2]

1. We must bitterly admit that one of the best successes of the Nazi government's implementation of the rules was the organisation of the elimination of disabled people and mental patients.The premise was rooted in the necessity to purify the German population, the "race", from "worthless life forms". To accomplish this, all means were justified. As Bauman says: "Depending on the circumstances it was called "elimination", "suppression", "evacuation" or "reduction" (read 'extermination'). On the 1st September 1939, Hitler ordered the creation of centres at Brandenburg, Hadamar, Sonnestein and Eichberg that masqueraded a double lie: in the low-voiced conversations of its experts they were called "institutes for euthanasia", while the vast public called them by another, even more, deceptive and misleading name of charity foundations for "institutional assistance" or "transport of ill people" or by an other insignificant codename "T4" (Tiergartenstrasse 4, in Berlin, the address of the office which coordinated the extermination)". (Z. Bauman, 1992, pp. 102-103). "Boulher and Brandt [nominated by Hitler] didn't meet any problems in gathering a group of doctors that had to carry out the mass euthanasia, but some of them, together with some officials, preferred to work under pseudonyms.Their job was to eliminate, in the *Heilanstalten* or German sanatoriums, 20 percent of the physically and mentally handicapped, and about 70.000 chronically ill that had been in hospital for five or more years." (A. J. Mayer, 1990, p. 395).
The sign T4 - hermetic and bureaucratic acronym - was the synonym of a supposedly necessary purification, which used a certain kind of cautious but efficient publicity. For example, some showed two persons, one sit-

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[2] Andrea Canevaro, Director of the Department of Education Science at the University of Bologna, teaches special Pedagogics, he is the author of numerous publications among which: "Educazione e handicappati" - La Nuova Italia, "Handicap e luoghi dell'educazione" - EIT "La relazione di aiuto" - Carrocci.

ting down in a position of complete abandonment, visibly incapable of thinking, clear from his lost look, flabby muscles and lack of energy; the other person stood upright, energetic, ready and powerfully built. The text that commented the image read: should we sacrifice a useful life for a useless one? Or other slogans having more or less the same meaning. The propagandised idea was that some lives were worthless; some people were parasites and could conveniently be eliminated because their survival would mean subtracting energy, resources and food to others - the worthy ones-. They were useless and harmful beings.

This is one of the episodes in human history - unfortunately not the only one - that saw the cancellation of the disabled people's right to life.

Between brackets, some people deduce from this episode an analogous catastrophe regarding the legalization of abortion. We do not share this opinion; we believe that there are substantial differences, and there is an area of research and uncertainty that is far from clear, however, even though we are against abortion, its legalisation has saved it from clandestine exercise and has reduced the number of abortions.

We wanted to explain this because very often this passage is quoted to suggest an analogy between these two radically different facts. The annulment of the rights of already existing people, grown up people, people who were isolated from their families, under the pretext of being cured better whereas they were actually killed, means that an extremely complex masquerade mechanism had been organised, in which the division of the work - and basically this is what Bauman speaks about-allowed a vast involvement of the population, each one with his own detailed task.

Let's give an example. One of the places where the so-called euthanasia, that is the suppression and extermination of disabled children, took place was the castle of Artheim, near Linz. The German name of this castle, which had previously been used as a nursing home in the past, was "Heilanstalten" or "place of well-being". However, it was transformed in a place of death, of extermination. In the castle of Artheim someone had the job of writing letters to the relatives giving a false cause of death. Others, the medical personnel, had made a long list of false causes of death and those that wrote the letters had to insert them in the standard letters, picking them from this list; once at the bottom of the list they started all over again, in this way different death causes were given to avoid that two families would receive the same letters. Someone also took care of sending home the ashes collected at random; the dates of the correspondence were falsified in such a way as to allow an automatic authorisation for cremation, normally the latter could only happen after a certain period, without the possibility of claiming the body only the ashes.

This artificial masquerade needed a meticulous organisation. What strikes most is the fragmentation of the jobs, which made every reaction or moral objection useless. By dividing the tasks everybody was a small and easy to replace wheel in an ever continuous process. This also created a vast involvement that could become complicity but also caused a rapidly spreading sense of guilt; this prevented accusations because being involved people preferred to keep silent.

Bauman interpreted the breaking up of tasks as an element of modernity, of complex organisation that can go beyond extermination, being structurally present in a society that allows, according to Bauman, the denial of rights by using processes that seem to be determined by the attitude of many people at the same time. According to us, it looks like the mechanism of a modern stoning, where every individual throws one or two stones without really causing death. The fragmentation of the organisation process renders the single individual not decisive for the whole process.

In modern times, the denial of rights can become one anonymous act made of a network of different actions performed by single persons and then put together. This is one of the interpretations we can give to the history of people with diversities and in particular those with disabilities. But we know that the Holocaust, a name imposed by the American mass media but not liked by many, did not only regard disabled people; it regarded Jews, a category that counted the most victims, it regarded gypsies, homosexuals and political dissidents and finally disabled people. In short, we are talking about diversity and when children are involved also their mothers and women in general are involved. In fact, the lack of rights for women precedes the denial of the rights of children, disabled and non.

2. In our most recent history, Lorenzo Milani gives us a good example of the relation between the growing awareness of active citizenship and laws. Talking about the respect for laws we have to mention Lorenzo Milani, in his book *L'obbedienza non è più una virtù* (1968) he talks about the conscientious objection against military service. He describes the awareness of the need to take laws seriously, even by transgressing them, in order to incite change and organization or to choose laws that are more rightful. We can find the same motive in *Lettera ad una professoressa* (1967) and in *Il dovere di non obbedire* (1965).

Lorenzo Milani's activity is always twofold: on the one hand there is the individual's respect for laws, inside society; on the other hand the commitment of the individual to obtain the necessary knowledge that allows him to make a responsible choice. The individual must respect the law or must notify or rebel against unfair laws, even if this means being punished, on the other hand, not rebelling means not being punished. We could say that the punishment of the conscientious objection against, the challenge of denouncing an unjust law is a way of showing that the citizen takes the law seriously, he doesn't rebel against the punishment received for his revolt against the unjust law, he doesn't flee, he doesn't want respect for his rebellion: he expects the law to change, which is something completely different.

Lorenzo Milani is an educator who is active in the development of linguistic and logic competences of youngsters, who, in order to make their way in life, shouldn't be respected for what they are but should be accepted and encouraged to avoid their isolation and their becoming outcasts. Loving them for what they are would mean leaving them in isolation, whereas thinking, presumptuously, that the love of an educator can save them from isolation might on the other hand create subordination to the same educator.

Rebellion against unjust laws is accompanied by a strict education that teaches the individual to grow and become an active citizen in a republic, or rather in a society that works for the common well-being. Republic not like res publica but like "common well-being". The respect for the common well-being requires an active, capable and competent citizen. Don Milani is a radical educator because he wishes that the boys, whose education he is responsible for, grow up and become competent, capable of using words and with words capable of using reason, i.e. linguistic structures linked to logic structures, going from capability to research: not only understand what is written but why something is written in a certain way in a newspaper and why the same fact is written in another very different way in another newspaper. It is important that they find a connection between facts instead of leaving them isolated, they should build a context to collocate simple information in. All this means growing up, taking on active responsibilities with respect to laws, being aware of the fact that one should follow them or modify them if they are unjust. Adapting the laws can't be the consequence of an injustice against a personal idea or wish; we need to think in social terms. Don Lorenzo Milani says that in front of a problem there are two possible attitudes: one is facing it and "solving it together", this is the political attitude. Then there is the individual attitude:"solving it alone is avarice".

3. We quote Don Milani because we consider him an important example and also because we believe that in the two words "rights" and "protagonists" there might be a trap. Rights should be built together, in full participation but the protagonist might get addicted to this role and this could severely hinder the construction of rights because he'd only think about his own rights. 'Protagonism' derives from an important word, which at the same time defines its expiring date. But one should be a key actor and remain a protagonist even off stage, or when you're not in front of a television camera.

Compared to the rights and the achievement of the active citizenship, people with disability have to face some risks and should work out some key points. We'd like to organise the risks and the key points knowing that we are by no means exhaustive; there will always be other risks to discover and to be wary of and other key points to discover to direct oneself.

We identified the following **risks**:

- **Protagonism**: as already mentioned above, the protagonist substitutes the active citizenship in order to put himself intentionally in a gaudy position, constantly at the centre of the attention, he doesn't give the others any space, he is intrusive. "Protagonism" is the exploitation of exhibited and utilised disability. We might also place it in the context of showbiz, sensation press and what it incites, it seems that in order to be someone, one should constantly be on stage if not one is easily forgotten. Referring to mass media and disability, the risk exists that disability is used to draw attention or to obtain permission, to make career, perhaps even a political one.
- **"Victimism"**: it is a bit of a distressing element because victims believe that their role of victims resolves some of their personal problems as for example: being assisted. We know how corrosive it is for people when catastrophes, wars or ecologic disasters happen for which they have to be helped by other people: the risk is that they become victims. Whole populations, as the single individual, can risk becoming victims. The same risk exists for the disabled person who mistakenly believes he

has special rights being a victim. On the contrary, with "victimism" these special rights may become a noose that tightens and getting out of it is dangerous.

- **Antagonism** among disabled people may also be a risk. The different categories of disability enter in antagonism to obtain resources for example.

- **Mistake strategies for objectives**: for example special route to obtain a house, a job, or reasoning according to proportion - for example in every sector there should be a certain percentage of disabled people - , not having to wait in line because one is disabled, one can skip the line and go directly to the counter. All this may seem right, but it looks like an objective whereas it is a strategy that allows a social life that omits this stage and allows the organisation of a society that doesn't need ambiguous short cuts for certain categories.

All these risks are related: they are linked to each other but they are also different. They let us envisage a certain quantity of elements that might reduce the good relationship between rights and protagonists, disabled people and active citizenship.

And let's have a look at the **key points to orientate oneself**:

- With best **practices** we intend good organisation for everybody. How many times do we have to reflect because the expression "best practices" is often mistaken for or thought to be the equivalent of good examples, good actions, and beautiful achievements. They do not refer to beautiful, exceptional accomplishments; they are good organisations. Sometimes one might also say: "We have gathered a great amount of best practices". The sentence doesn't make any sense because many best practices signifies many good exceptions; but with *many* good exceptions one can build *a* system of best practices meaning a good organisation. This is a key point in the organisation of the relation between rights and protagonists

- The **life project**. One needs to reflect on a project of life and one should not be satisfied with single situations but observe how they open the individual's prospect of having his life project. This century has revealed the need to consider the individual instead of favouring the mass. The individual is a social being and he needs his own project inside a wider, social context. His project must consider the others. A life project means a project of an individual that allows him to live without suffocating the others. In the same way the others should give space and opportunity to this project of life so that it can live and grow.

- The **competent dialogue** with different experts. This point recalls what we've already revealed and discussed regarding Don Milani: to reason and discuss with different experts means to prepare oneself, to reflect and not simply to bring forward one's plain need but to relate it to the need of the others. Competence is the individual's ability or need to reason for the others as well; wanting something useful for himself but also for the others, respecting priorities and not wanting to be on top of the list of things to do but realising that there are certain already existing priorities to respect. The competent dialogue with different experts is a clear and important point.
- **Representation without nepotism or "clientism"**. Representing a group of disabled people doesn't mean putting oneself in a position in order to obtain personal advantages- knowing and being in contact with those that have an institutional role or some kind of power. The system of "clientism" might cause the failure of this important role of representation, the meaning of its history and reception as well as the knowledge that the world has a multi-cultural development and the motivations of the disabled people must conjugate with this multi-cultural world, accepting the experiences of the others instead of thinking they already know what the others want to do. The others may be people from Senegal, Morocco, Mali or Pakistan; there are lots of people that want to understand and be understood. And a reference to Don Milani is more than relevant here.
- The **active and competent participation**. One should understand the dynamics of social and political life. Participation in social and political life is one of the noblest and highest ways of achieving the common well being, and this puts the relationships between rights and protagonists in the right order.

We have made a short list of risks and key points to orientate oneself. We believe that those who read this text have the possibility to continue and understand how important it is to live one's citizenship as a gift but also as a commitment. A commitment to understand how a complex organism, such as society, works, what the tasks of institutional bodies are, not basing one's life on charity but on duties and institutional rights.
More precisely, it means that one should not go to a certain person because he is nice, understanding and friendly towards a person with disability, even if he has a completely different job than the one he is consulted for, or because we prefer him to the person we should have

consulted in the first place but who is too severe, hard and incapable of listening. But this choice, humanly comprehensible, is one of the elements that create confusion as regards one's rights: here benevolence is confused with rights.

Benevolence is a beautiful word, we have nothing against it, but we should be careful not to confuse it. This noteworthy book will help us to understand that rights are also built with the full knowledge and respect of the rules or by refusing them, if we are willing to follow Don Milani's example.

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INTRODUCTION

The Peer Counselling Handbook "*From victims of history to protagonists of life*" is one of the final results of the project "Walking Roots - Methodologies and means against violence on women with disabilities"- Daphne programme 2004/2008 To Prevent and Combat Violence Against Children, Young People and Women and to Protect Victims and Groups at Risk n° 2004-2/094/W.
This project, which lasted for 12 months, found its roots in a network of issues that are of great importance for the Association D.P.I. (Disabled Peoples' International) Italia Onlus, namely: the protection of the Human Rights of people with disability; the multiple discrimination of women with disability and the Peer Counselling activity.

The Partners of the project are: D.P.I. (Disabled Peoples' International) Italia Onlus - Italy, D.P.I. Europe - United Kingdom, MEOSZ (National Federation of Disabled Persons' Associations) - Hungary, APD (Associaçao Portuguesa de Deficientes) - Portugal and CRIC (Centro Regionale d'Intervento per la Cooperazione) - Italy.

To promote the culture of disability, D.P.I. Italia Onlus starts from a concept according to which non discrimination and equal opportunities are the basis for the respect of the **Human Rights** of persons with disabilities. Each and every non justified, special treatment, every social and/or material disadvantage a disabled person has to face because his specific needs were not included in common policies and services, represent a violation of his Human Rights.
From this point of view, D.P.I. Italia Onlus dedicates a special attention to gender issues. Thanks to three projects, financed within the DAPHNE I programme, it examines the problem of multiple discrimination suffered by disabled women, as women and as disabled persons.
In claiming her rights, a disabled woman basically has to fight for two reasons: for her **visibility** within her living environment and for her **equal opportunities**. Thus D.P.I. Italia Onlus chose to carry out projects in which disabled women play a leading role both in designing and in carrying out these projects.
The following projects have already been carried out by D.P.I. Italia Onlus:

- *"Disabled Girls and Women - Victims of Violence - awareness raising campaign and call for action"* n° JAI/DAP/00/052/W, 2001, the project carried out a research on the different types of violence suffered by disabled women, namely psychological, physical (abuse, abortions, sterilisation) and sexual violence, violation of privacy in different contexts both institutional and not;
- *"Alba - new opportunities of care and support offered to women in contact with disability"* n° JAI/DAP/02/007/, 2002, the aim of this project was to let two female realities communicate, the reality of the disabled women, victims of violence and the reality of the mothers, possible victims and authors of violence in the relationship with their disabled children;
- *"I Care - disabled women and personal assistance against violence"* n° JAI/DAP/03/207/W, carried out between 2004 and 2005, the aim of this project was to analyse the relationship between the disabled woman and her personal assistant, two people, each of them with his own ideas, emotions, fantasies, values, expectations and experiences that meet during the personal care activities.

In its activity of cultural promotion, D.P.I. Italia Onlus tends to draw attention to disability as a common human diversity, but it also wants to favour the relationship of inter- independence and reciprocity, typical of everybody's growing process on various levels: human, civil, cultural, and environmental. In order to achieve this, it concentrates on disabled people as persons and on their empowerment process, through which they are "reinforced" in their abilities and possibilities in order to regain their personal resources and control over their lives.After analysing the necessity to develop empowerment processes, D.P.I. Italia Onlus structured a methodology and gave life to a new activity, namely the individual and/or group Peer Counselling.This is a method based on a help-relationship between two or more disabled persons that enables those, who want to start or strengthen their process of emancipation, to face fear and personal limits as well as objective problems, by identifying the most suitable solutions and attitudes in order to achieve their personal life projects.

Ever since we started the Peer Counselling activity, we have always unintentionally dealt with women. Looking around, in other Italian and non

Italian contexts, we noticed that this activity takes place and is developing in a predominantly female universe. This is certainly not a coincidence. The core elements of Peer Counselling - namely the central position of the inter-personal relationship, the sharing of experiences, the listening, the personal care, the special attention for the body and of imagination - mostly belong to women. Therefore we may say that there is a profound relationship between the female world and Peer Counselling.

These assumptions urged DPI Italy to write a Handbook on Peer Counselling, it was carried out by various authors and dedicated to women. The title itself *"From Victims of History to Protagonists of Life"* wants to transmit to its readers the desire and the determination of disabled women to get rid of their centuries-old reclusion and to activate a process of self awareness of what one really is and not of an identity made of acquired inabilities. This is why the text has been divided in three parts: the first regards a general contemplation on disability and explains the context in which this experience is integrated, giving particular attention to the Independent Living Philosophy and Movement; the second part illustrates the method and contents of Peer Counselling; the third part exemplifies some specific experiences: one regarding a service provision experimented on families in Italy and another regarding a Hungarian experience.

DPI Italia Onlus strongly believes in this book because it deems it to be an efficient instrument for people with disability and especially for women in order to break down the wall of silence around them, that sort of "transparent visibility" often ascribed to them by those that surround them.

PART ONE

CHAPTER 1.

FROM VICTIMS OF HISTORY TO PROTAGONISTS OF LIFE: AN ITINERARY FROM VARIOUS VOICES

> *From the depth of solitude, of separation woman draws the sense of her life's uniqueness: of the past, death, the passing of time. She experiences everything more intimately than man; she is interested in the adventures of her heart, her flesh, her spirit because she knows they represent her destiny on earth.*
>
> Simone de Beauvoir

It is commonly known that the development and behaviour of every human being are the result of a complex interaction *between genetic and environmental factors,* aspects that are indissolubly correlated.

The confusion between the fundamental concepts of "nature" and "culture" *(genetic heredity vs. learning from the environment)* has always been central in every historical era and still inflames the dominant ideas. This confusion is not only part of an academic research but also has a significant impact on the real and concrete lives of people: policies, actions and decisions are the result of the conviction, matured throughout time and history, that owing to their biological features some people are superior and others inferior.

In fact, there have been episodes where the "nature" of some individuals, as for example of women and disabled people, were considered as a "cultural" condition of inferiority and marginalization within to their society. Due to this confusion between "nature" and "culture", the condition of discrimination, exclusion and segregation to which disabled people have been condemned, and the condition of subordination in which women have been exiled, have been considered as an almost natural, indisputable and unchangeable fact.

During the second half of the 20th century, women and disabled persons with disability have given birth to two of the most important social, political cultural and intellectual movements in history. The feminist movement and the disabled people's movement, each in different ways and times, endeavoured to show that the natural condition of people is not a choice and that it is possible to build a "culture" capable of including and embracing all that is different, considering it as something that enriches.

A new society and culture can be built only by recognising the differences, even the slightest ones, as essential and integral parts of their structure and not as wild fragments one has to destroy because they are dangerous and de-stabilizing for the system. A different culture is built by eliminating the dichotomies, typical of our society, between body and mind, animal and human, primitive and civilised, normal and abnormal, disabled and non-disabled, etc.

The two movements dealt with extremely significant and relevant issues for all individuals and for the entire society: they invited and continue to invite everyone to question him/herself on his/her identity, body, emotions and sexuality.

By pushing people to delve deeper into these issues, until now ignored and neglected, the two movements, in different times and ways, encouraged a real "awareness revolution", determined to make these people question themselves seriously about their existence and about their "more responsible belonging to" society. "Freedom and possibility of choice become qualities of a person who is capable and conscious: capable of entering in relation with *the other*; conscious of opening himself towards meeting and dialogue"[3].

The two movements have been fighting and are still fighting, in a broad and general sense, to obtain equality, justice and emancipation of all people in every culture and community of the world. The acquisition of this new feeling is the basis for a global cultural, political, social and economic transformation.

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[3] A. N. Donnarumma, *Guardando il mondo con occhi di donna,* EMI, Bologna 1998, p. 183

1.1 The Feminist Movement

The feminist Movement made its first appearance in the 18th century and rapidly spread in Europe and in the USA. Its goal was to achieve political, social, economic and juridical equality between men and women and to create a new protagonism of the latter, deeply influencing the culture and customs of the Western society. Its diffusion undermined the dominant culture that considered women as less strong and less intelligent than men, giving them a social marginal role, entirely related to the care of the family and children. Thanks to the feminist movement, women, as protagonists and without delegating anybody, started a fight to guarantee their right to education, employment, and vote and to obtain equal rights inside the family.

The development of the feminist movement was closely linked to political, economic and cultural changes. Inspired by the reform movements of the end of the 18th century and the beginning of the 19th century, women started to denounce the strong discrimination that victimised them in their society and at the same time they started to claim gender equality, imploring the universal extension of the rights to freedom, equality and fraternity without preclusion of gender. Even though they fought in the frontline in all the 20th century revolts, women still have to go a long way to achieve social, political and economic equality.

The enormous changes that took place in the Western society in the sixties strengthened the feminist movement. Women didn't only claim equality between the sexes but they strongly asserted the uniqueness of the female identity. In this phase, the feminist movement brought into question the social institutions and the prevailing values, denouncing the discrimination that women often underwent in every field of life: family, education, employment, sexuality, etc. and opened the door to the confirmation of their identity and freedom. Starting from a conscientious reflection on how collective, cultural and social models determine and condition our identity, the aim of the feminist movement is no longer emancipation, but the liberation of women, putting the "difference" between men and women in the first place. What is discussed is not the objective anatomic difference between men and women but the cultural difference, the social position of power and the social relationships men and women are placed in on grounds of "gender difference". The gender equality issue has become fundamental and the theory according to which biological facts determine a person's fate and opportunities are distributed according to one's gender has been rejected.

Women accomplished a long process that has opened new ways of understanding and started a new feeling, though society is not always aware of it. In fact, "in modern times, the political scene has been built without female representatives, even if women take active part in it. Their contribution, of a clearly political character, even if carried out within the microcosm of their private lives, has never been singled out as a pretext to reflect on the political meaning of gender reality".[4]

Lots of things have changed and improved. Compared to the past, women are less discriminated today and their quality of life has definitely improved, but this is not true for everybody. Although, in the last decades, in most countries of the world, women have obtained the formal recognition of a lot of rights, many of them still haven't obtained social, economic and political equality. We shouldn't forget, in fact, that the world is not only made of rich industrialised countries. Physical and psychological violence, sexual abuse and discrimination of women are quite common in almost all developing countries. Women, constantly, have limited access to essential medical care, to contraceptive methods and care during pregnancy. Furthermore, women are and will always be easy victims of malnutrition and sexually transmitted diseases, commonly ignored by most of the Institutions in these countries because of prejudice. The high death rate of women is certainly due to the difficult conditions women live in but also because, in some countries, gender selection is still practiced: baby girls are still eliminated by means of abortion and infanticide. Even in the so-called "civilised" countries, situations in which women get less information compared to men and have less control over decision-making processes and family resources are not uncommon. In short, the situation in which women find themselves is almost always unfavourable and often linked to the economic value given to their roles inside the family. They are trapped in a vicious circle of insufficient or total lack of education, inadequate nutrition, precocious and frequent pregnancies, poor health and poverty.

Scientists speak about the "feminisation of poverty" because on the international level as much as 70% of the poor are women. Whereas, until some decades ago, the poverty of women remained hidden inside the

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[4] Ivi, p. 222

families, increasing their dependence, today it has become more and more visible because very often the network of family protection is absent: instability of conjugal relationships, widowhood due to the longevity of women compared to men, women that live alone or support their children. They become increasingly poorer mainly because they continue to be included in the labour market according to penalising procedures dictated by the obsolete and unrealistic logic that considers the income of women as secondary inside the family.

In Western society it is difficult to find examples of explicit exclusion of women from participating. But nevertheless, a woman, even if she has become an astronaut, may continue to undergo, in her private life, a condition of inequality, she may be ill-treated, suffer from deeply rooted uncertainties or a sense of inadequacy regarding her womanhood. Family influence, psychological and cultural pressures are equally extremely efficient in excluding her from social relationships, pushing her to isolate herself inside her house and limiting the possibility of her social and political participation and cultural growth. The difficulty lays not so much in achieving something but in being free in one's condition.

According to us, talking about gender issues is something more than just requesting a place for women in political, juridical and social institutions. In fact, it means discussing gender thoroughly as part of our identity, of our fantasy, of our unconsciousness, of what we are and of how we see ourselves in the world. Therefore, adopting the gender point of view means dealing with the difference between what men and women do and the way in which their socially defined roles favour or damage them. In this way, the aim is not to research and take action for the "public" person but above all, reflect on the individual identity behind all this. It means understanding the value of the female presence in history, recognising the civilisation activity they have been carrying out throughout centuries thanks to their specific sensibility; it means enhancing the value of the diversity of female thinking, in its various expressions, because it looks upon life from a new and richer point of view; it means recognising their "creative difference".

Women have come a long way and it has taken more than fifty years, since the Universal Declaration of Human Rights, to achieve the clear affirmation that "The Human Rights of women and children are an unalienable, integrative and undividable part of the Universal Human Rights. The complete and equal participation of women in political, civil, econo-

mic, social and cultural life on a national, regional and international level and the abolition of any kind of sexual discrimination are the priority goals of the international community".[5]
In 1946, the UN started a process in favour of women, with the creation of the Commission for the Juridical and Social Condition of Women, it was accomplished in different phases: the Convention on the Abolition of the Illegal trafficking of People and of Prostitution Exploitation (1949); the Convention on Women's Political Rights (1951); the Declaration on the Protection of Women and Children in case of Emergency and Armed Conflict (1974); the International Year of Women in 1975, on this occasion The First International Conference of Women was organised in Mexico City; The Declaration on the Elimination of any kind of Discrimination against Women (1979); The second International Conference of Women in Copenhagen (1980); the Third International Conference of Women in Nairobi (1985); The second International Conference on Human Rights in Vienna (1993); The Declaration on Violence against Women (1993).
This fifty year enterprise of the UN came to a close with the organisation of the Fourth International Conference of Women in Peking in 1995. This Conference was an important stage in a long process that started from the silence of women and their passive acceptation of oppression and evolved into their denouncement and struggle, their projects and organisation, solidarity between South and North, West and East. The Declaration and the Action programme, drafted on this occasion, engaged all the participating Governments to undertake actions and policies in order to guarantee gender prospect by means of instruments such as gender approach, mainstreaming and empowerment to achieve a concrete improvement of the condition of women in the world.

The commitment has been time-consuming and difficult but the principles of equality and of non-discrimination, pursued and confirmed by women, are at the base of all International Documents on Human Rights. With their observations and hard work, women emphasize the need to let the process of equality and difference coincide, showing thus that the fundamental freedoms and the principle of self determination are interwoven in every aspect of human life.
"All human beings are born free and equal in dignity and rights"[6]. Can we

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[5] Declaration and Action Programme of Vienna, Part I, Par. 18

[6] Universal Declaration of the Human Rights, adopted by the General Assembly of the United Nations, 10th December 1948

say, today, that this is true for all the women in the world? We don't think so, considering the enormous gap between men and women, particularly referring to the presence of women on the top levels of decision making positions, both socio-economic and political.

1.2 The Movement of people with disability

If the history of women is made of discriminations tailored on the social, economic and political system, the history of people with disability is made of invisibility as well.

Throughout centuries the image of people with disabilities has taken on different meanings that reveal the cultural and social values of the correspondent eras. In the collective image, the mental representation of disability has undergone the effects of the input of these values, namely those of a culture within a certain historical period, which, each time, give way to certain attitudes.

Even the most enlightened minds of ancient times confirmed these positions: Plato, when he imagined his "Ideal City" suggested to accept only the children of the finest women and men and to lock away deformed children in a dark, separate place with the plain intention to let them die as soon as possible; Aristotle suggested to legitimise infanticide by issuing a law that prohibited the upbringing of disabled children; and later on, Cicero confirmed that a deformed baby, *monstrum*, had to be killed immediately at birth, as was clearly authorized by the Roman Law that only considered an individual as a person when it had a human aspect, meaning only when it was not *contra formam umani generis*.

While in Babylonia the birth of a disabled child was believed to be an omen of the kingdom's bad luck and dire economic growth, in Greece the idea according to which only the *kalos,* i.e. a healthy and handsome man, could be *agathos, g*ood, was widely diffused and consequently every illness was considered as something immoral. Therefore, no one was surprised when Licurgus imposed certain rules on Sparta: a governmental commission had to examine babies: the disabled ones were thrown into the Taigeto and the others had to sleep outside, even in winter, so that only the strong ones survived.

In some historical periods an attitude of reverence for people with disability prevailed: these "abnormal" people were considered as mediators between "normal" man and supernatural powers. In other epochs the person with disability, subject of curiosity and interest, was identified with his "illness" and "deformity", which were signs of sin and of his rightful expiation: physical deformations were expressions of a negative karma accumulated in a previous life; a drunkard might have fathered abnormal children, with a deviant behaviour and physically deformed; practicing a less conventional form of sexuality may also generate malformed children.

Things didn't change in the Middle Ages and neither did they in the Modern Age, most of the time disabled children were eliminated at birth and in case they survived they lead a life that was anything but human. Paradoxically, the most fortunate were perhaps those that were severely deformed and exhibited as monsters at village fairs.

With the expansion of industrialisation and the affirmation of the values expressed by the upcoming middle class, the model of "a normal person" had to coincide with that of the citizen and producer. "Diversity (biological and none) met a strong culture of normalisation".[7]

Also the development of sciences as medicine, biology, genetics, psychiatry and also the discovery of physics and chemistry contributed to this, they added a lot to the understanding of man and his health condition.

In this period an ever-increasing number of institutions popped up. They were the answer to the demand of treatment and normalisation and became more and more self-sufficient and excluding: orphanages, institutions and lunatic asylums. This started the culture of segregation in separate places to cope with the difficulties of the disabled people, which still exist today.

Progress, mainly achieved thanks to genetics, started to give noteworthy answers to the questions of modern man, who finally became aware of his raison d'être and of the quality of his life. However, the progress in knowledge didn't resolve anything at all for the disabled people; on the contrary, genetics presented other, more serious, dangers than the ones they had already suffered in the ignorant past. The 20th century started to accept the elimination of life forms that were considered unworthy with justifications as: the suffering disabled people caused for their relatives and the economic cost of their care for the State. Subsequently, a eugenetics attitude towards them expanded, which was materialised in the aberrant "Aktion T4" operation, a real euthanasia project worked out by

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[7] M.Zanobini, M.C.Usai, *Psicologia dell'handicap e della riabilitazione*, ed. Franco Angeli, Milan 1995, p.259

the Nazi regime to eliminate people with physical and mental disabilities that represented a threat to the Arian race.

In the same period Scandinavian countries issued laws that were not so different from the Nazi ones. Their aim was not the physical elimination of the people, or their persecution, but rather the improvement of the population's genetic quality, by means of more or less forced sterilisation of tens of thousands of people. In the United States as well, up till 1949, 50.000 sterilisations were carried out.

In the recent past, the disabled person was still identified with his pathology, and the overriding concern was to cure it. Practically, he was treated as an "object" to be repaired and restored to precise standards of functioning; a broken object, without decision-making ability, without existential priorities other than those of adapting himself, as soon as possible, to the cliché of normality. *"First we'll cure him and if the treatment doesn't give any positive results we'll put him in a separate and segregating place to continue the cure"*. The person's will or desire to take part in this perverse game wasn't even taken in consideration. In short, the difficulties of integration and the lack of equal opportunities were attributed to the psychophysical condition and health state of the disabled people. Disabled people were therefore humiliated in their resources, limited in their Human and Civil Rights and cancelled from ordinary social life.

The fight for emancipation first and later for freedom implies a personal engagement that involves an awareness of being a person and citizen with rights and duties. It implies the formation of an identity, also as the outcome of the interaction with one's living environment and with society in general. It also implies a membership, being part of, even in a situation of exclusion and isolation. If we examine the individual and collective history of people with disability we realise that for a long time in human history they weren't even aware of this condition. The birth of the movement was the result of their growing awareness that they didn't have the same rights as all the other members of society, that within themselves they had the means to fight, creating alliances with others, that they wanted to get their hands on the instruments, necessary to achieve their social, political, cultural and economic goals and build a more receptive community. But the birth of a movement is, first of all, the awareness of being people with full rights, of being there, of existing and of finding the strength and courage to pronounce it in a loud voice. However, we also have to note that when an individual is not esteemed by his own family, by his community and by society in general, he can't even dream of having a living condition different from the one he is living.

Centuries of segregation and invisibility were hard to break down. Only by the end of the sixties the movement of people with disability had its breakthrough, overwhelmed by the social, cultural and political changes of that period. The awareness of being a citizen with equal rights moved them to unite themselves in order to emancipate from the degrading condition they had been condemned to for ages.

The turning point took place at the end of the seventies when a new approach towards disability came to life and the concept of disability was internationally accepted as a Human Rights' issue. From this moment on, the political and civil rights of people with disability have been recognised, as well as the need to adopt all the necessary measures that allow them to live their lives completely. So, their right to social and economic security, to employment, to live with their families, to participate in social and cultural life, to be protected from every form of exploitation, abuse or degrading condition, were finally recognised.

Today the people with disability are aware of being an integral part of society, even if many still consider them as an eyesore, a burden to be eliminated, and a defect to be hidden. The motto "Nothing about us without us", adopted by the movement of the people with disability in 2003, the European Year of disability, wanted to highlight that the final aim is to reach their full participation and equal opportunities, it is also a memorandum to make everybody aware of their need of physical and social "access". With this motto they want to underline that people with disability are AMONG us and WITH US, and that we can't deny their existence, their right to be a person in every sense, their right to participate in the active and social community life, even if some, not recognising their diversity and their uniqueness, still consider them as different from themselves, to be hidden, to be denied and to be isolated in the darkest corners of their personal fears.

Despite the cultural, social and political changes of the last years, attitudes of contempt and antipathy often assail the world of disability. This is conditioned by the culture we live in, which tends to consider beauty and physical strength, rather than intelligence, as absolute values. In order to reach these absurd, almost paradoxical standards, people that do not match these criteria are marginalised. So, what happens to a disabled person? What happens to a woman or a man who needs specific attention or adequate structures so that he can move around freely, so that he can participate in a social context made of window-shopping, going to the cinema, going to the pub, and doing the shopping in a supermarket? We absolutely must give you, here and now, an answer to all this. Let's try.

These discriminating attitudes and ways of behaving are determined by the notorious, negative image of disability, which lead to the building of separate places in which all people, that do not match the standards established by prejudice, are locked away.
The movement of the people with disability encourages people to observe things from the point of view of disability, in fact, from this diverse angle one realises that it is the environment that disables people and that produces discrimination. The inaccessible physical and social environment gives the people with disability a sense of inferiority; even those that have reached an excellent level of awareness of their limited choices and of their dependence feel humiliated each time they have to ask for help. It is therefore important that society sets in motion inclusion processes, because this would entail a collective awareness: if man is responsible of building a restrictive environment, he is also capable of building a free and liberating environment for everybody. Nobody chooses or wants to be disabled, but a lot of people have learnt to accept and live with their disability. These people enrich the lives of all the others because they disclose a new perspective from where to start the creation of a society based on models of inclusion, acceptance and respect for diversity.

Like the Feminist Movement, the Disabled People's Movement has achieved some important objectives in the last few years: The International Year of Disabled People, in 1981 and the Standard Rules of the Equal Opportunities of Disabled People, adopted by the UN in 1993. But the most important conquest will surely be the implementation of the "Convention for the Protection and the Promotion of the Rights and Dignity of People with Disability", currently discussed by the UN.
In these documents, as well as in others, it is confirmed that principles such as equality, self-determination, fundamental freedom, independent living, non-discrimination, social inclusion and mainstreaming, indisputably belong to people with disability because they are individuals and citizens as all the others. Although these are important and positive results

we shouldn't forget that the citizenship and active participation of disabled people largely remain an empty promise. For this reason it is absolutely important that the movement of people with disability doesn't slacken its attention and its endeavours to obtain the promotion of the Human Rights and equal opportunities of the people with disabilities. All over the world many of them still suffer serious discriminations, extreme poverty, abuse and exclusion.

1.3 Women with disability

The feminist movement and the disabled people's movement have definitely shown that the Human Rights are unalienable and universal rights of all human beings and that in no case and in no place they depend on the laws of single States, but on their belonging to the human race, composed of women and men, physically different and with a different identities, but equal in their natural rights.

Even though they share the same conditions and objectives, these two political and cultural entities have never really met on their long and intense journey towards emancipation.

Thermometer of this failed creative involvement is the veil of invisibility with which both movements have covered disabled women, their connecting link that could have created, within different cultural and social contexts, a major awareness of how the physical, sexual, and emotional diversity of every individual should be included and not only tolerated: freedom and inclusion of every individual is the natural meter of the freedom of the whole universe.

Inside the movement of people with disability, gender has been regarded as something irrelevant, the same has happened to the social dimension, the class dimension, the ethnic dimension and the dimension of sexual orientation. Disability is considered as a unitary concept that overshadows all the other dimensions. The current approach shows a tendency to hide the gender factor when examining the lives of people with disability and overlooks the influence gender has on them. In short the movement of people with disability still hasn't recognised the multiple discrimination of disabled women, determined by the combination of gender and disability and this has lead to a lack of interest in designing activities and programmes, actions and policies aimed to fulfil the specific needs of the latter.

It seems as if women with disability were not involved or regarded at all when women radically brought into discussion the age-old predominance of men over women, which turned the symbolic order of non equality between men and women upside down and which rightly condemned abuses and violations inflicted on women.

The feminist thinking continues to ignore and exclude disabled women. Women joined men, with or without disability, banishing women with disability to a level that is inferior to their intellectual and political capability. The keenness to diffuse an image of strong, powerful, capable and attractive women is one of the reasons why disabled women have been excluded from the feminist movement; in fact, their image of defenceless, sexless, dependent, needy and passive beings only reinforces the traditional stereotypical image of women. One has always regarded the disabled woman as inappropriate for the traditional roles of mother, wife, housewife and lover and she is also considered unsuitable for the new roles of society where the myth of productivity and appearance dominate.

To understand the multiple discrimination of disabled women better, we will examine the three main aspects of life in which we will compare their condition with those of other women and those of disabled men, namely: affection, education and employment.

Affection

This field is linked to the sphere of femininity and sexuality.

When a baby girl is born, her parents, especially her mother, have already made a life project for her, even if unconsciously. This project is a script that has been repeating itself for ages: she grows up, goes to school, has friends, becomes a woman, gets engaged, gets married and has children, etc.

When a disabled baby girl is born there is no such plan and while growing up she develops a strong relationship of dependence with her mother. This exclusive limitation to the mother figure risks to generate a return-to-the-womb behaviour and the disabled girl will always remain a “mamma’s girl”, and consequently as a grown up she will lack any form of sexuality. The sexual dimension, basically a taboo in disability, is not recognised at all, the maternal language doesn’t even name it! The disabled girl, once she has become a woman, can’t identify herself with the maternal body that denies her daughter’s sexuality but at the same time lives her own sexuality through its generative ability. All this strongly hinders the disabled woman in developing her female gender identity.

Normally, the others identify a woman as a woman, first her mother, then her father and later her partner, in this way she can define her own identity.

As sexless beings, women with disability hardly ever get any information about sex and birth control. They suffer much more sexual violence and abuses than other women. They undergo abuses and sexual violence in every living context but for those that live in institutions the risk is much higher. Notwithstanding this, the collective image thinks they lack any sexual interest. How can this be? The answer is simple and cruel at the same time: abuse and sexual violence are more a matter of oppressive use of power than a matter of sex and desire. The oppressive power is mostly exercised on vulnerable individuals and their vulnerability increases when they live in conditions of isolation, exclusion, segregation and dependence. Women with disability, the most vulnerable among the vulnerable, are an easy prey for assaulters and jailers.

If the right to sexuality and respect of the body are the hobbyhorse of the feminist movement this is not so for disabled people and particularly not for disabled women who demand that the right to sexuality will become a political problem like the right to accessibility, transport, etc.

To realize one's emotional dimension one also has to go through the stages of being a wife and a mother. These roles are difficult to accomplish for disabled women, whereas they are hardly desirable for women in general because they are not considered as the best meter of social success. Disabled women marry less or later than other women or compared to disabled men. A disabled woman is more likely to be abandoned by her husband if disability is contracted after marrying, while this rarely happens when the husband becomes disabled.

A lot of women are trapped in difficult and abusive relationships because of the precarious financial state in which they are forced to live; this is even more the tragic case of disabled women because their only alternative might be an institute. Moreover, for many of them this hard and difficult relationship is the only one they have ever had in their lives, so for many it's better to have an abusive relationship than no relationship at all.

As far as being a mother is concerned, the disabled woman has always been considered as dependent and needy of care, and this makes it difficult for many people to imagine her as a mother. It is a very common and diffused opinion that she can't and shouldn't have any children; doctors, the social environment and her family hardly ever encourage her to make this choice. It is also very difficult to get information and services that could help out with her specific needs. So when she becomes a mother, she may have to face difficulties in asking for child-care provisions, normally provided without taking into consideration her accessibility needs and in case of divorce she is more likely to loose the custody over her children.

To all this, one has to add society's fear, most of the time unjustified, that a disabled woman might bring disabled children into this world.This fear has caused harsh discrimination and violence and has legitimised sterilisation practices, selective abortion and infanticide.

Education

Access to education will always be and remain a serious problem for people with disability. Traditionally children with disability were put in special and segregate schools or in separate classes inside ordinary schools and their instruction was largely inferior compared to that of other children. In this context of segregation, girls and disabled women receive less schooling due to the stereotypical opinion that considers both women and disabled people as dependent, emotionally unstable and needy of care and therefore it is not only difficult to educate them but is also a waste of time. But even if women have conquered a significant place in this field and today can easily attend university courses that prepare them to become as professional as men in every field of knowledge, this is not the case of disabled women who are still directed towards certain training choices that lead to subordinate positions and roles in the labour market and consequently to less paid jobs.

Employment

Inclusion in the labour market still implies a lot of problems for women with disability, who when entering the job world lack the necessary competences due to their discriminatory training. To this we must also add the prejudice of the working world towards people with disability and women in general, considered as failures, as passive and dependent individuals. The lack of job opportunities and financial possibilities is typical for women with disability, exposed to higher risks of financial poverty and lack of social relationships.

As you can see, people with disability and women must face a lot of obstacles in their fight for equal opportunities and they continue to endure serious discriminations. But the double discrimination, of gender and disability, experienced by women with disability show how they have been ignored both by the movement of the people with disability and by the feminist movement.

Only in the last decade there have been serious efforts to identify and understand the forces that mould their lives. These attempts mainly concentrated on how the condition of being a woman and having a disability might interact, and on how women with disability see and experience their lives. But today they still belong to the most vulnerable; the most isolated and most discriminated groups of society. It is therefore necessary to develop a major understanding of their lives so as to remove the remaining obstacles in order to obtain their complete inclusion and participation and to guarantee their equal opportunities, their total freedom and their right to self-determination.

All people should understand that an attentive society, which is capable of embracing instead of isolating, capable of offering instead of taking away, is a better society. The world we live in should be a world for everybody and not for the happy few. As long as a world hides what it doesn't like, as long as people are afraid of what is different, this planet will remain a small isolated dot in this immense universe in which some solitary Ulysses will loose his way looking for the constellation of Cassiopeia or the star of Aldebaran.

Because the universe is a whole… and everybody should be part of it so it can continue to exist!

CHAPTER 2.

HUMAN RIGHTS AND PEOPLE WITH DISABILITIES

> *Man's importance is measured by what he is looking for and on the persistence with which he continues his search.*
>
> Martin Heidegger

2.1 Disability within the Human Rights' context

The deep transformations the world has been going through during the last twenty years have produced some real economic, political and cultural earthquakes. The economic life of each of us has changed, as has the eco-system balance of our planet, the forms of information and communication, the international political powers, and the weight of the financial multinationals. We can go on and on with this long list, which risks to increase and grow faster significantly in the future. Speed, economy and new technologies seem to be the new imperatives of the beginning of this century. Fortunately, parallel to these values other values have been added that contrast them at the roots because instead of starting from the external needs of the human beings (the market, the economical development, the war arsenal), they start from the latter as the essential basis to attain a general re-definition of this society.

The culture of the Human Rights, developed at the end of the Second World War and written down in the Universal Declaration of the Human Rights, adopted by the UN in 1948, has progressively become the paradigm on which the framework of relationships among human beings, people and States should be built. This new way of thinking that, by now, permeates all international treaties that make up the juridical foundation both of the national laws and jurisprudence as well as the regional legal instruments, is becoming, day by day, the concrete basis to evaluate and control the policies and institutional systems, while respecting the individual freedom and the development of the rights of the individual.

The international movement of people with disability based itself on this model when it created a new cultural image of its condition. This cultural image is no longer based on the medical model, which considers disability as a disablement, underlining its tragic aspect, but rather on the social model that enhances the value of the human diversity of race, gender, sexual orientation, of culture, language and of psycho-physical condition.

The social model introduces a new idea into the debate on disability and on the social and political action strategies, namely that, the disadvantage attributed to disability depends on a social factor and no longer on a physical or mental disablement. For this reason, this condition does not derive from the personal qualities of the individual, but rather from the relationship between the characteristics of the individuals and the ways in which society organises his access to and his use of rights, goods and services. So a person has a disability not because he uses a wheelchair, communicates through labial language or uses a guide dog but because buildings have stairs, because prejudice dictates that a person can only communicate through oral language and can only orientate himself through his eyes.

The result of this Copernican revolution has been the growing awareness of the fact that people with disability are discriminated and have no equal opportunities, that they suffer continuous violations of their Human Rights. In fact, in a society where technological applications make buses, trains and ships accessible and computer technologies allow blind people to read and deaf people to hear- only think of the vocal synthesis or the text display of a computer-, in a society where people with disability can go to normal schools and do their jobs, every diverse treatment cannot be justified, every segregation in an institution (a recent research estimates that in the European Union about 500.000 persons with disability live segregated in 2.500 big institutions) or in protected working places, every web site that doesn't respect the rules of accessibility[8], every bus without adequate support for those that can't walk, can't see and can't hear, represents a violation of the Human Rights.

The main goal of the social model is not so much to defend the person

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[8] *Web Access Iniziative* (WAI)

with disability but to create services that break down the social and environmental barriers, so that a full social, physical and work participation is made possible for all people. For that reason, the social model tends to emphasize the social conditions that disable the individual, groups, social classes, cultural and ethnic minority groups and so on, giving special attention to any form of language that might favour the stigmatisation of some individuals, the penalising judgement or insult. In short, this model has offered to studies and policies on disability, as well as to culture in general, a rich analysis of the language, an conscientious disapproval of every disrespectful form of classification, well knowing that behind every word a world of different meanings is hidden that make social contact possible.

This new approach towards disability has been approved by numerous Documents of International Institutions (The Standard Rules for the Equal Opportunities of People with disability, UN 1993) and European ones (European Social Charter of 1996; the Declaration of Madrid of 2002), and it has become the basis for the request to adopt an International Integral and Complete Convention on the Promotion and Protection of the Rights and Dignity of the People with disability, for which the Assembly of the United Nations appointed a special Ad Hoc Committee. For the first time the UN acknowledged the civil society, represented by organisations of disabled people and their relatives, the right to be part of a workgroup that wrote the first draft and to participate directly in the Ad Hoc Committee. In a few years time this International Convention on disability will become the legal instrument for the universal protection of the Human Rights of the 600 million persons with disability in this world.

The contribution of the social and cultural actions of the disabled people's movement doesn't limit itself to the application of the Human Rights paradigm to 10% of the world's population, up till now excluded and humiliated; it is much larger because it spreads and enriches the individualistic concept of the Human Rights. In fact, whereas it was traditionally concentrated on the inalienable rights of the single person, it now extends itself towards a vision that gives society full responsibility in order to guarantee the social inclusion of all citizens. The protection of the Human Rights is, on one hand, linked to the respect for individual freedom and, on the other hand, to the cultural and social creation of an all inclusive society, in which prejudice and barriers are eliminated and everybody can live without having his personal characteristics affected by social, legal or practical stigma.

Thus, a new field of cultural and political action is created, which involves the whole society: the way to include the human diversity in society (central theme in the confrontation between the Western world and the Arab world) and in the models of social and economic development (let's think about the huge theme of poverty). The specific theme of the re-definition of the cultural and social image of disability also becomes a model in the comparison with myths and ideologies that have widely been accepted and were built on centuries-old practices of segregation and exclusion, inadmissible today.

We must build a new social universe based on a worldwide approach aimed at the creation of environments, goods and services as described in the *Universal Design;* and on the condition of equal opportunities for all citizens; on the elimination of every form of discrimination. We should overcome the idea that there are some characteristics that are socially undesirable because of the skin colour, gender, sexual orientation, religion or psychophysical features. This extraordinary contribution unites the Human Rights both in the individual field and in the social one, giving full accountability of actions and behaviour both to people and to the Institutions.

2.2 Disabled Peoples' International

In the last few years the role of *Disabled Peoples' International* (DPI)[9] has been decisive. The aim of *Disabled Peoples' International* (DPI), an international organisation present in 135 countries all over the world, is the promotion of the Human Rights of people with disability by means of their full participation, equal opportunities and their personal and social development. This NGO has always been in the front line during all the most important battles for emancipation and cultural, political and social change regarding disability, contributing with extraordinary ideas and fights. From the CBR *(Community Based Rehabilitation)*[10] to the ICF *(International Classification of functioning, disability and health)*[11], from the equal opportunities to the non-discrimination

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[9] www.dpi.org

[10] www.who.int.

[11] http://www3.who.int/icf/icftemplate.cfm).

(*American Disability Act, 1990; Directive 2000/78/CE of the Cabinet, 27th November 2000 for Employment*), from Bioethics (*Universal Declaration on Bioethics and Human Rights, UNESCO*)[12] to the fight against poverty (*Millennium Development Goals, 2005*)[13]. The slogan **"nothing about us without us"**, on which its philosophy is based, is also suitable as a universal slogan for the emancipation of every component of the population, of which the Human Rights have been violated.

Within this framework the demand for Independent Living, taken for granted by everybody, gets an ethic and social value, essential for the people with disability. Therefore, we must change the policies that force people to live in conditions of dependence without any chance of self-determination because of physical and social barriers, discriminating treatments, prejudices that see them as invisible or second-class citizens whose life value is inferior to that of the others. Within a frame based on autonomy, self-determination, independence and inter-independence, not only health and assistance policies must take care of them but also the whole system of policies that must include the disabled people by using an approach based on *mainstreaming.* This approach, both the content of a policy as well as the method through which it is carried out, puts the disabled people back among other citizens, inserting their needs amid the primary needs, to be satisfied by the policies and ordinary resources of society, in fact, people with disability are students, workers, travellers, athletes, tourists, women and men whose rights should be protected in the same places, same ways and forms as is done for all the other citizens. This is how the resources, that first seemed to be insufficient, taken from the assistance and health expenditure, become resources for everybody and must be used to guarantee access, use and support to obtain a full citizenship for everyone.

Naturally these requests for a better world, which completion will take another few decades, should not overshadow the real condition in which disabled people have been living up till now. In fact they have been locked up and put away in ghettos for ages: the segregation in places detached from society and the reduction of these people to their illnesses, has cancelled from this society an enormous amount of people, deprived of their right to citizenship and also socially and individually

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[12] http://portal.unesco.org/

[13] www.un.org/millenniumgoals/

impoverished. Even today they are still discriminated and without any equal opportunities: the concept of poverty extends itself and includes unequal treatments that diminish the ability and capability and humiliate the human dignity. It is therefore clear that disability is the cause and the effect of poverty: cause because if one has a socially undesirable characteristic, one is automatically excluded from society, and effect because one's poverty often leads to one's disability (of health, culture, gender, etc.) Therefore it is obvious that people with disability need actions that change the image they have of themselves and of the world that surrounds them and at the same time they need actions that strengthen their self-defence instruments. For this reason DPI, and also the International Movement of people with disability, have identified empowerment as one of the essential actions necessary to protect Human Rights.

Empowerment is an English word with a double meaning: the first is linked to the individual and the strengthening of his possibilities and abilities, the second to the social field and to power acquisition. The people with disability need both a strengthening of their individual abilities as well as the acquisition of more power in order to decide on how society should include them

One can't deny that people with disability all over the world suffer continuous violations of their Human Rights and this often leads to the fact that they see themselves as inadequate, unable to live in society because of their condition. The first objective of empowerment is to change this image: we can start our process towards emancipation only by being aware of the discriminations and the oppressions society forces us to live in.

For this reason DPI was created as an organisation for the protection and safeguarding of the Human Rights, based first of all on the *empowerment* of those that have been excluded, discriminated and cancelled from society. This change doesn't only happen through the conscious social action of the associations but also through the conscious action of every individual with disability, capable of changing the cultural and social image of disability inside his living environment. As Antonio Gramsci said, society can only be changed molecularly, so everyone has to put forward his contribution in order to overcome prejudices and discriminating myths. The more the image disabled people have of their disability changes, the more will the social demand to the Institutions

and public and private bodies that plan and make the rules of our society, change.
It is here that the concept of empowerment takes a significant turning-traditionally it was linked to a laissez-faire idea of the social responsibility for inclusion: each person defended himself alone and the State did not intervene in the free expansion of the market; now, the duty of the State is to include everyone in the decision making processes and development and at the same time to offer everyone the possibility to increase his abilities and awareness.

We are far from the belief that social actions are only possible when there are extra economic resources; while the issue of inclusive development and a participative democracy cannot be banished to the world of utopia anymore. According to DPI, societies that protect the Human Rights must pursue two essential elements: *direct participation,* meaning that every person must be the protagonist of every decision that has been taken for her, and *inclusive development*, meaning, "every intervention linked to development must also include people with disability."[14]

The new paradigm of disability, based on the respect of the Human Rights, not only has become and will become even more the instrument of emancipation of hundreds of thousands of disabled people in the world and its international agencies, governments and parliaments will refer to it in the years to come; it will also represent an overall reflection on society's development, on the instruments of democracy and of the protection of rights, on the possibility to build societies that are open to everybody, in which everybody can contribute to the growth of society, where reciprocity, more than competition is a universal human value.

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[14] R. Barman Bieler, *Disability and Inclusive Development Team of the Latin American and Caribbean Region of the World Bank* (typescript)

CHAPTER 3.

TOWARDS AN INTERINDEPENDENT LIFE

> *Empowerment is not an immutable feature of personality but a dynamic and evolving structure guided by context: it takes on different forms for different persons in different contexts.*
>
> Marc A. Zimmerman

3.1 The Independent Living Movement

A movement for Independent Living: a revolution?
It certainly is a deep philosophical and actual change in the way of experiencing and in the way of considering disability and consequently in the way of thinking and generating services and policies in regard. As every real transformation this one also arises from the awareness of an inadequate condition, from a collective and individual acquisition and from a clear motivation to obtain a goal. It therefore presumes not only an individual commitment but also a change in social relationships. Whoever claims that Independent Living is an individual philosophy is wrong. The philosophy of Independent Living does refer to the individual, but it also has implications in the social, economic and cultural field. In fact, to achieve the social aim of Independent Living, one should plan and carry out a collective action which results in the fulfilment of every individual as a person, with observance of his Human and Civil Rights, equal opportunities and self determination.

The Independent Living Movement was born and evolved in the sixties in the United States of America; parallel to the Youth and Students Movement- the historical connection between these movements should be re-evaluated because again we are dealing here with common requests expressed in different ways. In these years we witnessed the start of the big fights for civil rights using new strategies: there were demonstrations, actions in order to obtain visibility in the mass media, new laws, etc. The hobbyhorse of this vast social movement was self-representation; no one could speak on behalf of the others: only Afro-Americans could speak about their rights, only feminists could speak about women issues, only people with disability could speak about their problems and propose solutions for them. Since the beginning of the revolution millions of people have become its key actors claiming in a loud voice the right of self-determination, i.e. the recognition of their autonomous and independent choice.

Edward Roberts, at that time a young university student at Berkeley, California, was the pioneer of the Independent Living Movement. He and other students with physical disabilities attended Berkeley University in those days, but their social life was practically non-existent, in fact the student facilities on the campus were inaccessible and forced them to live isolated in a kind of hospital ward. Caught in the hurricane of liberation movements in the Western world, in the world of black Americans, women and gay people, in the frame of individual and cultural awareness acquisition as the university one, they decided to claim their right to study and to live as the others and with the others, refusing to be "deported to special wards", confirming the right of choice and self determination.

In its early stage the Movement took on an image of assertion, characterised by a strong opposing attitude, necessary to overcome age-old entrenched schemes: first inside the university world in order to have the benefit of the same services and the same places as the others, then on the outside, for the viability of roads, the accessibility of transport, services, shops, cinemas and theatres.

Subsequently, the first "Centre for Independent Living" was founded in 1972 to share with others the result of their experience. It was a self-managed service, addressed first of all to the local people with disability, where those that had already gone through a process of autonomy provided information, orientation and services to others that had the same problems and the same aspirations.

But not everybody had the courage to go to the centre or to express his or her demands: how to cope with this renunciation? And the fear?

Obviously opening a centre was not enough. Some other fundamental element in the wide array of services was missing.

The claim for rights implied a political job of modifying the institutional and legal solutions and also a cultural job of modifying the image of the people with disability and their condition. But how to face the primary and invisible barriers, called fear, insecurity, inexperience and lack of self-esteem? How can one avoid the change process from being paralysed by a negative self-image?
Students found out that this vital energy, this ability to develop themselves, could be contagious. They discovered this by dedicating time to each other: "One talks about his studies, about his problems with assistance, about the daily forms of discrimination, about his feelings.
The others listen. A short break and then the others talk and the first one listens to them"[15] This way of formal and informal sharing and support is not uncommon among students in the USA. The experiences of self-help are very diffused in the American society, especially among the marginal social groups, only think about the Anonymous Alcoholics or the oppressed minority groups. These are the first experiences of Peer Counselling. The Independent Living Movement developed this practice as a strategic instrument to favour the empowerment process of people with disability that want to take back their "destiny", as all the other ethnic, religious or anyhow marginalised minority groups.

In 1972 Ed Roberts, supported by a group of people with different disabilities, founded a Centre for Independent Living at Berkeley (CIL). It was the first time that people with different disabilities united themselves to start defending themselves all alone, to experiment a new way of organising the community they lived in and to help other people with disability to discover the abilities, necessary to claim their rights and to participate in the creation of an all inclusive community. In a few years time a lot of CILs were founded: if in 1972 there were only 52 centres, after one decade there were about 300 of them, each maintaining the same activism and ardour for the defence of the rights of people with disability. This proliferation of the CILs in the United States of America was also determined by the involvement of the Federal Government, which, in 1978, ratified a Law for the funding of the Centres of Independent Living.
The CILs, which structure was defined by local needs, are funded both by Public bodies, the Federal Government, the States, the Municipalities

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[15] C. Patterson, *Peer Counseling Training Manual,* Indipendent Living Resource Center, San Francisco USA 1990

etc. as well as private Institutions, foundations, sponsors, etc. They generally provide some standard services: information about services and accessibility, housing - search for accessible houses-, personal assistance service, support for job integration, legal counselling, advocacy (counselling on rights), peer support and peer counselling.

The fundamental principles of the Independent Living Philosophy are:

- The only real experts in disability are the same people with disability;
- All people with disability have the right to choose autonomously the way in which they want to live;
- Each person, who receives State services or services offered by private and public Bodies, should be able to decide on how and from whom he receives them;
- As citizens of a Country, the people with disability must have the same rights and the same opportunities as the others and must assume the same responsibilities as the other citizens.

Soon these principles were diffused all over the world and they also arrived in Europe, where in 1992 the ENIL (European Network Independent Living) was founded.

The year 1989 was also very significant because at the European Parliament of Strasburg a Conference was organised that discussed and identified instruments, policies and actions to increase and develop personal assistance services. A group of 80 persons with disability, coming from different European countries, approved a Resolution that sanctioned a programme based on the development of the personal assistance service, essential to achieve an autonomous life.

Its key elements are:

"3. The services will allow the disabled person to participate in all aspects of life: home, school, employment, free time, travelling and political life. These services will allow disabled people to build a family and take on all the responsibilities connected to it.

4. These services must be available on a long term, 24 hours a day, seven days a week, and on a short term or depending on the needs. These services will include communication assistance, household assistance, mobility assistance, personal assistance and other related services."

The first Manifesto of the European Movement strongly confirms the principle of self-determination and of the protagonism of people with disability, claiming the role as the Institutions' direct spokesman concerning the policies that regard them.

As Adolph Ratzka confirms *"…we must break down the monopoly of the non disabled experts that speak on our behalf, we must define our problems and suggest solutions for our needs. We must create efficient organisations that represent the point of view of the disabled people. The governments must recognise our organisations as collaborators in the elaboration of policies on disability. We, disabled people, must help each other to change our destiny…in short "nothing about us without us."*[16]

Surely the Swedish experience is, still today, the most significant of all those carried out in Europe. Adolf D. Ratzka came in contact with the Independent Living Movement in California during his university studies. This brought him to start a remarkable process for himself but also for many other Swedish people with disability. In fact, on his return to Sweden he started the diffusion of the Independent Living Philosophy and at the same time a political action that lead, after quite a lot of political and cultural resistance, to the foundation of the association STIL (Stockholm Cooperative for Independent Living), thanks to which, today, a lot of people with disability actually live an Independent Life and where the meaning of self-determination and autonomy manifests itself in the direct management of funds used to pay personal assistants.

Equally important are the experiences carried out in Germany, both in Magonza, where the development of the Movement was again carried out inside the university world, and in Erlangen, where the CIL took on the role of coordinator in the creation of a network of centres for Independent Living.

In Ireland, in particular in Dublin, the local CIL is concentrated on personal assistance services, essential to obtain an autonomous life, specialised in organising training for people with disability on the self-management of personal assistance. And last but not least, also in England the centres and services for Independent Living focused their attention on self-managed assistance and on the role of the person with disability as employer.

In Italy, during the nineties, the practice and principles of Independent

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[16] Adolph Ratzka, Manifest of Independent Living, Stockholm, 1989.

Living spread amongst the associations of people with disability, achieving, after some important local experiences, (in Tuscany, Lazio, Piedmont and Calabria), a first and essential result with the Law of the 21st of May 1998, n. 162 which, as an integration of the Law of 5th February 1992, n. 104 - "Outline Law *for the assistance, social integration and rights of disabled people*", makes provision for, funds and regulates self-managed personal assistance.

In a first moment, the principles of Independent Living were taken in and diffused by the ENIL Association Italy. Subsequently, also thanks to actions undertaken by DPI Italy, the Italian Assembly of Disabled Peoples' International, they were accepted by the other associations of people with disability, opening new prospective in policies inherent to disability. On a cultural level, the image and vision of disability has been changed, as this book clearly shows: it outlines the attempt to understand the demand, put forward by the people with disability, not only of autonomy in choice and self-determination, but also of active and responsible participation in collective and social life, of interaction and reciprocity. Freedom does not exist in a world apart, but is nourished by confrontation and daily exchange with the others through communication processes, work, free time and all the moments in which we are, by choice, active.

3.2 Independent Living: the roots of equal opportunities

A fundamental action instrument of the disability policy development was the creation of umbrella organisations that went beyond the practice of corporations and specifications, and that have worked to resolve the problems of all people with disability; namely, cross-disability associations and organisations. On a European level, there is the Association DPI (Disabled Peoples' International) Europe that handles the policies inspired by Independent Living and ENIL (European Network Independent Living), and promotes the development of services, particularly the self-managed personal assistance, and of the CILs.

The approach based on the Independent Living principles represented a real revolution that put the individual and his needs in the centre and no longer the abstract and stereotypical vision of disability that gave no space to personal identity, needs and abilities of people with disability.

If we go no more than a few decades backwards we find total institutions and also standard support actions, as for example the assignment of a disability percentage and of a financial benefit equal for everybody; that correspond to an image of social burden on the one hand and on the other hand to the image of a static reality with no way of out or no chance of developing.
The approach based on Independent Living returns the prospective dimension to everybody. In its implementation it shows, through individual testimonies and stories, that starting from an attentive analysis of his living conditions and context, the individual can realize himself by means of appropriate resources and by starting from his necessities and personal aspirations.
In less than 30 years the cultural image and consequently the social and institutional answers regarding people with disability has radically changed. We have passed from segregation, masked as rehabilitation, into isolation and then into the right to assistance, from insertion to integration, from Civil Rights to Human Rights, to social inclusion.
The rapid transformation of the terminology, which is still going on: from handicapped to disabled, to people with disability and differently able, etc. witnesses a process of change that hasn't stopped yet. It is therefore necessary to guide it into the right direction of respect for the needs of the people, avoiding the temptation of assistance revival, based on cuts in public expenditure, often very short-sighted and inefficient.
In this process the Independent Living Movement has been the symbol of a decisive turning point because it gave voice to the immediately involved, overthrowing the concept of delegation and representation, accelerating the above-mentioned change process. Principles of assistance, tolerance and solidarity were substituted by the principles of freedom and self-determination.

The concept of people with disability as an undifferentiated mass has been changed into individual protagonism: until the eighties, the political manifestos of the movement were mainly represented by the life stories of the group members. This continuous and explicit appeal to the existential condition, hic et nunc, represented the best weapon to destroy ages of disquisition, of theories and definitions made by the ideologies of the moment against people without having any real contact with these people, for example the Nazi ideology of mass extermination.
The connection between the Independent Living Movement and the

emancipation movements of the marginalised social groups is quite obvious. Also the implicit matrix of Marcuse's philosophy is evident, which not only recognises and enhances the value of the liberation movements but also assigns them the important role of the motivating driving force behind change, in contrast to the system that produced "*a one dimension man".* The oppressed assume a role of guide in the passage from a condition of unauthentic existence to an authentic one. The motto "nothing about us without us" recalls "this body is mine and I'll manage it myself" of the feminists, or the "black power" or other expressions that later became slogans, and it is connected to the rejection of medical and assistance practices that crush the possibility of free choice. At this point, and it is this stage we're currently going through, the demand directs itself towards the conscious participation in social life by means of an interactive process, the only one that consents the creation of a itinerary of exchange and of reciprocal growth. Choosing Independent Living means living "completely". It implies having clear ideas about one's goals as regards to the organisation of one's life and having a certain degree of maturity and responsibility, because the choice is not exempt from risks and critical moments especially because personal assistance services and instruments, support devices and transport haven't been adapted at all to the growing needs.

On the level of social policies the new approach implies some innovating elements, for example:

- ***Participation***, as is written down in the Standard Rules for the Equal Opportunities of People with Disability, norm 18: *"The States should acknowledge the organisations of people with disability the right to represent people with disability on a national, regional and local level. The States should also acknowledge the organisations of people with disability their consultative function in the decisions on issues that regard disability."* This leads to the development of services that are more and more personalised and focus on their needs.
- ***Project-designing***, an element that allows the organisation of services based on the priorities and the needs of each individual and the available resources, and also their monitoring and evaluation; the organization of activities based on individual projects, on the Italian model defined in article 14 of the

Law 328 of 2000 “Outline law for the achievement of an integrated system of actions and social services.”

- ***Focus on the demand***, the organisation of the actions and policies that were traditionally concentrated on the offer, or to be precise, on the interest and pressure from the managing establishments that acted as employers -rehabilitation centres, expert organisations, corporations and associations-, is now focussed on the demand, or to be precise on the real needs, needs people are becoming more and more aware of. Resources are pushed in this direction and the structure of the services has been changed, increasingly closer to the individual.
- ***Right of choice***, the person who uses the services becomes a “client”, and is no longer the ”assisted” or “user”, and therefore he can determine the service- provider’s presence on the market.

On the cultural level the image of the individual, who chooses independent and autonomous living process, upsets the stereotypical one that until today was entrenched in the collective image, namely the image that sees the person with disability as passive, suffering, needy, dependent; and sometimes even upsets those involved.

The Independent Living Principles, based on a new image of disability and initially promoted only by a restricted group, are slowly spreading among the major organisations of people with disability and are accepted by the more advanced and innovative services. The main aim is to make them common and shared property so that no central or local Government action can ignore them any more.

The main motivations adopted by the Institutions to justify the lack of policies to obtain autonomy always centre on a lack of funds. An analysis of the cost-benefit balance concludes that it is a waste of money for the Governments to invest in autonomy-services, because people with disability aren’t productive inside the economic system, being considered as incapable of producing. But the real obstacles are the failed rationalisation of costs and the lack of an inclusion policy for people with disability.

“…He answered me seriously: All these people fight with you because they identify themselves in your struggle for life. Life, you represent life. If you can win, we’ll all win”[17].

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[17] Rosanna Benzi and Saverio Paffuti, “Girotondo in una stanza”, Ed. Rusconi, Milan, 1987 p. 37

These words, told by a hospital doctor to Rosanna Benzi, who lived in an artificial steel lung for twenty-five years, express the sense of commitment and struggle of a person for his Independent Living. We're dealing with a challenge: to conquer and perform one's role in the world, beyond any form of conditioning, especially the one linked to the condition of disability. More precisely we are talking about the struggle for "Independent Living", but on looking closer, we realise we're simply dealing with accepting the universal challenge of life.

Those that have to face and deal with extreme situations, as for example disability, or at this point even war, natural catastrophes, or the manifold forms of persecution; end up becoming reference points, they are the lighthouse for those that are looking for a meaning, a search that is becoming increasingly urgent in complex and confusing times as this passage from one Millennium into another.

This to say that our challenge is in no way "different" from the common condition, and what appears as "extra-ordinary" to an outsider, is the only possible solution for the one who experiences it, in coherence with what one is and what one wants.

We are trying to transform this phase of "being exceptions" to a vision of "being ordinary"; winning this game will enable a real dialogue with the other existential approaches and the other multiple ways of living in this world.

Independent and autonomous Living will be obtained when nobody will notice our disability any more, not because we are invisible as we once were but because we will have a name and a story to tell. Talking about Leopardi, a famous Italian writer, nobody would dream of calling him "a disabled man".

3.3 Empowerment, Human Rights and the bio-psycho-social model

When we talk about equality and inclusion we intend that all men and all women have to enjoy an equal status, the same benefits and rights, must have equal opportunities of choice and equal freedom without being conditioned by gender, ability or disability, or other differences. This means that when creating policies, laws, services, practices and actions one should be free from prejudices, conferring "power" to all human beings. Power not intended as dominance over the others, but as reinforcement of oneself, as an individual acquisition of the possibility to do and to be: meaning, possibility and freedom to interact with the world, possibility and capability of choice, starting from existing limits and going to the implementation of one's possibilities, making an excellent use of personal resources but also of external resources, typical of the social environment one lives in.

How can one get hold of this kind of power? It is possible by means of a "process of empowerment", which stimulates the active competences of the individual, enabling him to exercise a real control over his life, and to face changes and to produce changes himself. These processes are instrument to combat social problems and to respond to the needs of all those people that live in a condition of exclusion: people with disability, women, race minorities, etc.

By being dependent, due to their particular needs determined by their condition, and by submitting themselves to the decisions of others, people with disability have lost or have never had any control over their lives. Consequently, what dominates them and the people that surround them is a feeling of impotence.

The first step to take to "increase power" is therefore the acceptance of oneself and the awareness of what one is: this allows the individual to take on responsibility in all fields of his life. Obviously being aware of oneself doesn't mean that one can prevent acts of discrimination; it rather means that one can choose to react against the inequality, the violence, the discrimination and the age-old exclusion each person with disability had to suffer and continues to undergo. It, therefore, means assuming one's responsibility and to know how to confront obstacles, to know how to experience and shape one's destiny in order to reach and carry out a life of quality.

Thanks to this self-awareness, the individual acquires a major self-understanding, knowledge of his limitations but also of his abilities, which teach him, in time, to have confidence in facing difficult situations. This leads to the empowerment of the individual and to the inclusion of typical assertive values in his personal value system, namely personal dignity, freedom, autonomy, self respect and respect for the others. Moreover, self-awareness leads to having full control over the sense and significance of one's actions and to the conviction that it is possible to reach one's objectives; it steers towards change.

Once he has become aware of his need and desire to change, the individual starts a correlation process with other individuals, with groups and resources expanding his array of possibilities and choices. In relation to his needs and changes, the individual will acquire new abilities or information. For example, a person who wants to find a new job will acquire new competences and try to establish a relationship with people that can help him.

The moment he does so the person with disability becomes active, mobilising himself for his participation. From this moment on he will be the real protagonist of every action to claim his rights, of the creation of increasingly more inclusive communities and societies.

The empowerment activities that aim towards the emancipation of the individual, achieve that he himself will "take back his human potential, his participative power, his social competences".[18]

The areas in which empowerment has been implemented refer to theoretical approaches: socio-political, medical, psychotherapeutic, managerial-organisational, of adult pedagogic and of community psychology. It is divided in differentiated action strategies according to the level it deals with: the individual/psychological level, the organisation level or the social community level.

The *individual empowerment of* people with disability regards various aspects:

- Emotional - redefinition of the emotions based on construction and transformation rather than on limitation and destruction
- Perceptive - redefinition of life experiences based on the social model of disability.
- Intellectual - comprehension of the cultural instruments one should have, learning their lingo.
- Behaviouristic - transformation of the human and social relationships based on a new awareness
- Ability - learn how to do things even in different ways
- Information - identify and know how to use the laws and resources of one's territory.

S*ocial empowerment,* on the other hand, regards groups that risk social exclusion that get together in associations to discuss and to carry out actions and strategies to obtain adequate answers to their specific needs.

The S*ocial empowerment* of the associations of people with disability and their relatives regard various aspects:

- Training on Human Rights,

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[18] M.Tognetti Bordogna, *Promuovere i gruppi di self-help*, Franco Angeli, Milan 2002, pag. 123

- Ability to carry out *lobbying actions towards* the Institutions and Public Offices,
- Knowledge of laws and territorial resources,
- Ability to produce the *empowerment* of people with disability and their relatives,
- Support the launch of promotion and protection of associationism.

It is important that people are assisted in increasing their ability to go from a situation of *learned passivity,* in which they developed a feeling of impotence when confronted with alienating or frustrating experiences, to the *learning of hope* derived from a feeling of increased control over events, thanks to the participation and engagement in one's life context.

Empowerment, as an instrument of individual and social emancipation, aims to the protection of the quality of life of people and of their environment, and consequently it recognises itself in the Human Rights approach. This approach was adopted by the International Health Organisation when drafting the ICF - International Classification of the Functioning, of Disability and of Health - approved on an international level by the 54th World Health Assembly, 22nd May 2001. It is the result of the review of the ICDH - International Classification of Disability and Handicap -, published for the first time in 1980 by the International Health Organisation and inspired by the principles of the Standard Rules for the Equal Opportunities of People with Disability adopted by the UN. Disabled Peoples' International (DPI) participated in the drafting.

The ICF is an instrument used to describe the situation that regards the human functioning and its restrictions. It therefore allows us to have an exact outline of the health condition and well being of every individual compared to his environment.

It has a universal application and it doesn't only refer to people with disability, but to every person who needs an evaluation of his health condition, both on a biological and psychological level as on a social level. "*Health condition is the umbrella word used for illness (acute and chronic), disturbance, injury or trauma. It also involves circumstances as pregnancy, aging, stress and congenital anomaly or a genetic predisposition*"[19].

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[19] ICF International Classification of the Functioning, of Disability and of Health pag.168

The ICF explains the fundamental role of the environment in defining disability. It is a reference instrument for the mainstreaming of the disability experience and it recognises the latter as a universal human experience. This means that any individual in any moment of his life can have a health condition that may become a disability in a negative, unfavourable environment.

From this perspective this classification system has adopted two conceptual models that are opposed to each other, but characterised by a profound dialectic relationship: the medical model and the social model.

"The ***medical model*** *sees disability as an individual problem, directly caused by illness, trauma or other health conditions that need medical assistance under the form of the individual treatment by experts. This action wants to cure disability and, when this is not possible, to change the individual's attitude in order to make him adapt himself to the environment as it is. The medical assistance is seen as a priority issue and, on a political level, the main answer is the modification and reform of health assistance policies.*

The social model *of disability, on the other hand, starts from the supposition that society is the cause of the individual's handicap and therefore we should modify the physical and social environment to guarantee the full inclusion of every individual in society. Disability is not a characteristic of an individual but rather a complex interaction of conditions, many of which have been created by the social environment. Consequently the management of the problem asks for social actions and it is the collective responsibility of society as a whole to implement the environmental modifications, necessary to assure the full participation of the people with disability in all the areas of social life. The issue regards attitude and ideology and asks for social changes, which on a political level become a Human Rights problem. According to this model, disability becomes a political issue."*[20]

In putting-together these two models, the ICF bases itself on an approach called **"bio-psycho-social model"**, this observes human health in its various dimensions: biological, psychological and social. With this broader vision we hope that people with disability will be considered as a whole and that in doing so solutions are identified that involve the different aspects of their lives.

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[20] Ivi, p.23

These are:

- Answers that regard interventions as medical and rehabilitation care, created to support the functional limitations that characterise the particular health condition;
- Answers that take in consideration the fact that the individual with disability is a human being as all the others, with life experiences, with emotions to feel and to express, wishes to carry out and aims to achieve;
- Exclusively social answers that consider the people with disability as citizens as all the others, that include them with their specific needs in ordinary accessible places without any physical barriers, or psychological and cultural obstacles that limit their participation and equal choice opportunity in various daily life contexts.

To conclude, putting people, their health and their environment in an interactive prospective and considering disability independently from aetiology, the ICF stresses the social role of the Institutions to activate public policies that are more and more inclusive, with a specific regard to welfare-, health-, education- and employment policies.

Therefore, only by starting from a similar integration of the different intervention fields and from collaboration between pertinent Bodies, it is possible to identify solutions that guarantee services aimed at the achievement of autonomy and Independent Living.

SECOND PART

CHAPTER 4.

PEER COUNSELLING

> *The most deeply rooted conviction of the single individual is the fear of not being accepted or loved once he meets someone. A fascinating aspect of this process is to see how this conviction disappears in a group. To discover how a whole group of people finds it easier to deal with the real Self, instead of dealing with appearances, is a touching experience for the single person but also for the other members of the group.*
>
> Carl R. Rogers

4.1 The history of Peer Counselling

The history of Peer Counselling finds its origin in the United States of America at the beginning of the sixties. In those years, students with disability were forced to endure, in a predominant way, discrimination and social exclusion. For this reason some students of the University of Berkeley, pioneers of the Independent Living Movement, decided to meet regularly and to dedicate "time" to each other to exchange their experiences, to confront and prepare individual and group strategies necessary to face problems related to their disability.

Ever since, more and more people with disability, inside and outside the university context, have taken up the idea and have used this method. Peer counselling has thus become an important instrument capable of encouraging and strengthening the development of the competences of disabled individuals in order to activate a process of independent living.

The evolution of the Peer Counselling groups of disabled people in the USA is closely linked to the history of the Civil Rights movement of Afro-Americans, women and homosexuals, from whom they borrowed some successful emancipation techniques. Self-help groups were created, based on the people's need to share similar experiences and to exchange emotional support with each other.

The same as with other self-help groups, this lead to a more conscious search of their identity. The solidarity of a group of people with the same sensibility and the same background of discrimination and exclusion brought them to a stronger political commitment as regards their daily difficulties. This gave way to the premises for the promulgation of the anti-discrimination law, the American Disability Act (ADA, 1990) that consolidated the protection of the disabled people's Civil Rights.

At present, in the USA, Peer Counselling is considered on a par with the best-known forms of support and therapy, and most of its activities take place in Independent Living centres.

In the eighties the method arrived in Europe and found fertile soil to grow and to evolve. Its value was acknowledged by the disabled people's Movement and in some countries even by the official governmental bodies.

The American model was accepted and diffused in Europe by DPI (Disabled Peoples' International) Europe and by ENIL (European Network for Independent Living) again it was mostly exercised in Independent Living Centres. Moreover, the efficiency of the approach and the diffusion of Peer Counselling experiences have drawn the attention of some private centres that provide rehabilitation services to disabled people and direct these people towards independent living. Some of these centres have started to recruit people with disability, experts in the field of disability, as peer counsellors.

In Italy the value and the efficiency of the Peer Counselling method are widely recognised inside the disabled people's movement, whereas the professional profile of the peer counsellor is not yet included in the official list of professions. Recognition was obtained on the institutional level with the Prime Minister's Decree of the 9th of April 2001, "Uniformity of treatment as regards university studies, according to article 4 of the Law of 2nd December 1991, n. 390", registered at the State audit Court on 6.6.2001 (reg. 7, fg. 173), art. 14, regarding actions in favour of students with disability (comma 10), the text reads: "… the role of tutor can be carried out by "peer counsellors" i.e. people with disability that have already faced and solved problems similar to those of the people that ask for support".

In 1998, DPI Italia decided to promote a pilot project "Peer Counselling: a method to project an independent life" aimed to qualify people with disability for the role of peer counsellor, the project lasted for two years (January 1998- December 1999). After this first stage the Province of Catanzaro financed a second level of training for the same students.

Subsequently, the University of Calabria (UNICAL) inserted in its Service for Disability, provided for by the Law n. 17 of the 28th of January 1999 (Integration and modification of the Outline Law 5th February 1992, n. 104), the activity of Peer Counselling for students with disability, managed by people that had received a competence certificate to exercise the Peer Counsellor activity, after attending the training course.

4.2 An Italian experience

The training course, promoted by the project "Peer Counselling: a method to project an independent life" was funded by the European Community, within the programme "Actions to favour equal opportunities of disabled people - European commission directorate general employment, industrial relations and social affairs". This project wanted to widen the competence field of those people with disability that work in the Information and Documentation Centres on Handicap or behind the Information Counters of the Associations. The close contact with other disabled people in these contexts brought to the surface a strong need to promote services capable of answering their complex desire of autonomy. The project started from the conviction that in order to develop his autonomous living process it is undoubtedly important that the individual re-elaborates his own living experience related to his disability. The awareness of oneself, of one's skills, but also of one's limitations is the instrument, which more than any other, allows the individual to be active, realistic, and capable of proposing and planning inside his living context.

The project included a training course for peer counsellors offered to 24 persons with disability - 20 students and 4 tutors - coming from four different regions in the south and centre of Italy: Lazio, Campania, Calabria and Sicily.

The location of the activities was an extra value added to the results of the project because the participants came from backgrounds where disabled people still live in conditions of extreme discrimination and social exclusion, where the lack or scarcity of services makes it difficult to live one's autonomy.

The goal of the project aimed to the development of empowerment processes by means of the Peer Counselling method, to favour the autonomous and independent life of people with disability.

The objectives aimed to:

- Favour the acquisition of instruments necessary to develop the autonomous and independent life of people with disability, participants in the Peer Counsellor training course.
- Acquire professional skills for the management of Peer Counselling services, addressed to other disabled people that want to develop their personal independent and autonomous living project.
- Manage Peer Counselling Services experimentally.
- Strengthen the local, national and international network to favour the synergy of resources to protect the rights and to promote the equal opportunities of people with disability.

The project was structured according to the following actions and activities:

Promotion

- Seminars and conferences organised to present and promote the project
- Activation of local, national and international partnership networks

Selection and training of the target group

- Selection of the students
- Peer Counselling - two periods of theoretical and practical workshops for a total of 150 hours. Students resided at the centre. Teacher: Peter Van Kan
- Communication and body language workshop - for a total of 100 hours. Students resided at the centre. Teachers: Mr Jerome Liss, Mrs Marina Galati, Ms Caterina Penna and Ms Caterina Ferrara

- Distance training on: motivations, instruments and resources to obtain an autonomous and independent life - for a total of 150 hours. Teacher: Mr Giampiero Griffo

Experimentation of the Peer Counselling Service

- Peer Counselling training for a total of 100 hours

Monitoring and evaluation

- Evaluation ex ante, in itinerary and ex post

The training contents were both theoretical and practical, developed in three modules (Peer Counselling, communication and body language workshop, distance training). Within the project, these activities defined the professional profile of the Peer Counsellor best. Not all students reached the right competence level as to perform the role in full autonomy; only 50% got the certificate of Peer Counsellor, but all of them worked out their own autonomous life project.

Years after this experience, DPI Italy promoted the diffusion of the Peer Counselling method among the organisations of people with disability and their relatives, among organisations and services that deal with orientation and job inclusion of people with disability and most of all among universities.

Regarding the collaboration with the latter, the most important and almost unique experience can be found at the University of Calabria, where for the last four years the Peer Counselling activity has been included in the Service for Students with Disability provided for by the Law n° 17 of 1999. With such a service the university aims to the social inclusion of its students, by carefully observing their potentiality and transforming every limitation in a stimulus to plan and carry out the concrete development of their individual abilities.

4.3 Experiences and fragments of the training

In this paragraph we'd like to illustrate the significance, the experiences and the emotions experimented during the competence acquisition, built up during the training course of the project "Peer Counselling: a method to project an independent life" carried out by DPI Italia.

Here are some moments of this significant training course.

During the workshop on communication, one of the first experiences that left a “mark”, in the sense of strengthening an ability, was the “contact” established, there and then, with the inner world - emotions, moods, experiences -, through the body - sensations, breathing, body expressions.
Another element was being able to make communication “flow”. This flow, which starts from the inner world and, passing through the body, extends itself towards a relationship with the others, is more than ever intermittent because obstacles continuously block it, particularly by painful situations. This flow was facilitated by elements such as breathing, music and movement that allowed the integration of the inner world with external stimuli. It was possible to “touch” our dark side and give it voice; this part of us can be identified with our “limitations”. The next step was to receive this side and, as the teacher said, “find a way to caress, as a river, what is present without throwing it away”.
In the role of Peer counsellors, the obstacles in the flow actually mean that our hidden and unresolved aspects prevent the same problems from emerging in the other person, so instead of facilitating there is the risk of interrupting the “contact” and reacting with refusal and anger which induces us to pour out on the other what we are afraid of telling ourselves.
So what can be done? Learn to identify, recognise and share this dark side. This is what was achieved during the communication and body language workshop.

The exploration and sharing of the other person’s limitations and possibilities can only take place after having dealt with our own, following a circular process. As the teacher explained, “what we really can exchange with other people, besides our roles, is what we have achieved as human beings”.

Work on limitations and possibilities

Teacher: “Today there is an atmosphere of unity in the group. So starting from this atmosphere we’ll do an individual exercise. Let’s start from a reflection obtained by the free association of ideas; let's write down everything that passes through our minds, without any logic. Important is to start from ourselves, everybody must breathe and "stay". Let's start by listening to ourselves. The topic is the following: the aspects of ourselves that we experience or undergo as "limitations". Everybody writes them down for himself, regardless of the fact that you will read them to the others or not. In the second stage there will be a listening exercise: everybody will listen to each one of you".

During the activity one can hear background music.

Teacher: "Write down your limitations and then the mechanisms that you use and that reinforce them; on the back of the piece of paper write down your possibilities or opportunities and what makes it easy to express them. In the end each one of you will take his piece of paper and share with the others whatever you choose.
Stop talking, take ten deep breaths and let's start the exercise".

Sharing the limitations

A: *Among the limitations I wrote: "I am", because I sometimes keep silent, I avoid talking for the sake of a quiet life, I seem aggressive and self-confident however I am afraid of everything and I limit myself. Another limitation is my level of social homologation: In my living context I am considered as a drag and I don't dare to ask for respect. Other limitations: indifference, my laziness, the falsity I meet, and my fear of knowing.*

B: *Ever since childhood, my limitation is my need of affection, a kind of sadness, and a lump in my throat that I can only swallow when I am with others. Fear of life.*

C: *The difficulty I have in expressing my feelings the way I want to. A sense of defeat, the desire of being rewarded, not knowing what is wrong in my relationship with men. I neglect myself, and everything close to me, so close as to touch me even if it's not physically.*

Sharing of possibilities

A: *I am a possibility. Speaking, loving, showing myself as I am, writing to communicate, fighting, claiming justice, being optimistic, knowing how to face my limitations, all this can become an opportunity.*

B: *Availability to communicate, ability to stimulate the others to let themselves go, ability to face pain.*

C: *Determination, stubbornness, luck, potentiality, being able to move, and not closing the door. In order to give one should also receive and the other way round.*

Meeting the others

First experience
Teacher: "Each of you chooses another person of the group with whom he will make contact without talking. Then everyone will tell us in which way she/he allowed contact and how she/he hindered it".

Sharing

F: *I felt M's softness and her reception. I could express by desire for contact. I felt her hands and her shoulders. By starting to talk we stopped this contact.*

M: *I felt a strong wish to welcome the other person, her frailty; I felt my tenderness and the wish to protect her. I discovered an aspect of myself that normally doesn't emerge. There was a reciprocal and natural acceptance.*

D: *I liked feeling the other person by touching her, but I stopped myself, thinking it might be too much.*

E: *We started chatting so we didn't make any physical contact, we didn't allow it to happen.*

Second Experience

Making a ball of the tissue that decorates the room, the students throw it, each in turn, to a chosen fellow student calling out his/her name.

After this game the participants have to stand in line on each side of the room. Each one of them chooses another student by looking at him/her, then, alternating, they come closer experimenting and experiencing the distance, the space, the closeness, choosing whether to stop or to come closer, choosing how and how far they want to go. After this, two participants, back at their starting position, go towards each other and, if they want to, touch each other. After this there is a feedback of the pair on this experience.

Working on communication also makes people start expressing their personal experiences, even the most intimate ones, and start sharing them just by telling them. Proof of this is the courageous account of one of the students talking about his sexual and love experience: a perfect example of communication experience.

The story of D.: *Talking about the sex life of a disabled person is like opening old wounds that have never really healed. We're not dealing with itching sores but with real blood. If talking about this issue is difficult, not talking about it is even more difficult. I think that a lesson on sex would be very useful, because it gives us an opportunity to confront ourselves with the others.*

Sex, pain and delight. I imagine love as Saint Sebastian in love. Where there is pain there is also delight. Bread and sex was the food of the "entronauts", men that wanted to be God or gods that envied the human condition. There is no big difference between the two, in both cases we're dealing with a desire of transcending oneself towards the "immense". Flesh becoming poetry has always seduced men and women of every age and condition. Disabled or not, we are all bewitched by sex.

For the disabled people their handicap is always the spoilsport. Disability reduces; takes something away, makes everything complicated both in sex life and in love life. Functional problems, *impotence, insensitivity of the skin and of erogenous zones, lack of orgasm, a flabby, rigid or spastic body, scarce self-awareness, and then there are the prejudices, the fear of being refused, self-negation, reducing needs until desire extinguishes completely. How can we deal with all these difficulties? Who can help us to heal these insufficiencies and in how far? Is it possible for us to have sexual experiences and can we continue having them? Is someone still sexually desirable after becoming disabled? The disabled person has loads of questions and unfortunately the answers are few and uncertain. Everyone should find the right answer to his own condition.*

For many years, being confronted with the difficulty of being a tetraplegica patient, i.e. having upper and lower limbs paralysed, and having lost skin sensibility over three quarters of my body, I chose to remove the problem completely. I must admit that it gave me a certain feeling of serenity. With the shrewdness of my rationality I succeeded to live beyond the needs of my body and mind. I had "wisely" recognised the manifold difficulties and accepted to give up what, at that time, seemed to be impossible. All this seemed the consequence of a mature decision. As soon as I had locked away my sexual desire, my anxiety disappeared. I felt free, stronger and better. I looked down upon the others that were still struggling with their daily futile problems. The miracle of asceticism! But it was as if together with the bathwater I had thrown out the baby, as the Italian saying goes. I paid for this thoughtlessness by concentrating on words: talking about sex, talking about feelings, talking about life, I was a river of words but my body remained numb, fleshless, a-sexual. This went on for years. Perfectly calm as a frozen lake. I had become nothing else but a big, boundless lack turning his back against the future.

One day I told myself that I had had enough. I decided to turn the page and take my life in hand and take back what until then I had denied myself. And my disability? And my problems? The refusal, negation, fear and impetuous reactions of the others? I convinced myself that no problem, no disappointment, even the most bitter one, could stop me from trying the real experience. I had already lost a lot, too much of the life I had been given.

I met a girl and we fell in love. She didn't see me through the grid *of handicap but considered my disability through her feelings for me. I was D. to her, without any connotation of diversity; she knew me the way I was, leaving aside my disability, but without any negation or underestimation of my condition as a disabled person. The only real problem was trying not to have any prejudicial limitation in our sexual relationship, for example: this is ok, that is not, in this way it goes, not in that way. Desire had to come naturally without limitations, free and happy. Our feelings for each other made all problems and fears melt away. Little by little we invented love games that helped me to overcome my difficulties in moving and to have complete erections. I discovered that in spite of my handicap I could reach a certain amount of pleasure; that beside the genital sex there were other and different ways to give and receive pleasure and each one of these attributed to the satisfaction of reaching an orgasm for both of us. In this way the love making became a feast, every rational distinction between body and mind completely disappeared and our flesh experienced sensual accession, without denying itself, on the contrary, recognising itself completely and fully, and handicap was only a war relic on the wall.*

My most ambitious desire is to be able to live together with the person I love. But love cannot hide or underestimate the objective difficulties of my handicap. It is not only the practical problems linked to my lack of autonomy, which could be solved by a 24 hour assistance service, but starting a relationship with someone who could have other opportunities in life. Choosing a disabled person as a life partner means accepting his problems and not all of them are small or medium size. One needs enormous strength and determination to make this choice, which cannot be conditioned by affection: if you love me well then you must… I, had to accept my condition, despite myself, I didn't have any choice, I was with my back against the wall; she, however, is free and can choose for a less complicated life. This doesn't mean she doesn't love me.

I am 52 years old, and I don't think that in my future there is any room for this desire.

CHAPTER 5.

PEER COUNSELLING: AN EMPOWERMENT METHOD

> *"Know yourself" doesn't express the request to know what I am, as if looking into a mirror, but to act on myself so that I will become who I am. In my self-reflection I should turn away from the worldly things towards myself, examining my actions, my motivations and my feelings to find out how much I recognise myself in them and how much I want to recognise myself.*
>
> Karl Jaspers

The word *counselling* derives from the Latin verb *consulo-consulere* or *consulto-consultare*, which means: to consult, advise, examine, take care of, give a thought, question oneself, consider.

Counselling is an interaction between two persons - the counsellor and the client or consultant -, its aim is to make the client aware of his capability of choice and problem solving when facing situations and problems that involve him directly. It is a long and complex process because instead of starting from the person's problem it grafts in what remains of the person's competence, in order to make him grow. As Rogers says, this process activates and re-organises the resources (emotional, affective, cognitive, etc.) of the individual so that he is stimulated to take care of himself.

"Counselling is based on the original "Rogers" - intuition, according to which, if a person is in a difficult situation, the best way to help him is not to tell him what to do (giving attention to the rational content of this advice: or see to it that it makes sense in this situation) but rather to help him understand his situation and how to handle the problem in assuming on his own the full responsibility of possible choices. The counselling process emphasises the importance of self-perception, of self-determination and of self control …"[21].

5.1 What is it?

Peer Counselling is a particular form of counselling, based on the experience of associations and of people with disability, to favour an individual empowerment process and consequently one of social emancipation.
Living freely, according to one's tastes and personal choices, and to one's way of being, implies a complex process for people with disability, it involves the overcoming of some basic obstacles as for example: the historical burden of a culture of refusal and deportation of diversity to ghettos, a culture made of stereotypes that are still present in social and interpersonal communications, of which we still pay the price; the individual 's experience is determined by his personal history.
These elements often form a kind of "wall" around the authentic nucleus of the individual, hindering his self-expression and development. Breaking down the wall would mean revealing his real face again, together with his needs, aspirations and appeased potentiality. All the other obstacles, which we might call ordinary, regarding the old problems of accessibility barriers, of services and employment, can be fought with conviction and determination only after the two above mentioned basic elements have been faced and worked out. Otherwise one risks remaining conditioned in a decisive way.
That having been said, one may affirm that Peer counselling can be defined as a psycho-social intervention and it is organised as a method based on a support relationship that aims to activate elaboration processes of experiences, emancipation from disadvantage and personal autonomy.

Depending on the person's needs, Peer Counselling can therefore allow a radical change of direction regarding the organization of his/her life. In the same way it can help to repair or to start a new process that can

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[21] R. Mucchielli, *Apprendere il counseling. Manuale di autoformazione ai colloqui di aiuto*, Erickson, Trento 1999, p. 16.

affect his/her personal future. With regards to this Daniela's story is very interesting, she is a woman with disability who attended a Peer Counselling course.

"*My experience with the peer counselling course has been important and significant in my life, because ever since that course I have started to give sense to my being a person with disability, which was a new condition for me to handle.*

I remember that when someone proposed me to participate in the selection I wasn't up to it, I didn't believe in my abilities, I was afraid. At that time I didn't even know what I wanted to do with my life, I was practically confused and full of uncertainties. The first thing this course stirred up in me was a big curiosity mixed with an alternation of contrasting feelings, but subsequently these fears and uncertainties were transformed in self respect and desire to play the game. In short, I started this process of inner growth without even realising it and I started to like myself from the outside to appreciate what I had inside.

Thanks to Peer Counselling I discovered myself, day by day. Surely, I got into terrible conflict with myself, in not wanting to accept this inner change and this clashed with strong feelings and emotions such as: anger, love, pain, happiness and joy. All things that one tends to suffocate or not to express because one isn't aware of being a person.

By starting an awareness process of your capability, by accepting your own limitations, you can also start working to improve your life, which up till that moment you have been living without seeing or without listening to yourself.

From that moment on you start working on yourself and on the others, you start looking for the right and positive way to face life without hiding yourself. You really start to understand that you have to commit yourself during this self awareness process and you can't give up, not even when conflicts arise or when you fall flat on your face. Today I can say that Peer Counselling made me acquire an awareness of what my abilities and my limitations are.

Today I can say that I have been able to finish some of my independent living projects, for example: I moved to a flat four years ago, where I am still living all by myself, I got my driving licence and bought a car. This year I accomplished another goal namely I obtained my diploma.

On the other hand, I have learnt, something not tangible but nonetheless real, to be self confident and to respect myself, besides being able *to give support and comfort to other people with the right words at the right moment, showing them that Peer Counselling helps you to help yourself.*

The themes Peer Counselling deals with and the aims it pursues can be very different. One starts from the sharing of the experience of disability and subsequently issues as the management of personal assistance, discrimination in the job context and mobility problems are handled. Almost always the specific themes are a stimulus to bring to the surface the whole personal world with its experiences, emotions, relationships, starting from "here and now".

Peer Counselling, as any other form of counselling, is a support- relationship that can be exercised in a group or individually. The flexibility of these two solutions allows the consultant to make progress in the problem areas of his life.
For example, Peer Counselling "vis a vis" can put at ease the most introvert and vulnerable people, who can't handle the emotional discomfort and feedback typical of group work, on the other hand, the group allows everyone to strengthen and widen the interpersonal abilities and to eliminate the feelings of isolation, guilt and shame. Both forms are characterised by a circular process, in which everybody activates the individual resources of the other person in relation to his problems and specific objectives.
"What you talk about" is not important, but rather "how you talk about it". Essential is that the process activates precise functions in the individual: the *choice,* since the consultant has to experience that he has his own field of actions and freedom; the *awareness,* so that he can allow himself to come in contact with some parts of himself, even those unexpressed, including his needs and feelings, making them his own again; *precision or clearness:* meaning re-construct his condition, inter-psychological and in relation to the world, again "hic et nunc", because only in this way the next step will surely be the right one. Here again, as in any other personal process, what really counts is the way in which one acts and not the goal one intends to achieve.

The elements that motivate and support this process are basically two.
The first one is the relationship with the counsellor who represents "a role model" that inspires trust during the emancipation process. The latter, in fact, is the living proof of the feasibility of the objectives that can

give a sense of completeness to the existential condition: "If it was possible for him it will also be possible for me". The second element is the group energy - in case of a group exercise - in which a confrontation with a rich variety of experiences creates a "resonance effect" that evokes and stimulates re-elaboration.

The duration and frequency of the sessions are not rigid or pre-defined. There are interventions that can be successful after one or two meetings whereas others take months.

In conclusion, the process that develops thanks to Peer Counselling leads to the acquisition of *self-awareness* and thus to the use of those internal instruments - psychological, emotional, fantasy, rational abilities - and external ones - human support, laws, support devices, technologies, etc.- that allow one's self-realisation.

These concepts of independence, autonomy and self-determination make even more sense when we include them in a frame of inter- independence or, better, of integration, in as far as disabled people, equal to all other human beings, are social beings that interact reciprocally to build a society in which everyone is a citizen with equal rights and duties towards the others.

However we need to clarify the above-mentioned concepts of autonomy and independence. These are often linked to a "mythical" concept of a more or less autarchic freedom, according to which the more an individual is fulfilled and happy the more he is satisfied with himself. These conquests actually imply a process of assuming responsibility on the one hand and on the other hand an ability of dialogue: this allows to build a positive relationship with one's context and to interact with it, receiving benefit from the collaboration as well as offering one's contribution in the same way. This is what Andrea Canevaro, Professor in Special Pedagogies at the University of Bologna, clearly explains when he says: "Autonomy doesn't mean doing everything all by yourself. It means collaborating, asking, putting together"[22]. The development of autonomy inevitably passes through the recognition of oneself and of the other, promoting and enhancing the individual's dignity. "Recognition, meaning being recognised as free subjects, adults, or adolescents is closely intertwined with the dignity of autonomy"[23].

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[22] A. Contardi, *Libertà possibile. Educazione all'autonomia dei ragazzi con ritardo mentale*, La Nuova Italia scientifica, Rome 1992, p. 9.

[23] *Ibidem*.

We need to underline that the Peer Counselling activity, focused on the individual, affects the subjective dimension but it is also closely linked to the social dimension, in order to implement the Civil and Human Rights and to build Equal Opportunities. Thus, it finds continuity and support in the specific information and counselling activity of Peer Support, carried out by associations, which gives concreteness to the consultant's personal project of autonomous living. In other words, the peer counsellor must also be able to direct the consultant in his use of laws regarding disability; he has to know the services and resources of his territory, as well as the competences of the institutions, public and private offices as regards to the needs and necessities of the disabled citizens.

5.2 Characteristics

Many approaches see the relationship of counselling as balanced out in favour of the counsellor who, having the technical and professional instruments, intervenes on his client to help him. However, what characterises Peer Counselling is the analogous life experience of both the counsellor and the consultant. This priority element allows the spontaneous phenomenon of "mirror- effect": an initial form of identification that represents a major stimulus to begin a counselling process. In this way, the more the disability- level of gravity and type - is similar, the more intense will the relationship and the level of reciprocity be, and the easier will it be for the consultant to open himself.

In any case, the counsellor must understand that the place and time of the meeting belong to the consultant, key actor of the relationship, and that his most important task is to listen. In this way Peer Counselling carries out Rogers's principle of "*Therapy focussed on the client*".

5.3 Effects and implications

Peer counselling affects both the subjective dimension of the person with disability as well as the socio-environmental one.

As regards the subjective area, Peer Counselling is a method at the service of the individual that allows him to make projects and to take initiatives, something he normally wouldn't have done. It allows achieving acquisitions, on a psychological level, that contribute to his growing-process and autonomy development. It stimulates processes of *recognition, empowerment, inspiration and proportion*.

Recognition

The fact that peers share some life experiences allows them to recognise themselves in each other and to share an atmosphere of trust and opening, without fear of not being understood. This recognition gives back dignity and legitimacy to the individual, to his needs, to his problems instead of leaving him alone with his difficulties.

Empowerment

The consultant must be strengthened in whatever he thinks is the best way, best approach or decision in a certain situation, he must be supported in his ability of self-determination. The conviction: "I can make it " substitutes the idea of being defenceless, inadequate or inferior. Total autonomy becomes a choice instead of a dream. All this favours his psychological growth and increases his self-respect as well as his self-esteem.

Inspiration

A peer counsellor represents "a role model" for the consultant who feels inspired and encouraged when he meets people that share the same condition of disability. These people have already fought the battles he is still fighting and have, notwithstanding the internal and external difficulties and obstacles, successfully achieved the set goals. Learning from these people or "learn from life" is an efficient way of acquiring ability, of finding possible solutions, of working out ideas and taking on new attitudes.

Proportion

The proportion process inserted by Peer Counselling allows the people with disability to recognise and distinguish the responsibilities of the single individual towards the whole society.

The consultant, in his mirror-effect process with the counsellor acquires awareness of the fact that the obstacles he meets do not depend only on him - previously they made him think: "I am the most unfortunate of all men, something is wrong with me"-; but also on the environment, organised according to criteria that don't include him.

Peer Counselling unhinges emotional, psychological, cultural and political conditioning, which throughout human history turned people with disability into an “oppressed minority”. Thanks to this activity people with disability achieve important results as for example they increase *their awareness* of their own life and its difficulties; they obtain a *major freedom* in making choices on personal and social levels; they increase their *sense of responsibility* in choosing the above-mentioned solutions.

Substantially, both the individual and society benefit from these changes in attitude and in the accomplished independence levels.

5.4 To whom is it addressed

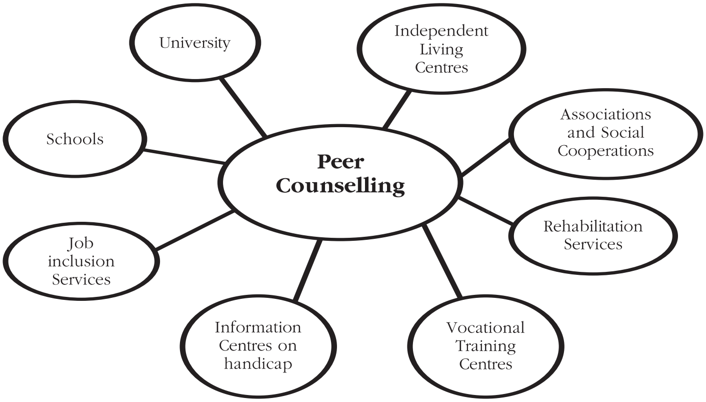
The Peer Counselling experience is, as any other human relationship, characterised by its uniqueness and singularity, because this is how its participants are. It requires from the person, who decides to embark on this process, a strong motivation to change, this implies taking on responsibility and freedom of choice, based on a precise knowledge of what one is going to try out. Such a change can be more or less total and in the same way the process can be more or less difficult and complex.

Furthermore, the consultant has an indispensable availability to:

- Undertake a personal growing process, or to be precise, to know himself thoroughly familiarising with his most intimate Self
- Acquire the necessary instruments to realise himself
- Resolve personal problems and carry out ambitions and projects, that is, improve and insert himself in a new situation and job.

5.5 Application context

For the opportunities it offers and the results it aims at, the Peer Counselling activity needs a structure or a frame in which it can create a suitable setting to accompany the consultants in the exploration of their abilities and to believe in them. Therefore, it can be considered as a profession or activity to be integrated in the wide array of public and private services addressed to people with disability, adapting its specific goals according to the intervention area. (See graph).



To summarise, while writing this book we often said that Peer Counselling is an activity carried out when a disabled person asks another person, who shares the same disability condition, for help to solve another person's problems. It can also be carried out in a group setting, and in this case a certain amount of people with disability receive support simultaneously not only from the peer counsellor but also from the interaction with the other members of the group. We also wrote that the consultants are seen from an empathic point of view and that the advice given doesn't make part of this kind of intervention. We have also underlined that, in relation to the goals and objectives of Peer Counselling, even if the counsellors help the consultants to identify and handle their problems, they don't want to change them or make them citizens with a higher degree of adaptation. If there is any change, it is a direct consequence of their commitment and their personal achievements.

CHAPTER 6.

THE PROFESSIONAL PROFILE OF THE PEER COUNSELLOR

I can be open to what will happen only if I can leave the past behind, I can only let go of the past when I am open to the future- If this is not possible, dwelling in the present is also impossible.

Wolfgang Blankenburg

We have confirmed more than once in this book that the method of Peer Counselling can be an important instrument to generate empowerment in people with disability.The Peer Counsellor is, therefore, a strategic and competent figure inside the service system in support of social and cultural policies that outline for the people with disability the right and the possibility to live an autonomous and independent life, with equal opportunities and with respect for their Civil and Human rights.

More than once did we assert that people with disability themselves are the best experts in all the problems that regard their lives. But we must also admit that not all of them can be a "role model", a positive mirror, and not all of them express the necessary skills, motivations, candidness and competences.

To be honest, there still doesn't exist an unambiguous definition of the Peer Counsellor's professional profile, even if there have been several attempts in Europe.

In short, to be able to exercise this activity one needs an indispensable personal growing process that leads to the acquisition of a self-awareness related to one's experiences as a disabled person, to one's limitations and potential, as well as to one's ability to build a relationship with others. Besides this individual emancipation process, a training process is equally indispensable, to learn specific techniques and methods, necessary instruments to carry out a support-relation as Peer Counselling.

6.1 Deontological principles

The role of peer counsellor clearly is a particularly delicate one, because it affects the most intimate and personal dimension. Therefore it is necessary to identify clearly the deontological principles:

- *Be Reserved:* Exploring one's Self and one's problems is difficult and sometimes painful. Therefore it is necessary to create a safe and serene setting, where reserve is the leading principle of fundamental importance. The information regarding the participants of a peer-counselling meeting is strictly confidential and as well as what is shared in a group or individual meeting.
- *Never judge.* The consultant's desires, rights, values and beliefs must always be respected in every way. The counsellor never evaluates or judges; on the contrary he unconditionally accepts what the other person is telling him.
- *Inform don't advice*. The whole activity is designed to leave space to the other person so that he can decide, organise, act, experiment and strengthen his personal abilities. That is why the solutions should not be suggested. To indicate a way that has already been outlined is against the final goal and it is often better to calm down the consultant's "anxiety for a solution", than answering his actual needs.
- *Don't instruct*. The peer counsellor must give vigilant attention to the consultant without taking any initiative. Whenever he wants, the consultant is free to make choices, to finish the session, not to answer the questions, not to take on responsibilities in a group.
- *Be transparent*. The peer counsellor must give clear information on what Peer Counselling is: on its goals and the application of its techniques, before using them. This stimulates the protagonism and the active participation of the consultant. It confirms and strengthens the "peer" relation.
- *Recognise the limitations.* When the consultant needs sup-

port outside the Peer Counselling activity the peer counsellor will indicate him the right organisation, institutions or an expert that can resolve his problem better. This principle implies a good knowledge of the intervention field. In this case it is better not to be a mediator but rather give useful addresses or references so that the consultant can contact them by himself.

6.2. Requirements

Considering the fact that the peer counsellor is basically a "facilitator" of the other person's personal development, to perform his role he should have some fundamental requirements related to his personal dimension:

- *Disability*. To perform this professional role it is necessary that the counsellor has experienced all emotional, social and practical difficulties inherent to the condition of disability. The peer counsellor has to be a "… "Survivor", that is, a person who has already successfully dealt with the same problem and for this reason he has acquired useful competence based on concrete experience rather than on specialised training"[24].
- *To be "integrated "inside*. The counsellor must have a certain awareness of his inner world, which allows him to manage his inter-psychological dynamics better and to improve his capability of living autonomously. The peer counsellor must be able to handle his own feelings without projecting them on the consultant, with the risk of conditioning the support-relationship. On the other hand he must also be able to live his own feelings introducing them in this relationship, without fear or shame.
- *To have a positive relationship with one's body.* The counsellor must have worked out the process of lack, inside himself he must have a realistic picture of his personal condition and he must have accepted his functional limitations.
- *To be socially integrated.* The counsellor must have those social abilities that allow him to introduce himself in a network of interpersonal relationships, ready to meet confir-

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[24] P. R. Silverman, *I gruppi di mutuo aiuto*, Erickson, Trento 1993, p. 32.

mation or disconfirmation. With relational contexts we mean family, friends, school, job, associative etc.

- *To have communicative and relational skills.* The peer counsellor must have an aptitude to listening and communication, using all verbal and non-verbal communication channels.

6.3.Tasks

The peer counsellor's role is based on a process management linked to the following professional reference tasks:

- *Orientation and information*
- *Organisation and management of self-help groups*
- *Management of Peer Counselling activities (individual and in group)*

6.4.Competence analysis

Besides the requirements regarding the personal dimension, it is important to underline that one should also have technical skills, acquired through a well-organised training course.

Therefore, to carry out his activity in the best possible way the peer counsellor must obtain *knowledge* from the following disciplines:

- Basic principles of humanistic psychology focussed on the client
- Social psychology
- Universality of languages
- Laws regarding regulations on disability: international, national and regional
- Elements of computer science

In particular he must acquire knowledge related to:

- Constituent elements of verbal and non verbal communication
- Communicative languages: gaze, voice, movement, breath
- Forms and ways of communication
- Inter-psychological dynamics
- Interpersonal dynamics
- Group dynamics

- Principles and history of the Independent living Movement of people with disability
- Principles and method of Peer Counselling
- Principles and method of the help-relationship
- Stages of Peer Counselling and relative techniques
- Stages of self-help and relative techniques
- Regional, national and international general and specific laws regarding people with disability
- Principles related to the autonomous and independent life of people with disability
- Institutional competences in the field of disability
- Procedures to claim rights
- Technical and financial instruments for the people with disability
- Resources of the territory
- Role and organisation of the associations of people with disability.

Besides the knowledge, the peer counsellor must master *operative procedures*, among which the ability to:

- Conduct a peer counselling session
- Be a "role model"
- Conduct self-help sessions
- Use the following techniques: active listening, expression and analysis of emotions, problem solving, planning, relaxing and awareness of the body
- Build up empathic and authentic relationships
- Manage groups
- Analyse and resolve personal problems
- Direct
- Inform

Furthermore more specifically, he must be *able to*:

- *Support* the disabled person in the stage of creating links with institutions, agencies and organisations that supply services.
- *Educate*, that is stimulate the disabled person to learn new ways of behaving using all his potentiality in his interaction with the contexts.
- *Be a model role* in as far as he has reached a level of inner independence and of social integration, which stimulates the

consultant to undertake the same growing process that might lead to the full development of his potentiality.

- *Be an emotive support* through his presence, listening and sharing of emotions and experiences.
- *Supply information and advice*, giving indications regarding regulations, procedures, best practices and whatever else may help to face problems linked to disability.

Finally, he should have the following *behaviour* and *professional attitudes*:

- Adaptability
- Docility
- Empathy
- Communicativeness
- Authenticity in the individual and group relation
- Availability to listening and dialogue
- Cooperative attitude
- Attention focussed on self-training
- Attention focussed on the comprehension of the expectations
- Attention focussed on the respect for work
- Self-awareness of body and emotions
- Motivation for the role of peer counsellor
- Easiness of expression and communication
- Clearness of the goals in personal life project
- Awareness of the rights of people with disability
- Involvement in the activities of associations of people with disability
- Motivation to overcome obstacles linked to the condition of disability

6.5.The Supervision in Peer Counselling

The management of the Peer Counselling activities must necessarily have a supervision stage, because it works in close contact with people.

The word ‘supervision’ has a clear etymology: *supervidere*, or to look upon, to supervise.

In this context the word certainly shouldn’t be interpreted as “control” but rather as an “external and expert eye” that observes from a higher position.

Thanks to the supervision process the peer counsellor is given the opportunity to discuss his job with an expert and qualified colleague in order to identify the problem areas that create indecision and if necessary to supply a guide line. This activity must be an essential part of Peer Counselling and cannot be considered as facultative.
The supervisor helps the peer counsellor to offer the consultant a quality service, because he represents a wide range of opportunities that help the counsellor to grow and develop personally and professionally within the field of Peer Counselling skills.

One or more persons who have the following characteristics exercise the supervision:

- They stand outside the activity in order to have a complete vision. They are not involved in the relationship dynamics and therefore they have an objective and detached vision, useful for the analysis and verification of the counsellor's job.
- They are experts and competent. This allows the supervisor to perform the function of guiding, directing and refining the counsellor's skills.

An important feature of the relationship between counsellor and supervisor, as well as of the relationship between counsellor and consultant, is the reciprocal trust, especially from counsellor's side. Moreover it is important to reflect on the analogies in approach and training background.

Functions of the supervision

- Feedback of the work done and elaboration of the contra-transfer, i.e. of the relation between counsellor and consultant and of the reactions evoked in the consultant.
- Verify the progress of the activity and introduce possible corrections.
- Assure the correct formulation of the Peer Counselling relationship and protect the consultant from possible mistakes and manipulations, even from unintentional ones, that may occur.
- Carry out a monitoring and evaluating action in close collaboration with the consultant, using the proper instruments.
- During the supervision, the peer counsellor can reflect on the work he is doing, identify the problem areas and clarify them.

He can look into the techniques and strategies he is using, highlighting the concrete and potential difficulties he is dealing with and discuss the given encouragement or the proposed challenges inside the Peer Counsellor relationship.

Objectives of the supervisor

- Help the peer counsellor to have more confidence in his own abilities and to develop an awareness of the dynamics used in his relationship with the consultants.
- Support the peer counsellor in handling the consultant's problems and if necessary his own personal problems that might influence the help- relationship.
- The supervision contributes in carrying out a definite programme of Peer Counselling by avoiding dispersion and fragmentation of the activity.

Instruments and implementation methods

To obtain supervision it is very useful that the counsellor holds a kind of logbook in which he writes down the entire individual and group activities; particularly useful is the description of difficult situations and moments and relative considerations.

The risk exists that the supervisor is considered as an intrusion in the group or for the single consultant. In this case we want to make clear that the consultants should be informed about the supervisor's position. If necessary, the supervisor is given some information about a consultant; the latter has the right to know the reasons and to express his consent regarding the use of his personal data in advance. At that moment he will be informed about the supervisor's didactic function for the counsellor, who, thanks to this relationship will do a better job in creating an efficient help-relationship. So indirectly, the consultant will benefit from the supervision as well. Naturally also the supervisor, as the peer counsellor, has to respect professional secrecy as well as an ethic-deontological code.

CHAPTER 7.

METHODS AND TECHNIQUES

> *That I may have the strength to change the things I can change, that I may have the patience to accept the things I can't change, and most of all that I may have the intelligence to distinguish them.*
>
> Thomas More

Peer counselling is defined as a structured method of psychosocial intervention appropriately called counselling.

Thanks to the Peer Counselling method people with disability increase their self-awareness by working on their body, emotional, fantasy and logical-rational dimension, as well as on their ability to enter in relation with others. For each of them, apart from their specific life condition, growing as a person means "harmonising" these different dimensions, obtaining a positive relationship with them - of contact, listening and not of mortification- and let them flow freely so they can integrate with each other.

The key of the process linked to this method is communication: with oneself and with the others.

The scientific roots of Peer Counselling can be found in humanistic psychology, more specifically in the theories of Carl R. Rogers and Robert Carkhuff, and it has structured its operative methods drawing from the socio-political experiences of the emancipation movements, developed in America by extremely discriminated social subjects.

As far as the methodological part is concerned, the experience of DPI Italy availed itself of:

- The management techniques of self-help groups developed by the American psychiatrist Jerome Liss;

- The techniques of body-awareness, more in particular of breathing and relaxing introduced by the Dutch peer counsellor Peter Van Kan;
- The techniques of non-verbal communication and the use of expressive communication specifically linked to Stefania Guerra Lisi's theory of the universality of languages.

7.1 The key elements of the method

The elements that distinguish the Peer Counselling methodology are represented by:

Listening
The attentive, vigil and active listening of the counsellor implies a message, which we can define as the trigger of the change process. The listening, implicitly communicates the following message: "*what you experience, say or think is justified; your needs and desires can be expressed and are seriously taken into consideration. I recognise them and I recognise you, now you can recognise yourself*".

Empathic Comprehension
As Rogers states, empathy is the ability to put yourself in the other's place and look at the world from his point of view. "Empathic comprehension regards the helper's ability to understand accurately the other person's personal situation: from what he is saying (from the objective contents of his expressions) and from what he is (from his revealing himself non-verbally")[25].

The mirror effect
The consultant mirrors himself in the counsellor and thus finds a new image of himself: a person who chooses and decides, a successful person, a person that moves beyond anger and refusal. The acquisition is immediate: "if it was possible for him it will be possible for me as well". Little by little the dimension of impossibility and negativity fades away.

Concreteness
In his relationship with the consultant, the counsellor stimulates the former to establish some small or big concrete objectives and avail himself of his own resources to identify strategies and instruments to achieve

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[25] R. Carkhuff, *L'arte di aiutare. Manuale*, Erickson, Trento 1987, p. 24.

them, for example to live alone or to tie one's shoes, find a job or get a driving licence, achieve an emotional equilibrium or manage to go to the cinema alone.

7.2 The reasons of the method

In this paragraph we will explain some concepts and themes linked to the disabled people's experiences with their body, their emotions, their fantasies and their thoughts. Concepts and themes that allow us to analyse and clarify the reason why we use this method and on which experiences and contexts it is based.

The self-image and awareness of one's disability "what is wrong with me?"

The self-image is built in the first months of life, when a baby starts to distinguish itself from the rest of the world. Through the exploration of its body and grasping objects the child learns how it can interact with its environment and how it can influence the latter by means of its movements.

Action and movement put the child in contact with reality: with things and with the others but most of all with itself. In this way the child starts to build its own body scheme, which is not something, predefined or static, but rather the result of the child's dynamic psychophysical growing process related to the manifold experiences it has in the course of its life.

This also happens to a child born with a disability. However its psychomotorial development is conditioned by the limitations and/or deficit of its disability. The experiences and frustrations caused by its physical inability and by the impossibility to explore space freely, hinder it in producing an image of itself as a separate entity. Therefore it is difficult for a person with disability to recognise himself as "a unique person", because there are only few external stimuli that reinforce his individuality.

Equally difficult is accepting oneself and one's body when one becomes disabled in the course of life. In this case self-knowledge undergoes a sudden and total change, because the self-image must be re-elaborated and re-modelled and so must the previous personal and social relationships.

The experience and perception of one's body is a moment of confrontation with oneself and with the others. Within the body dimension new ways of communication, rewarding and frustrating relationships, ability and capability, the person's social and evaluative projection are experimented. For people with disability this experience is very significant because it is linked to the awareness of their physical condition and to the way in which they experience it in social relationships. To this one must add the life experiences that have deeply influenced their self-perception: institutionalisation, lack of free and equal social relationships, humiliating and degrading medical treatments.

It is obvious that the negative experiences, often characterised by dramatic episodes, produce a series of perceptive distortions as regards the acceptance of one's psychophysical condition. A lot of these experiences are the result of prejudices and do not represent real conditions. Every person with disability progressively confronts himself with real and ideal elements, which distinction one cannot always perceive easily. When working on oneself, one needs to distinguish between what is directly linked to the condition of disability and what derives from a negative social vision. The distinction between these two levels, the personal and the social, allows the individual to regain a realistic perception of being a person with disability and to give back to the social context those prejudices that negatively influence the contact with diversity.

The sexual experience. "Me and you can only be friends..."

The relationship with one's sexual impulses and the communication levels of this dimension represent for all of us a confrontation with the others. This experience involves the affective and emotional dimension, the one of pleasure and frustration.

People with disability live this dimension in a problematic way for a series of objective reasons and subjective perceptions caused by functional limitations. A critical aspect is the so-called "Peter Pan syndrome" made to fit people with disability whose sexual dimension is not recognised. Only think of some trivial things, for example in public places there is only one accessible toilet, no distinction is made between gentlemen and ladies' restroom.

The truth is that people with disability aren't given any sexual potentiality, it is as if they live in a limbo without any impulses, it is as if they are eternal children, victims of morals that make them feel guilty. Surely this subtle and unexpressed difficulty is the most difficult to fight, but it is not the only one!

The lack of autonomy and the functional limitations cause obvious and objective difficulties, but there are also those caused by a scarceness of meeting occasions or by the problems regarding self-acceptance, that condition the individual's ability to see himself and to recognise himself as an attractive body.

Apparently men's experience of their body and sexuality is different from that of women. There are many deep cultural and social implications linked to gender. Compared to women with disability, men with disability have more chance of building their sexual identity also because cultural stereotypes place the male category in a more privileged position than women. On the other hand, women with disability remain victims of those cultural schemes that see the female image conditioned by the abstract canons of beauty and attraction and social perception identifies them as "failed women" with an a-sexual body and without any femininity.

Love. "The one who was kissing you… is your brother, isn't he?"

Knowing how to live a love relationship means having awareness and being able to confront oneself with the deeper dimension of one's psychological side, which is always linked to pleasure and pain. The love for parents, the complicity of a friend, sexual and affective attraction for another person are different aspects of the emotional dimension.

People with disability hardly ever experience their love life serenely because their love relationships are diminished by the condition of dependence and need of care taking of a body that is not perfectly functional. The fear of being abandoned, of not being assisted in daily needs leads to the fact that most of the time people with disability aren't free to choose, to start or to finish a love relationship.

A body that is seen and experienced as imperfect and that doesn't fit the canons of "normality", the fear of being refused, the difficulty in communication, etc. don't consent them to live love peacefully and even less to express their feelings. To bridge the gap of imperfection and the stigma of "diversity" every person with disability should be able to experiment and re-discover the vital energy of his body that, as all others, transmits sensations, emotions, desires, needs and impulses.

The social image."If you see a hunchback touch wood!"

Beauty and physical strength, the image of men and women transmitted by the mass media, publicity, culture and customs interact with the perception that every person has of himself, producing an inevitable confrontation with these ideal models, which causes frustration, feeling of inadequateness, incapacity and impotence.

The negative image daily transmitted by society affects people with disability negatively. Getting rid of the cage called " bearer of handicap" and understanding that one is "a receiver of handicap", and living one's diversity as a natural condition is one of the most emancipating and liberating experiences ever known! Freeing oneself of the need to become normal at any cost and living as one is, is a long and complex process but it is possible!

In nature everything is based on diversity: all trees, all flowers, all animals are different from each other. And so is every person different from the others due to different chromosomes, different characters, different life experiences, and different psychophysical abilities. Only a cultural convention confers negativity to such diversities!

Limitations and barriers:"What are you doing? You can't!"

Facing and overcoming limits even in the smallest daily activities involves a process of growth and maturation. The condition of disability is often experienced as an unsurpassable limit. In this way feelings of refusal and passiveness are enforced, which diminish the process of autonomy and become a mental habit.

We should reflect on the fact that the concept of limitation is neither static nor unchangeable and mainly depends on the cultural context and on the available instruments. In India, where wheelchairs are considered as a luxury for the rich, people with a motorial disability move themselves using rudimentary devices, like wooden boards with wheels, wooden supports or solutions that favour the "dragging" movement. The western culture would define this behaviour as degrading, but in that context it is taken for granted and it is culturally accepted!

In the human species these factors are influenced by culture and social conventions that can determine, in one way or another, the improvement of technological solutions.

It is clear that every limitation is dealt with according to the individual abilities and adaptation skill. In this sense everyone adapts himself to his condition. No giraffe would dream of living in a fox lair even if this is a limitation of its opportunities! Limitations and adaptation are thus complementary.

Autonomy. *"Where are you going without an escort?"*

The process of autonomy regards everybody and not only people with disability. It develops in progressive stages that see the subject transform himself from child into parent, going from a situation of dependence to one of autonomy, from individuality to sociality. Autonomy has its genesis inside the family. At a certain point of his life the child feels the need to be autonomous, building his own life spaces, social roles and external interpersonal relationships. Certainly this process, also made of tensions, conflicts and pain, doesn't happen for everybody in the same way and at the same times, but everybody must face a confrontation with his family and with the people that surround him, with the opposite sex and with love, with society as a whole.

People with disability meet more obstacles in this process of affective growth and autonomy because frequently inside the family attitudes of *overprotection* are activated that hinder them in acquiring the right instruments to confront themselves with the external reality. Other probable mechanisms are: *substitution*, that hinders them in experimenting and acting on their own and to develop the ability to identify proper solutions for themselves; the *degradation of one's abilities*, which increases the limitations caused by disability, underestimating the adaptation skills and abilities.

The affective growth of people with disability is a complex process, full of difficulties because they have not dealt with the unpleasant confrontations and strongly emotional responsibilities with the necessary clearness, determination and transparency. Autonomy is linked to the ability of wanting and knowing how to choose and to the progressive taking on of responsibility regarding the consequences of these choices.

To achieve all this we need a strong empowerment job.

7.3 The techniques

"In the classical Rogers-model, the help intervention stimulates the subject to take action. He is helped in achieving self-comprehension, exploring experiences/behaviour/emotions, in having a clear idea of the context of his choices, of possible personal changes, of the skills to acquire. Rogers believes that understanding is enough: the responsibility of the action is left to the person, who, once he is able to distinguish and to evaluate, should act for the best"[26]. We can find the same aim in Peer Counselling: first of all the counsellor should conduct the consultant to acquire awareness of his limitations and potentiality, then help him to establish goals and finally to achieve the latter by acting efficiently. The consultant is prepared for action by means of different techniques used in specific fields as: *Active listening, awareness of one's body, working with emotions and fantasy, Problem solving*, *Planning*.

Active listening

If I ask you to listen to me
And you start telling me that I shouldn't let go of myself like that
You hurt my feelings

If I ask you to listen to me
And you think you have to do something to solve my problem,
As strange as it might seem you don't help me at all in this way.

Listen to me! All I ask is that you listen to me,
Don't say anything, don't do anything just listen to me.

Listening is an active process that requires the counsellor's commitment and concentration, as well as the ability to put aside his own problems and worries. In fact, "what people say and the way in which they say it, tells us a lot about how these people see themselves and the world around them"[27].

One doesn't only listen to the content or the words but also to the way in which something is transmitted. The prosodic elements of the voice such as the tone, the volume, the intensity, the rhythm and pause are in fact aspects of verbal communication that supply further information about what the person feels and experiences in that moment. Listening also means observing the consultant in his non-verbal communication:

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[26] R. Mucchielli, *Apprendere il counseling. Manuale di autoformazione al colloquio d'aiuto*, cit., p. 19.

[27] R. Carkhuff, *L'arte di aiutare. Manuale*, cit., p. 79.

the expression on his face, his posture, the eye contact, his gestures and the physical contact.

Most of the time we don't listen, or worse, we don't "hear" the essence of what the other person is trying to express through his behaviour and words. We limit ourselves to listening to the sound of words without understanding them. "To hear means to grasp the authentic "music" beyond words and personal attitudes. To hear means to know how to focus our attention on how the other person sees himself related to his world"[28]. Words transmit the intellectual content of what the consultant experiences or has experienced; the tone of voice tells something about his feelings; whereas the way in which he expresses himself is an utterance of his energy. To understand all this the peer counsellor must have a fundamental quality: he must be *empathic*, meaning he must be able to gain access to things, to the people's life and experiences.

Listening is a very demanding task and many of us have never learnt how to do it. The conditioning and fear of opening towards the others tend to keep us on a superficial level. To be efficient in his active listening, the peer counsellor should give the other person an unconditioned attention transmitting him the possibility of meeting and the pleasure of understanding and being understood, without manipulating him. However, one should always keep in mind that the danger of manipulation actually exists, in as far as a person with disability, who starts a peer counselling process, lives in a critical and confused condition regarding himself and the world that surrounds him and he should be able to trust in full serenity and confidence.

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[28] R. Carkhuff, *L'arte di aiutare. Guida per insegnanti genitori, volontari ed operatori sociosanitari*, Erickson, Trento 1994, p. 45.

Simulation of a peer-counselling session in which the technique of active listening is used. This exercise was performed by the pupils during the training course carried out by DPI Italia (1st January 1998-31st December 1999)

Counsellor: *G.*
Consultant: *A.*
Theme to deal with and to work out: what the consultant has learnt in this course and what else he wants to learn in these days.
A.: tells about her own experience and most of all tells about the self-help seminar, during which she freed herself saying things she had never said to anyone before.
G.: "so, to specify, the course unblocked you. What do you expect from these ten days?"
A. "To improve myself more and to learn. The fact that I am here talking to you voluntarily is in itself already very important".
G.: "How do you imagine yourself after these ten days?"
A. "To share with others what I have learnt".
G.: "I think I understand that this course has strengthened your communication skills, tell me if it's right, you would like to sow what you have learnt here".

Group Feedback

The teacher invites the counsellor and the consultant to tell the group how they felt themselves in their roles.

G.: "I felt limited: it is very difficult to simulate in front of everybody. A. was very good because she started to talk so all I had to do was accompany her.
Teacher: "This is a very natural difficulty because we are not ready yet. In time this will disappear".
L.: "G. was very much involved, she was touched by what A. told her. Is the emotional involvement positive or something to avoid?"
Teacher: "Empathy is all right, but one should always remember that we're not dealing with the counsellor's problem and she/he is not responsible for the problems of the other."
R.: "G.'s facial expression was very stimulating for the other person. I think this is very important in order to create empathy.

A. “G’s calmness was very important because it helped the other person to go deeper.”
Teacher: “It was clear that A. felt at ease, G. followed what she said. But A. didn’t tell what she had learnt. I hoped that G. would have said: but what have you learnt?”
G.: “I understood that there was nothing else to say for A. except what she had been able to communicate.”
Teacher: “Her answer could have been ‘nothing’, but the question should have been asked. Important is not being guided by emotions or being blocked by emotions. Perhaps it helps when you say ‘it was the same for me’ to give more space to the consultant and make him feel at ease. I would like to underline the necessity of clear answers; I need to obtain what I asked. After the question: ‘What do expect from these ten days?’ A. was embarrassed, at that point she should have been given more space and she should have been put at ease. For example the counsellor could have said ‘I’ve also been embarrassed’”.

The techniques used by the peer counsellor to give unconditioned attention in the active listening process are:

→ *Giving attention*
→ *Using questions*
→ *Paraphrasing*
→ *Summarising*

Giving attention to the consultant means to listen to his verbal and non-verbal communication. The counsellor shows this kind of attention through his body language. In fact, the counsellor “acts physically” when he gives attention and he should pay attention to the position of his body, the expression of his face and to the eye contact, transmitting to the consultant not only that he is ready to listen to him but also that he is ready to satisfy his needs.
As regards the body position, the person who listens must feel at ease and relaxed and he must also keep “the right distance” from the person who is talking: he shouldn’t come too close and become intrusive, taking away space, but on the other hand he shouldn’t be too far away, giving the impression of being uninterested and detached. We should pay attention to our posture, because with it we communicate how much we are

available towards the other person. Our thoughts, feelings and sensations are reflexes and they show through our posture. If we take on an attitude of opening towards the other person we communicate that we are with him, that we are interested in what he is telling us. The best posture to take, to show attention, is sitting in front of the other person, face to face, putting yourself on the same level. When you are sitting it is important that you bend towards the other, whereas when you are standing you should reduce the physical distance getting close to the other person as much as possible.

Attention can also be revealed by using the senses adequately, especially the eyes. Therefore the counsellor must look into the consultant's eyes because his attempts to reach him by looking at him show his effort and endeavour to reach him in a wider sense.

Giving attention implies a more explicit physical contact as for example an embrace (in our case, being disabled persons with mobility problems, one can put his hand on the other person's hand or arm, etc). Broadly speaking, embracing is in some cases, in some moments and with some people the right thing to do, but in other cases one should avoid it because the gesture might put the consultant in a difficult position. In these situations the counsellor must evaluate whether or not he should show his support in this way.

Another way of showing that you are listening to the other person is to nod, say, "yes", "go on". Furthermore it is important not to interrupt the consultant while he is speaking in order to allow him to determine the course of the conversation.

Using questions. In every interpersonal relationship there is interaction, this shows that we are not acting and reacting only for the sake of our goals and objectives but also for the sake of what the others are telling us or doing to us. To obtain an interaction of a certain quality the peer counsellor should skilfully ask the right questions in the right moment, because only in this way, besides creating a welcoming atmosphere, he encourages the consultant, who asked for help, to talk and to focus on what interests him. The questions should be asked in such a way as to highlight the consultant's "experience" and not to remain on the surface of what he is telling.

Obviously, the counsellor should identify the right kind of question for the person sitting in front of him, relevant to his personal life story; but also for the stage the help-relationship has reached. The peer counsellor can use *open questions* when he wants to go deeper into an issue, when he wants to help the consultant to explore a problem, ideas, feelings or emotions thoroughly. Substantially these kinds of questions encourage the consultant to talk. They can be useful to loosen up tense situations and to guide the conversation towards a more personal or intimate point. We should however be mindful of the risk that the consultant starts babbling nineteen to the dozen, loosing himself in useless chitchat. To avoid this the peer counsellor should start using closed *questions or questions that ask for short answers*.

Closed questions are used to obtain more accurate information, to specify better in case information hasn't been too clear, to avoid random chatter, to calm down anxiety and fear and finally to verify the given information.

Obviously an indiscriminate use of closed questions can be counterproductive to the help relationship activated in peer counselling: in fact, they may smother the dialogue, provoke "yes/no" answers and create an impersonal climate.

An expert peer counsellor is intuitive and knows very well that questions shouldn't be asked to satisfy personal curiosity or to fill in "silence". We should, however, underline that these moments of silence are also a significant element of the peer counselling relationship and the counsellor should have an absolute respect for them. In these, apparently empty, moments the consultant re-elaborates what is happening, what happened before and most of all he has those intuitions that launch him towards the planning and building of a new life. One should not be afraid of silence, but rather listen to it and respect it.

To paraphrase means to re-formulate in a more articulate way the contents of what the consultant is saying, using different words, focalising mostly on the sentiments behind the words. The task of the peer counsellor is to reproduce the consultant's contents and emotions transmitting him empathy and comprehension.

In order not to disturb the conversation it is opportune to start the paraphrase with sentences such as: "let's see if I have understood everything correctly", "did you say that", "is, what I have understood, right?" One absolutely shouldn't finish with sentences as: "isn't it?" or "yes or no?" With this technique the counsellor mirrors the consultant, revealing what he is and what he told, helping him in explaining himself and in becoming aware of his emotions and thoughts, enriching his knowledge as well as his prospective. Moreover it helps the counsellor to verify whether he has understood what the consultant has been telling and expressing him and to communicate that he is listening to him and that he understands him.

To Summarise what has been told and what emotionally emerged during the peer counselling session is of a fundamental importance. This technique captures the essence of what the consultant has said; it identifies the consultant's themes, ideas, problems and tendencies. Therefore, summarising is something more that just repeating what the consultant has said; it is not only saying the same in lesser words. To summarise well one should capture the essence of the consultant's thoughts and how he expresses his sentiments and then explain the underlying message and problem. Choosing the right moment to summarise is crucial because a premature interruption of the story might inhibit or embarrass the consultant. One should give the consultant the opportunity to verify whether the summary corresponds to what he has said and, if necessary correct it. When the summary is used to conclude the session, it is necessary that both the peer counsellor and the consultant agree on it and consider it accurate. As with the paraphrasing also with the summary one risks to interpret or falsify what the consultant has said. One should, therefore, always conclude with the question: "Does my summary correspond to what you have told during our meeting?"

The summary, as the paraphrase, allows the consultant to realise that his experiences, his emotions and his thoughts have been recognised and enhanced. Moreover, an accurate summary highlights the consultant's incoherencies and contradictions. In the case of the latter it is necessary that the peer counsellor gives a specific attention to the consultant's internal structure, as to avoid insensitive or judging statements.

In conclusion, to make a precise and respectful summary of the consultant, three fundamental elements are particularly important: accurate comprehension of what has been said, accurate selection of key elements and themes that emerged, as well as their clear, direct and empathic verbal explanation.

Body awareness

The counsellor's ability to meet the consultant physically is an essential element of the Peer Counselling session. He can show his interest by establishing physical contact with the other person, however this only happens if he himself is aware of what is happening to his body, of the sensations and emotions going through it, of its strength and weakness.

Being aware of one's body, in fact, means being inside it and experience it, getting in contact with self-perceptive and outer-perceptive stimuli, being in contact with one's desires, needs, limitations and potentiality but most of all being able to manage all experiences linked to these.

For every individual it is important to have a certain intimacy with his body, through which he can start a relationship with the others and with the outer world. Self-respect involves respect for one's body and this guides us in our respect for the others. We can't feel at ease in the world or in society if we don't feel at ease *in* and *with* our body. In a broader sense the body represents an important element of the individual's complex condition, specifically referring to the psychosocial state. Disability is an experience that drastically leaves a mark on a person. A body with disability doesn't fit the canons of "normality" imposed by society and it is difficult to accept it because acceptance is the result of a long and hard process during which the body can be denied and despised and no attention is paid to its signals.

The peer counsellor is a person with disability and it is therefore fundamental that he has gone through this acceptance process of his own body that he has learnt to listen to it and to interpret it. His experience may help him in interpreting the consultant's body because:

- The body can express messages that contradict the verbal ones: a defence situation or an interior conflict can be revealed;
- The body may express emotions that haven't been revealed yet: a blockage or a rigidity of one of the body parts may give access to essential themes;
- The body parts involved in disability "talk" and should be "listened to": they complain of being neglected, and even of being denied, they want care and attention. One should re-establish contact with them and they should be integrated with the rest of the body to obtain a new self-perception.

The techniques used in the specific field of body awareness are:

→ *Relaxation*
→ *Posture*
→ *Breathing*

Relaxation means consciously "letting go" the different muscle groups as much as possible without any excessive strain. By concentrating on the different parts of our body, one at a time, we become aware of every tension in them. At this point one needs to contract for some seconds the part where the tension is felt, focalising attention on the breathing rhythm: while contracting, one needs to breathe deeply and hold one's breath then release the tension and breathe out. Through breathing, first breathing in and then breathing out, one can free oneself from accumulated tensions, allowing the body to relax gradually. A relaxed body allows us to recognise our real needs and our emotions. One should breathe deeply and slowly.
Visualising situations or objects may be useful and purposeful to relaxing. One can do the exercise sitting down or lying on one's back: It may be a good way of starting a session or an efficient pause during long sessions and a way of re-composing oneself after or during moments of intense emotions.

The right **posture** is very important in Peer Counselling because it facilitates breathing and allows the energy to flow freely. This flow is sometimes hindered by a muscular rigidity or by wrong and dysfunctional attitudes, sometimes the result of emotive blocks.
Every individual communicates through his posture, his moods and his emotions. "When he bends his head forward and talks in a smothered voice he communicates a depressed mood. Whereas, if he holds himself upright and talks and moves quickly he communicates euphoria and excitement. If he takes on a rigid position and is nervous in his physical and verbal behaviour he communicates tension."[29]
To reflect on the body language of the other person and to invite him to look for an "optimal" position implies the physical translation of the individual's hopes, fears and intentions. This element is particularly relevant during the peer counselling sessions. The person with disability must assume the responsibility of his physical well being, for example being comfortable on a wheelchair can be an important step to gain more control over one's life.

Breathing is a cycle of movements, conditioned by both physical factors, in case of defined pathologies, and psychological factors. When we breathe we act: these movements, also called schemes, are determined

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[29] R. Carkhuff, *L'arte di aiutare. Guida per insegnanti genitori, volontari ed operatori sociosanitari*, cit., p. 57.

by emotions that describe the person's way of being and feeling, expressed in a particular way of breathing.

Each one of us has his own particolar way of breathing: rhythm, volume, coordination - integration of the movement of the abdomen with the movement of the chest -, degree of fluidity- a jerky movement instead of a continuous one -, amount of air exchanged, differentiation degree- a delicate movement instead of a stocky one.

Our breathing is our energy source, our fuel. It is perfect when we use our lungs to the maximum and to make this happen we should find a correct position and hold it: if we bend over, our ribs can't move and our lungs haven't got the necessary space to expand. Controlling our breathing in the sense of being aware of the fact that we are breathing, can be an important instrument to deal with emotions- excitement, fear, anger and sadness- and to start the exploration of ourselves; it is also a means to get in contact with one's needs in a certain moment.

The muscular contractions generated by intense emotions can be released by means of correct breathing. The peer counsellor will invite the consultant to concentrate on his breathing and to describe how he experiences it. After that he will invite him to follow the rhythm of his breathing. The breathing must be deep: breathing in until he fills his lungs or even his abdomen, holding his breath for some seconds and then slowly breathing out. It is very useful to repeat this exercise for 3 or 4 minutes. Another exercise is asking the consultant how he experiences his breath, what does he think it does to him in that moment and what does he think it wants to do. A third exercise may be to teach how to breathe for 3-4 minutes only by using the abdomen or only the chest, or alternating.

These exercises identify in the person a more differentiated sensibility to breathing impulses and a temporary restoring of one's breathing schemes. The Peer Counselling session can start from these to obtain an improved awareness of one's body with which the person with disability must familiarise in order to integrate it in his living experience, more and more conscious of his specific way of being in this world.

Working with emotions

The growing process of a person with disability is crossed by tumultuous emotions that accompany his self-acceptance process. One can never say that this process is concluded or definite, but it can lead the person to a level of maturity where he can handle the strong emotions derived from a life transversally characterised by disability.

Fear, shame and pride hinder a lot of people in recognising their way of being and in expressing themselves freely.

During the peer counselling sessions it may occur that the consultant is not aware of what he really feels. It is therefore important to help him in identifying his real emotions and feelings, in putting in words for example fear, shame and pride. When we accept what we feel, we can recognise the limitations and abilities with which we can build a project. We can recognise what is impossible to change, putting an end to useless battles, against ourselves and against the others, made of continuous negations of our reality. We can use our energy to modify what depends on us, by growing.

Growing means going beyond the past, confirm one's self-respect in the present, looking forward to a better future. Growing means changing.

Change implies pain, solitude and separation. Growing means distinguishing oneself from the others, recognise and confirm one's uniqueness as an individual, making choices and creating a personal life style that allows us to satisfy our needs and desires. All this means accepting and loving ourselves regardless of our limitations.

To make emotions emerge Peer Counselling uses the following techniques:

- → *Key word or sentence*
- → *Body Empathy*
- → *Physical intensification*
- → *Message*

Key words or key sentences are the most recurring words and sentences in the consultant's discourse, they can be particularly emotional. In fact "…they are forcefully pushed to emerge in our conscious mind by an intense emotional impulse"[30]. The peer counsellor's ability should be capture them and ask the consultant to repeat them more intensely.

With this technique, as a kind of resonance chamber, firstly the sentiments and emotions are amplified, then, as after the storm comes the calm, the emotive load calms down and the mind is open to new ideas again.

[30] J. Liss, *Insieme per vincere l'infelicità. Superare la crisi con la collaborazione reciproca e i gruppi di auto-aiuto*, Franco Angeli/Self-help, Milan 1996, p. 99.

Through the **body empathy** technique the peer counsellor harmonises himself with the consultant's emotive rhythm and intensity, choosing a body position that reflects the latter's mood, sometimes supporting him with small gestures such as nodding the head or giving him a calm and open look.
"Sometimes we wish to create an empathic presence, but this positive intention is contradicted, and therefore hindered, by automatic and unconscious body expressions that are not on the same wavelength as our partner's physical expression"[31]. The use of this technique is fundamental in peer counselling, because it allows keeping a vigil eye on the consultant, but we should be careful not to take any initiatives that might provoke collateral reactions. In fact, it might happen that the anxiety to identify a problem or to find a solution pushes the counsellor, taken by his own emotions, to be too insistent and invasive in the consultant's physical space.

Physical intensification means that the consultant is asked to repeat a gesture loaded with emotion. "The physical intensification is almost a synonym of emotional intensification: this because emotions are rooted in our body"[32]. The counsellor must be very careful in identifying those gestures loaded with emotion and rich in meaning, imitate them, amplify and intensify them. Moreover he must help the consultant to identify the body part in which he has felt the emotion and through physical contact, for example by pressing his hand on the spot, help him to explore it, to release it and accept it. In order to know which gesture should be intensified one should pay attention to the non-verbal language of the person: a finger that points to the heart, a shoulder that is lifted, hands tightly around the knees, folded arms. After the physical exercise, the consultant can define and describe in words and images the emotions felt.

The peer counsellor can identify or bring to the surface the consultant's sentiments and emotions by means of a technique Jerome Liss called "**I-Message**". This technique echoes the consultant's feelings- for example one will say: "I am sad" instead of "you are sad" ("You-Message"). The counsellor, in repeating the consultant's feelings in the first-person, puts himself, for a moment in the consultant's shoes, fee-

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[31] J. Liss, *Insieme per vincere l'infelicità. Superare la crisi con la collaborazione reciproca e i gruppi di auto-aiuto*, cit., p. 87.
[32] *Ivi*, p. 89.

ling his emotions and in doing so he enters his inner world. The re-formulation of feelings and emotions through the "I-Message" is an empathy form which effects are more powerful and efficient than the traditional re-formulation of the "You-Message". The person who receives this kind of empathy analyses his emotions more easily, with less shame and more confidence because he feels that the counsellor accepts him for what he is.

Working with fantasy

Fantasy translates in figurative terms physical sensations, emotions and thoughts, giving the individual the opportunity to get in contact with some parts of himself, of the world and the people that surround him, in such a way as to be constructive and useful for his development. It is therefore very important that during the peer counselling sessions techniques are used that stimulate fantasy and that can help the individual to acquire awareness of what is happening inside of him, of his limitations but also of his abilities, often mortified and devaluated.

The techniques used when working with fantasy are:

- → *Visualisation*
- → *Mental images*
- → *Affirmation*
- → *Role play*
- → *Intuitive approaches*

In ancient times the **visualisation**, connection between mind and body, was already considered to be a powerful healing instrument. The ancient Egyptians and Greeks were convinced that images could free spirits in our minds that promoted the re-awakening of our organs; they believed that a visual evocation of an illness was enough to produce its symptoms.

Today we owe its diffusion to the work of the American oncologist Carl Simonton, who believes that concentrating on sensations of well-being can reduce the symptoms of an illness and the collateral effects of the treatment. Convinced of the theory's validity he asked a group of cancer patients to imagine their white blood cells eating and destroying the tumour cells in their bodies. This experience confirms how strong the mind's influence can be, even on organic factors.

To understand the visualisation processes better we should necessarily understand the link between state of conscience and the speed of brain waves.

LEVEL	BRAIN WAVES (VIBRATIONS PER SECOND)	CONSCIENCE STATE
BETA	14 - 21	Daily conscience, action
ALPHA	7 - 14	Sleep, meditation, deep relaxation
THETA	4 – 7	Sleep, dream
DELTA	0 – 4	Deep sleep without dreams

Our mind is on the ALPHA-level: half-asleep, in deep relax and meditation.

When the mind is on the ALPHA-level there is no negation, no duality, so there is no choice, judgement or conflict. Everything comes and goes spontaneously. The left and right brain hemispheres work harmoniously and the male and female perceptions of the world and of ourselves are balanced. The door of our sub-conscience is open and for this reason we can make its hidden contents or information conscious.

With the visualisation we can experiment:

- Our real Self beyond any resistance or defence
- Our spiritual nature
- The creative power of our mind
- The ability to come in contact with those aspects of ourselves we have always suppressed.

The exercise of group visualisation should be followed by a moment of sharing: through an introspective process it can give us precious information about our fears of the past, the present and the future, about our expectations and aspirations.

To visualise means to be able to see something with your mind. Here follows an exercise that helps to understand what we are talking about when we say "visualisation".

Choose an object and observe it intensely. After having observed it for some time, close your eyes. At this point one has to look at the object, in every detail and colours with the *eyes of the mind*, as Peter Van Kan defi-

nes them. If you find it difficult to visualise it, you need to open your eyes and look at the object again, after that close your eyes again and try to reproduce its inside image.
Visualising something depends on our concentration and imagination ability; often it is necessary to practice constantly before you can do it successfully.

The **mental images** create a kind of universal language, not linked to any language in particular, that helps the human thought, facilitates reasoning and guides behaviour. The mental images give us the opportunity to practice new tendencies and to develop new attitudes because they are a configuration that substitutes reality, giving some information about it and leaving out other.
We act and we feel not in conformity with the real aspect of things, but according to the image our mind has made of them. We have a mental image of ourselves, of the world we live in and of the people that surround us and we behave as if these images are the actual reality. Very often these images are distorted and unreal and consequently they lead to a wrong behaviour. This is what happens for example when we hold prejudices against certain situations or other people but also against ourselves.
Using the mental image as a technique triggers in the individual a creative mechanism that leads him to success. In this way, by mentally imagining the much-desired final result, we put some pressure on our "I" as to make use of the positive thought, actively facing fears and making a direct endeavour to achieve a goal. This exercise forms new memories and data easily assimilated in our nervous system and our brain, facilitating the creation of a new image of our "I".

The word **affirmation** literally means reinforcement. In Peer Counselling, the importance of the affirmation technique consists in mentally reinforcing an intention we are pursuing or we want to pursue.
We all make choices through which we create our life, we enrich and colour it; these choices are partly based on reason, partly on intuition and a part is determined by the subconscious conviction we have of ourselves and of the world.
When we use affirmations we send information to the sub-conscience and by doing so we act on it. They have to be repeated while our brain is working on the ALPHA level.
Thanks to affirmation the negative convictions that are rooted inside of

us and that work against us can be substituted by positive convictions that work in our favour. For example: facing a problem that incites fear and that convinces us that we can't cope with it, by repeating the affirmation "I can do it" we will gradually become more confident and victorious people. The more relaxed we are while repeating the affirmation and the more we repeat it, the more efficient will the effect be.

Criteria to formulate an affirmation are:

- Use of the present tense: in an affirmation one should imagine what one desires as something that is already happening;
- Avoid negations: one should never formulate an affirmation negatively. Never say "I am not tense and restless", because the negation doesn't indicate any content and our sub-conscience will only react to the words "tense and restless";
- Start the affirmation with "I";
- The affirmation should be short and precise.

An example of the application of the affirmation technique.

The counsellor gives the consultant a positive input by telling him: "raise your arm, give me your "yes".
Then he tries to press down the consultant's arm but he doesn't succeed because the physical resistance is at its maximum.
Then the counsellor tells the consultant again: "raise your arm, give me your "no"". In this case the consultant's arm doesn't resist the counsellor's pressure and the arm goes down.

This example wants to show how much the mental aptitude influences the result of our actions: if the energy is positive the result will be success, whereas if the energy is negative the result will be disillusion and **failure**.
Every negative thought has a negative effect; if we think, "I can't do this" we probably won't succeed in doing it, it's a kind of prophesy (self-prophesy).
When there is a project but no positive motivation towards it, we

probably won't be able to carry it out; enthusiasm gives the energy and allows us to accomplish our goal.
What we really are depends on what we think: the concept we have of ourselves are affirmations and they can be either positive or negative.
The positive affirmation should be a simple and clear sentence in the present tense and not in the future, because our mind is like a child, it only perceives the present. The affirmation technique is practiced when our mind is totally relaxed, on the ALPHA level.
The key to success is inside of us.

The goal of the **role-play** technique is to activate in the individual, who identifies himself with a role, a mirror process in which he sees his reactions and the way he acts in certain situations. In concrete terms, it is possible to discover other resources and potentialities or hidden and unknown parts of himself. Therefore it allows us to discover potentiality we didn't know before and other opportunities and possible choices present themselves.
The role-play consists in performing a scene. It shouldn't be a complete and prepared story, or a performance with a script, but rather an open situation where the participants invent their characters and their way of being at the moment. It is obvious that the closer one gets to the real character the more efficient the use of this technique becomes. However everyone should express himself according to his skills and fantasy and the progress of the performed scene, which may be repeated various times, will add new elements that are important for the resolution of the situation: dialogues, body position, mime, interrelation, etc.

The following is an example of a role-play

"I decide what to do"

There is a mother, her son in a wheelchair, who wants to go to the cinema and a **taxi driver who** is late.
Son: "the taxi should have been here at half past seven p.m. it's eight p.m. now".
Mother: "You're not going out tonight, it's late".

Son: “Will you take me”?
Mother: “You know I can’t drive.”
The taxi arrives.
Taxi driver: “You can’t get in. There is no place for the wheelchair. You must pay extra and anyway you can’t because you dirty the car”.
Son: “I’ll take the taxi and that’s final”.

The **intuitive approaches** are techniques that allow the individual to come in contact with the deeper levels of awareness and with his creative sources. Some of them are:

- B*rainstorming*: reasoning according to analogy, it is often used when a problem belongs to a field one doesn’t know too well. It consists of feelings, thoughts, fantasies, events and dreams that suddenly and spontaneously come to mind without exercising any selection or criticism and without any kind of omission. It favours a better access to the individual’s inner world.
- The *association of ideas*: it consists in spontaneously associating a personal expression with other expressions that can be linked to it. For example, the word ‘disability’ can be associated to ‘solitude’, ‘impossibility’, ‘invisibility’, etc. but also with ‘conquest’, ‘engagement’, ‘project design’, depending on the different cases or moments of personal experience.
- *Painting or drawing, working with clay or other materials:* these are instruments that consent to give form to the individual’s somatic and emotive experiences.
- *Telling stories*: this instrument helps to know the person better and to have more information about his way of perceiving his body, his emotional world, and on which convictions guide his life.

The following is an example of telling stories.

Each member of the group writes on the same piece of paper a sentence that together with the other sentences will make up the text of a single story. Producing collective stories gathers in a metaphoric way the demands, needs and desires of every person. It facilitates and enforces the group spirit and the communication inside of it.

The first story
It was a sunny day…
The view from the window was colourful and attractive.
Everything around you gave you a joy to live.
The sunset was beautiful and relaxing.
Everyone went to sleep except for me.
I also saw a princess outside.
The princess was "good", sweet and sensual and I realised I desired her.
But my ideas about what to do and the best way to behave were a bit confused.
So I asked my friend for some advice.
"It is raining" he said "and everything is allowed, go beyond the last red cloud".
Suddenly a storm broke loose.
The storm distracted me from that marvellous vision.
But the storm was also part of this vision.
I realised that the princess was nothing but a cloud.
Whereas I wanted her in flesh and blood.
From that moment on the princess came nearer so I didn't feel lonely anymore.
She gave me a feeling of being welcome; as if all the past was justified by that moment.
And I felt less lonesome.
And I shouted yippy yae!!
In that moment I felt very happy.

Among all these confused written words, I want to read, understand a great desire to be together here.

The second story

There was once a princess.

And a prince called Gianni.

The princess had something strange; in fact her name was Roberto.

When Gianni realised that Roberto was a man he said: "Oh! Oh! What a handsome man" and did everything to attract his attention.

The prince's friend told him about the many lovers he had, one in every kingdom on earth.

The prince was very amused and called him to his court to tell his stories and they founded a club called "The Arabian Nights".

From that moment on the story became funnier and funnier.

To enjoying oneself became a rule.

And enjoyment lost its charm.

Unfortunately.

Because the princess had different desires than the prince.

As we all know, Buddha said that desires are the cause of sufferance.

What can we do?

Meditate, know oneself profoundly and find in ourselves the light and strength that allows us to live our lives with joy and serenity.

But an ant asked," Isn't sex knowing ourselves and knowing the one we love?"

"Sure" answered Buddha "but it is a very little portion of knowledge: you will never love with your body alone!!!"

The third story

One day the sun met the moon and they recognised each other.

Yes, but they recognised their diversity.

The sun was also dark and the moon light.

But they had in common, the freedom to express the feelings.

"What do you think of this earth and its population"? The moon asked the sun.

"I think the earth is a wonderful place, where life renews its miracle every day, man should make this miracle shine more and more" answered the sun to the moon.

"Or better, mankind should first of all recognise its existence" added the moon.

"In fact mankind doesn't it do it enough" she added.

Perhaps because most of the time they are busy counting an evaluating their bad luck…what a pity!

We should also look at the beautiful things life offers us.

We disabled represent a reality that society rejects and no individual ever wants to reach, we members of DPI, will try to destroy these individuals.

We should, however, be careful of not always putting the blame on society because we should be optimistic inside regardless of problems such as handicap. Let's remember that LIVE IS BEAUTIFUL.

Let's try to transform less in more (minus into plus)

In fact it is for this reason that we aren't all the same, mainly because if we add less to more we get: more or less, or less or more.

Fourth story

… It happened about a month ago.

I decided to change my behaviour in my relationship with my parents.

I met an old friend, I've known since I was 16, who had come back from Australia.

I've anxiously been looking for him in all the hard moments of my life.

And then I started to confront myself with my "being".

And I asked myself: who am I really? Where do I want to go?

But my Australian friend told me "do as kangaroos do: jump! Or better still, do as the bees do: fly from one flower to another to collect the nectar of love from every country".

I realised that inside of me there are many countries as well.

And in every country there is a lot of humanity to know and to love.

I looked up at the stars and there I saw my light.

That wasn't a splendid light and it didn't even make kangaroos jump.

Jump? Doesn't a jump make us neglect something or somebody? It is better to have a clear, strong and splendid light … just like

Friendship is, or… who knows, love.

No, one jump doesn't make us neglect anything and anybody; one needs to know how to jump!

We are in this room with the walls that are warming us.

Sometimes jumping can be amusing, one only needs a bit of courage and… hoopla!

Fifth story
I am happy and really need the sun and the sea.
This afternoon after lunch I will go in the colours of the sky.
I always feel at ease in that garden.
Even though I am convinced that there must be another more beautiful and better place.
Yes, perhaps there is a better place!
We all dived in the view from the window…
However the beauty must come from us first, and subsequently we will see beauty everywhere.
We are what we think we are, but are we what we think.
And it is for this reason that we are a gang…
And now I feel confused. Confused, I don't really know why, I keep on thinking about the princess because she is beauty.
Beautiful, yes, because I have something to share with another person, life is also more beautiful when you find another dimension of yourself.
Life is something beautiful to live, especially if we think about what is happening…
Anna la Rossa climbed up the poplar in front of her house. She whistled and all the neighbours gathered to listen to her message.
I answered that signal with a message of love and peace.
And Anna felt well.
! ! ! ! ! ! ! ? ? ? ? ?
But one question kept on tormenting me: where is that beautiful dolt of a princess?
Is she with somebody else? If I find her I'll break her legs.
Eh, listen Princess, where is your Tristan?

Problem Solving

In the whole history of psychology the solution of a problem is part of its definition, regardless of the words with which intelligence is defined. Intelligence consists in being able to understand that the elements of a problematic situation can be re-organised in a whole that leads to the solution of the given problem.

Every person has a different way of handling and resolving problems, each of us interprets them differently depending on our personality, experience, creative skill, our emotional and affective life story.

In Peer Counselling sessions, the counsellor must help the consultant to cope with his problem actively. However he should not substitute him in his search for a solution, but rather guide him to act on his own. The individual should discover the solution using the input given to him progressively and develop his self-confidence.

In fact, people with disability, should be stimulated to identify on their own the concrete answers to the situations they live in, since in their families, very often someone substitutes them in solving a problem, setting in motion a delegation-mechanism. For the person with disability this is difficult to avoid because of his ever growing fear of experimenting himself in real situations.

In this way the person with disability is incited to verify his potentiality and skills of choice making and of taking on responsibility towards the decisions to make. Thus he starts to believe in his autonomy and self-determination, and to develop his self-esteem.

We realise we have a problem when we meet a difficulty on our way, when what we are doing doesn't allow us to achieve the desired effects. At this point we have two possibilities. The first is to remain anchored to the obstacle and continue to lead our alienated lives, mentally and practically using the same conduct over and over again, which only supports the problem. The second possibility is to change our behaviour and the way of seeing, feeling and understanding things. Substantially we should invent new, alternative and efficient ways to achieve our objectives.

P*roblem solving* is therefore the art of the strategies used to reach these goals.

The stages of problem solving are:

1st Phase – Definition of the problem

The first phase of *observation* is used to know the nature of the problem and the goals better. It implies an observation and cognitive attitude. However, here 'cognitive' has a broader meaning than the one normally attributed to the word. We're not dealing with a logical-scientific knowledge, but rather with having access to the more profound aspects of our lives, it means re-cognise and accept our authentic needs, desires and fears.

In the Peer Counsellor sessions the following questions are elaborated:

- On which problem do you want to focus attention?
- What are the main features of the identified problem?
- When does the problem manifest itself and with whom?

2nd Phase – Identification of the fundamental elements

The second phase is definitely the most *creative* of problem solving, in as far its goal is to generate possible solutions. In this phase one needs a behaviour that gives free hand to the thought and allows the individual to release himself to his visions, intuitions, feelings and even emotions. In this phase it is important to leave the mind free to connect elements that apparently are distant from each other, to have access to our resources and also to formulate those hypotheses we normally exclude because they apparently aren't very realistic or incompatible with our basic ideas. In fact, the search for solutions asks us to give up some convictions that guided us previously, or to integrate or modify them.

In front of a problem and in the search for a solution we are inevitably guided by a system of values and meanings that are important for our way of acting and for our person. For this reason, when the peer counsellor helps the consultant to identify a problem and its solution, he should always take into consideration that what the latter really wants to achieve, his dreams as well as his ethics.

We should distinguish the following elements in this phase:

- Emotive difficulties
- Practical solutions
- Factors that may facilitate or not the confrontation with a problem situation and the subsequent search of its solution.

3rd Phase – Selection: we choose and plan the solution

The third *critical-realistic phase* aims at producing real and appropriate, detailed action plans. It implies a realistic and critical behaviour. When ideas become projects it is important to evaluate their degree of realism, their impact on reality.

4th Phase - Evaluation: implementation of the project and evaluation of its results

The fourth *executive* phase implements the project. Its aim is to activate

the project and to include the empiric evaluation of its efficiency. It is characterised by an operative, practical and executive mental behaviour.
The peer counsellor invites the consultant to identify what might be the consequences when certain specific alternatives are activated, what might be the development of his decisions and choices: "What will happen if I follow this solution? What will happen if I do it in this way?"
Here the function of the Peer Counselling empowerment towards the consultant is very clear, the latter will be strengthened in his skill to reflect on possible alternatives and on the planning of all the necessary actions to solve his problem, exercising in this way his self-determination. Possible alternatives are identified and discussed, and one tries to discover which of them is the best to choose, the most desirable and the most practicable.
In the ensuing decision it is important that the counsellor executes the following stages:

- Summarise the available information about every alternative
- Discuss and paraphrase accurately the information given by the consultant regarding the available alternatives
- Keep the discussion focussed on the decision
- Discuss the details of the chosen project
- Give practical information to make the project's accomplishment easier

One can't handle or solve a problem only by having clear ideas or by using creativity, or only by being critical, by only using realism or by taking on a good practical attitude. Each one of these elements is indispensable. When we face problem solving alone, our aim will be to activate, stimulate and develop our "laziest" parts, contributing thus to our total development. In this case, the problem solving can rightly be considered as the art of harmonising our creative parts with the ones that observe, the realistic and practical ones and to direct them towards the goals we want to achieve.

Sometimes, the problem solving process fails, not because there is no solution to a certain problem but because one continues to believe in the same old things and thus one reaches the same old conclusions due to, for example, strong fears that hinder the search for a way out.

Therefore we need to look in a new way to the same situation and combine the same facts in new ways. The techniques of creative thinking help us to do so because they incite our mind to go beyond its self- created models.

Planning

Planning is generally defined as the ability to anticipate and regulate a sequence of actions in order to achieve a goal. The elaboration of projects directed towards the achievement of a goal or aim is without any doubt one of the most important and precious abilities that man has in his repertory. In fact, projects guide and regulate his behaviour because they specify a succession of actions that from a given present condition allow him to achieve another one in the future.

The planning process implies a continuous confrontation with the obstacles one meets on his way. For this reason it is connected to the solution of problems and to one's responsibility for choices and for the decisions to take. The individual necessarily has to be aware of his qualities and skills, as well as of his limitations. Moreover, he has to be able to learn from his mistakes.

The discovery process and the activation of energies and personal abilities should be aimed towards the accomplishment of concrete actions. Only when we act, effective changes take place, only when we take action the disadvantage, the real handicap, emerges: often the condition of disability entails that you entrust others with "the things to do".

Consequently even if you are able to take decisions and make choices you lack the necessary experience of "doing" and of organising "what should be done". You should therefore regain your operative dimension. One might consider planning as a kind of training to acquire and experiment this ability by actually using it.

Starting from his awareness of his capability to manage and affect the events of his life, the consultant is helped and emotionally supported by the peer counsellor to identify realistic and obtainable objectives. What is more he must be the key actor of the whole planning process engaging himself actively in the drafting of his project.

The execution of a complex task, such as planning, implies the activation of a sequence of operations according to an appropriate strategy. It is therefore necessary to consider the resources and the time element, as well as the possibility of a dynamic modification of the project or of the planning process, before the latter is completed, in relation to possible changes of oneself and of the environment.

To adopt a plan, i.e. starting its activity with the aim of accomplishing or finishing it, one needs to believe in one's skills and abilities and have the intention to achieve it. We supposedly know that if you want to go from Milan to Rome you need to travel by train, and if you want to take the train you need to buy a train ticket. First of all, in order to adopt this procedure one should carry out the following actions: buy a train ticket, get on the train, and reach the final destination. Then you have to verify if it is possible to buy the train ticket, reach the station, identify the train to take, identify the destination station. It's enough that you don't have the money to buy the train ticket, to stop you from moving. Naturally the above-mentioned conditions are only used to start the activity, but not necessarily to continue. The next phase presupposes the same sequence of operations.

In Peer Counselling the planning process is called "*Independent Living Project*", because the objectives pursued through this method are the autonomy, independence and the self-determination of people with disability.

A correct "I*ndependent living project"* has the following phases:

- *Identify the objective*
- *Draft a check list*
- *Define the process*
- *Evaluation*

The first task to carry out, in planning, is to **identify the objective**, in as far it facilitates the identification of the road one has to take. To define the objectives, we need to start from the deepest desires and expectations. In this process the consultant shouldn't do what is most convenient for him, what is useful or easier for him or what circumstances dictate, but rather what corresponds to him most. Once again he should begin with getting in contact and listening to his Self.

The identification of a desire and the choice of an obtainable objective should have the following phases:

- To become aware of desires and expectations, through visualisation techniques and others.
- Verify the congruence of desires, by using questions such as "Do I really want to achieve this desire?" "What

would happen if it became reality?" "Does this desire reconcile with my way of being and with my values?" "Can I use my skills to obtain this?".

- Evaluate how urgent, realistic, determinant the desires are for the quality of one's life.
- Choose the desire that clearly involves all these elements and transform it in a concrete objective
- Formulate the objective (see Table n. 1) choosing one ore more desires that are mutually coherent.

Table 1

How can we identify an objective

Using one of many systems of creative thinking can carry out the identification of an objective/aim.
Let your mind flow freely, compose free associations of ideas, expressed graphically in the form of flowers with the key word of your dream in the heart of the flower; identify the key word of one of your dreams, associate to this key word as many other words as there are petals; among these words/petals choose the one you feel the most and draw another flower, continue doing this until you have four or five flowers. Choose one flower, the first flower is excluded, read what is written in the flower and reflect on its result.
Subsequently this exercise can be continued in a group of 4 or 5 persons, in order to identify 4 or 5 concrete objectives for each of them. Each person will choose the objective he considers the most important and then he will design a project to achieve it.

At the end of this process both the consultant and the peer counsellor take on the responsibility to accomplish the agreed engagement, work out the "Independent Living Project" and take all the necessary time.
When drafting the "Independent Living Project" one has to follow the same procedure as when packing luggage for a long and important journey: gathering everything that might be useful, nothing should be forgotten. Substantially one should **make a check list** on which everything

one needs to accomplish it is listed: financial resources, friends, relatives, colleagues, acquaintances, computer, internet, books, car, training, information, etc. Moreover, one should necessarily establish a deadline to its accomplishment and identify a time sequence for every sub-aim: days, weeks, months and years.

The elements on the check list, initially gathered at random, are subdivided and grouped in categories, from two to six, which are given a name: financial resources, human resources, technical resources, training, information.

The identified categories (see table n. 2) will be the instruments of the project; they have to be activated one by one according to the set deadlines. In this way one defines the process to follow in order to obtain a certain objective. The "Independent Living Project", as any other project, is composed of sub-aims; the accomplishment of each one of these depends on the preceding one, developed according to affinity. It is therefore useful to establish exactly which steps should be carried out as a pre-condition for the following step and, ultimately, as pre-condition for the "operations" relative to the final goal.

During this process it is important to establish priorities, meaning putting "the things that must be done" in the right order and then carrying them out. What is more, one needs a good ability of choice making and discernment, as well as a good amount of constancy and commitment.

Independent living project	OBJECTIVE: purchase of an accessible car			
Project to carry out in 2006				
	January/February	*March/April*	*May/June*	*July/September*
Financial Resources	Personal resources as employee	Personal resources as employee	Personal resources as employee	Personal resources as employee
Human Resources	Business agent. People with disability who use these devices and adaptations		Personal assistant with accessible car. Business agent	Personal Assistant or relatives. Dealer and firm for adaptations
Technical Resources	Computer Internet Telephone Fax Specialised magazines	Computer Internet Telephone Fax	Converted car, designed to allow autonomous use	Purchase of accessible car equipped with adaptations selected to allow autonomous use. Guide to tax concessions
Training			Training with the car to verify the possibility to use it autonomously	Training: how to use the accessible car and on the functioning of the adaptations
Information	Acquire information on the different kinds of adaptations and cars which can be converted Verify the cost of cars and adaptations	Analyse further information obtained through informative services on mobility	Conditions and purchase procedure for the accessible car; information on benefits: reduction of VAT, road tax, contribution on adaptation costs, etc.	Information on purchase procedures and registration of the car, method of compilation of tax concession form, granted to disabled people who buy a car.

The **evaluation** of the project is a process in continuous evolution; it must be done in itinere, because this allows the correction, if necessary, of what is inadequate or of shortcomings, in order to achieve the final aim. Instead of asking ourselves “What didn’t work out?” at the end of a project, we create reflection and evaluation moments during the process; starting to question ourselves from the moment we decide which process we want to carry out.

In the evaluation moment the counsellor can ask questions such as:

"What happened to…","How did it make you feel?","What do you think would have worked out?".
Generally the evaluation is put into practice by introducing changes on the checklist and changes in the project's sub-aims. It is important that the person understands that these changes and variations are part of the project and not a sign of failure.

To conclude, this work, in the light of the experiences accomplished by the CIL and by the organisations of people with disability in different countries, regions and continents, wants to recognise, enhance the value of and support the scientific character of this method.
Compared to the first Peer Counselling manuals realised by the core of the Independent Living Movement at Berkeley University in 1972, and by the University of Magonza, in Germany in 1992, this manual avails itself of the last contributions of social psychology and wants to be an efficient instrument to obtain a change that, starting from the individual, affects the cultural, social and political dimension of society.
Metaphorically, we might say that in the individual's history disability has built a wall separating him from life. Generally either one adapts himself to this separation or one deceives himself into thinking that one can break it down with anger and refusal. Peer counselling allows the individual to recognise and accept himself, and by doing so he can make a hole in the wall that will allow him to find the place of his desires.

CHAPTER 8.

PEER SUPPORT

Thinking is doing something in the world, i.e. an intelligent human action. You think even while you are writing, without necessarily verbalising everything you write. You think while you are eating, distinguishing food, without verbalising every bite. You think with your hands, with your mouth, with your teeth, with your tongue or even with your feet. You don't always need to verbalise everything. You are often thinking while you are doing intelligent human operations, which are actions that can be repeated.

Carlo Huber

8.1 What is it?

Peer Support is a service offered inside the informative organisations that deal with specific problems regarding target groups that live a condition of social disadvantage. The group of people with disability is one of these groups. The Peer Support service is characterised by a relationship between "peers".

As we've already said in the previous chapters, the work between peers develops itself in the frame of the Independent Living Movement. People with a serious disability have identified positive solutions for their problems by confronting themselves with the experiences and lives of other people with disability. In and outside the Independent Living Movement this has favoured an awareness that the best experts in the field of disability are the same people with disability.

The condition of equality facilitates the help-relationship, in as far as the peer supporter avails himself not only of the technical competences acquired on a theoretical level, but also of his life experience, favouring in this way a better comprehension and communication of problems among the individuals that interact.

The Peer Support service prevailingly develops an action of information, orientation and defence of rights; it supplies useful information for the solution of problems and for the handling of difficulties linked to the condition of disability.

The Peer Support actions, that regard the philosophy of Disabled Peoples' International, don't limit themselves to the supply of information services and protection of Civil Rights, but base their activities on the paradigm of the Human Rights. Peer Support actions promote a culture that aims at enhancing the value of diversity and favouring policies of non-discrimination, equal opportunities and social inclusion. To obtain this they prepare documents, propose the drafting of new international, national and local legislative instruments or the modification of the existing ones. They activate a network among the organisations of people with disability and their relatives, favouring the empowerment development and active participation in all levels of society, so that each individual may develop an awareness of his Human and Civil Rights and ask for their full application.

The service supplied through Peer Support can be addressed to the single person or groups and it can offer information on specific themes. The Peer Support activity is useful to activate cultural, informative and political campaigns that aim at the improvement of the quality of life of all subjects, or of a certain specific part of the population, by obtaining services, structures, laws, etc. tailored to their needs.

8.2 The difference between Peer Support and Peer Counselling

"In several countries people with disability and Independent Living Centres help each other reciprocally by exchanging information, advice, legal help and peer support. The people that work there are disabled and know what they are talking about from their personal experiences. The centres work to obtain changes in society, such as increasing home and transport accessibility. In many countries the Independent Living Centres regularly receive state subsidies, because disabled people are recognised as the best experts in issues that concern disability"[33].

In a lot of European countries as well as Italy, the help relationships, Adolf D. Ratzka talks about, can be divided into two kinds of services: Peer Support and Peer Counselling. The first has a more general character whereas Peer Counselling is a structured method, as we have extensively described before.

What the two types of services have in common is the "peer" condition, meaning the relationship between equals. They are two complementary services: Peer Counselling carries out a training activity that directly involves the person in the elaboration of his disability and his life project; Peer Support directly involves the field of information regarding disability, legislation, services, support, etc. and the promotion and protection of Civil and Human Rights.

One of the highest qualities of a peer counsellor is to have the right Peer Support competences and to use them in the empowerment process, because this allows him to offer people with disability more support in solving their problems and in identifying the necessary strategies to accomplish their life projects. It is essential to underline that a peer counsellor doesn't always need to have this kind of competence, what is more important is that he is informed about where and to whom he should send the person with disability in case he needs specific information, as for example laws that regulate issues regarding disability, specific services, etc.

8.3 Competences

Peer Support is first of all a "reception" service and secondly a service that answers the demands of help. Who works in this service must have a broad legislative knowledge and thoroughly know the kind of services that exist on his territory. Practically, he must be able to direct the client so that he can claim his rights and at the same time obtain the most sui-

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[33] A.D. Ratzka, *Vita Indipendente: tentativo di una definizione*, http://www.enil.it

table strategies to interact with the offices concerned, which should supply the appropriate solutions to his problems.
In synthesis, Peer Support operator must have knowledge about:

- Communication Forms and methods
- Principles and history of the Movement of persons with disability
- Philosophy of Independent Living
- International, national and regional legislation regarding disability
- Institutional competences in the field of disability
- Procedure for claiming rights
- Technical and financial instruments
- Local territorial resources
- Computer science instruments
- Data banks that deal with disability
- Role and organisation of the associations of disabled people

Moreover he must be able to:

- Receive
- Listen to
- Conduct sessions
- Handle groups
- Direct
- Inform
- Build empathic and authentic relationships
- Analyse problems and identify possible solutions
- Manage data banks
- Manage archives
- Prepare documents
- Manage and promote networks
- Build partnerships
- Work out intervention strategies
- Continuously update information
- Classify and archive documents and texts

8.4 Application contexts

In Italy, Peer Support activities are carried out by Informative Centres, Resource centres, Independent Living Agencies and in activities of the informative counters of associations and public offices, etc.

The Peer Support service should be easily visible, easy to use and to have access to. It should be carried out in a welcoming environment: a place where every person, looking for information or help (disabled, relatives, citizen or operator), can feel at ease. Besides, it is important that the service has fixed hours and to offer an optimal service it should be equipped with the necessary technical devices: writing desks, chairs, computer, telephone, fax printer, photocopy machine and connection with internet, etc. Other fundamental instruments are: a documentation centre, a map of the territorial services, connections with networks, news, forums, etc.

To guarantee a perfect management of the Peer Support service it is fundamental to:

- Have an efficient internal organisation: for example it is a good habit to receive people by appointment to avoid useless waiting, which might make those who are waiting and those who are receiving counselling uncomfortable.
- Prepare a chart to write down information concerning the client, the procedure to follow, the instruments and the necessary strategies to obtain a solution to the problem, as well as the achieved results. This instrument will not only be used to explain and show the problems of a single case, but it will also be useful in monitoring and evaluating the efficiency of the service.
- Organise an archive and use a chart for every single client in full respect of his privacy.

8.5 Supply of the service

The aim of the Peer Support service supply is to provide the client with what can be called “the excellent answer”, capable of favouring the overcoming of obstacles in everyday life, discriminating situations and violations of Civil and Human Rights.

It can be divided into the following phases:

Reception of the demand

The client’s demand, problem or need should be accepted by the operator, who by means of attentive listening should direct him in his search for a solution.

Evaluation of the demand
The evaluation is carried out through the re-formulation of the demand by identifying strategies, information, instruments and resources that are useful in facing difficulties or the solution to the problem. The Peer Support operator should be able to formulate the intervention proposals expressing them in a clear and comprehensible way, giving different interpretations to the personal situation and possible solutions.

Information
Information should be clear, precise and comprehensible for everybody.

Accompaniment
The accompaniment is a support in all phases, from the reception to the evaluation and from the information to the identification of instruments and strategies, the peer support operator and the client should always agree on the tiniest details.

8.6 Advocacy

Advocacy is an accompaniment method in the process of defence and demand of Civil and Human rights. It is a kind of mediator developed between the person whose rights are denied and those who by means of their competence should guarantee them.
The advocacy methodology is used a lot in European countries and in the countries of the International Cooperation. Its form can differ and adapt itself according to the territorial needs and cultural influences; it is an integral part of the empowerment process. In the Peer Support model we propose in this handbook, advocacy is an integral part of the project and when addressed to the single person with disability, its function is to help him and to obtain all the necessary instruments for the protection of his rights, supporting him, if necessary, with legal action. In this case, again, the role of peer supporter, who is also an advocate, does not substitute the individual, but he accompanies him and his actions aim to make the individual independent and free in his choice making.
Here are some examples of Peer Support.

First example

Theme:Autonomy

A 30-year-old man, having muscular dystrophy wants to live alone.

- *Question:* is there a law imn Italy that answers my need? If yes, which one is it?
- *Answer*: The laws you should apply to are Law nr. 104/92 (art. 8 and 9) and Law nr.162/98.
- *Question:* What do the articles. 8 and 9 guarantee?
- *Answer:* Article 8 makes provision for social integration and guarantees personal assistance 24 hours a day; it allows to choose a personal assistant and takes into consideration the kind of assistance a person with disability needs. Article 9 gives you the possibility to choose in which context you want to live.
- *Question:* What are the prerogatives that allow me, disabled person to enjoy these rights?
- *Answer:* You should undergo further examinations at the ASL (social health service), to ascertain "the gravity" of your situation.
- *Question:* What should I do to make an appointment for this medical examination to ascertain that I am in a "condition of gravity"?
- *Answer:* You should ask for an application form at the Civil Invalids Office of the ASL, send it to the Territorial Medical Commission for the 104 Law. Then wait until you are summoned for the medical visit.
- *Question:* Once I have the certificate that certifies my "condition of gravity", are there any agencies or associations that can help, prepare and follow the procedure in its bureaucratic itinerary so that in the end I can accomplish and satisfy my need?
- *Answer:* Yes, you can go to the Informative counters and the CIDHA of the Associations
- *Question:* Does a service that can satisfy my needs already exist in this area or should it still be invented or created.?
- *Answer:* the 162/98 Law provides for it but it hasn't been put in practice yet.
- *Question:* Who should I turn to, to put it in practice?
- *Answer:* The municipality, by means of a written application to be sent to the office concerned, which might vary from Region to Region.

- *Question:* What should I ask precisely?
- *Answer:* You should ask for a 24-hour personal assistance, having obtained your "situation of gravity", as provided for in art. 3 of the 104/92 Law, being affected by muscular dystrophy you are classified as "very grave".
- *Question:* Can I handle the service of my personal assistance directly?
- *Answer:* Yes, but it should be agreed on previously and authorised by the office that supplies this service (Municipality, Province, Mountain Community, ASL) You should draft a contract that should be handed over to the office in regard. In this contract all rights and duties of the contractors (disabled person and personal assistant) are listed.
- *Question:* If I can't find a qualified person myself, to employ as my personal assistant, what should I do?
- *Answer:* In this case you shouldn't ask for the "indirect" management of the service, but rather for the "direct" management of the Office, which will use the human resources, it disposes of.
- *Question:* Does an expert who can support me in the achievement of my project already exist?
- *Answer:* Yes, the peer counsellor.

Second Example

Theme: Architectural Barriers

A person with disability wants to make his home accessible.

- *Question:* How can I make my house accessible?
- *Answer:* First of all you should call in a company specialised in architectural barriers, which will send an expert architect: the latter will prepare a project with the most adequate solution to your situation and propose it to you. Anyway, the most common solutions are: a chute, an elevator and a stair elevator
- *Question:* Do I have the right to do this? And which laws allow me to do so?
- *Answer:* There is a law that provides technical regulations for the implementation of the project; there is the 13/79 Law on breaking down accessibility barriers and the 104/92 Law, a outline law on the rights of people with disability that provides the possibility of

a financial subsidy for the costs of making a house accessible. The subsidy provides euro 2.500,00 as a total reimbursement in case the costs amount to euro 2.500,00. In case the costs are more, only 25% is reimbursed.

- *Question:* Do I have to pay for all the support devices?
- *Answer:* No, those provided for in the Tariff Nomenclature are free. Anyway, the company you call will tell you if the support device is free or not.
- *Question:* Do I need the consent of my apartment block?
- *Answer:* No, it's not compulsory. The other residents should be informed and even if they don't agree you can always carry out the modifications at your own expense, on the condition that no harm will be done to the structure of the building.
- *Question:* Whom should I send my request to?
- *Answer:* To the municipality where you reside.
- *Question*: my house is subject to obligations for its historic-artistic value. What should I do?
- *Answer:* You need an authorisation for the modification works from the Ministry of Cultural Heritage.
- *Question*: Which documents do I have to enclose?
- *Answer:* Your invalidity Certificate.
- *Question*: The request for reimbursement should be presented before of after the works have been carried out?
- *Answer:* Before.
- *Question*: What is the deadline?
- *Answer:* By the end of the month of March of every year.
- *Question*: Are the reimbursements granted immediately?
- *Answer:* No, they are granted after handing in the invoice that certifies the payment of the works, depending on the availability of the funds.
- *Question*: And what if there is no money available, will there in one way or another be a reimbursement?
- *Answer:* Yes, you can apply again in the following years.

THIRD PART

CHAPTER 9.

PEER COUNSELLING IN THE CONTEXT OF THE ASSOCIATIONS OF DISABLED PEOPLE'S FAMILY MEMBERS[*]

For someone like me, who is daily engaged in the accomplishment and in the promotion of operative strategies relative to disability, it is difficult to stop thinking about the *theory* or about the sediment of various experiments. The first difficulty is the risk of confusing ideology with protection of rights; the second is linked to the impossibility of contemplating systematically on an experience, due to objective reasons (job, family duties, choosing to be active in voluntary work).

In the past, DPI Italia, by means of specific projects for the creation of the professional "peer counsellor" profile, offered a lot of people with disability the possibility to start an awareness and development process that lead to the production of important documents for the emancipation of the collective conscience of the entire world of disability. We, the family, owe a lot to their "presence", both in the social and in the political field.

We, the same relatives involved in associationism, have remained a bit behind as far as the growing awareness is concerned, mostly because we aren't used to reflect on the deep motivations, I might even say intimate motivations, that make us act so intensely in favour of the disability world. Very often, instead of looking for an assessment in our "feeling", which is at the base of common action and is necessarily unique, we are obsessed with rigid instruments and acronyms.

Has this feeling got a name? It probably hasn't been invented yet, but it is very similar to the feeling of people with disability when they unite themselves to fight their battles, in different parts of the world, recognising themselves in different associative acronyms, which can be brought back to a common denominator, for example the promotion of human rights. To say it in other words Disabled Peoples' International.

Or even simpler: group solidarity among people that pursue the same objectives.

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[*] This charter was written by Pasquale Ezio Loiacono, Chairman of ANFFAS (National association of families of intellectual and relational disabled people) a non profit association in Reggio Calabria.

Silvana Ruggiero in "Lezione d'Amore"(love lesson) expresses this "feeling" in the following way: "Who has been hurt by life can give life to projects of hope, because it is in pain that the credibility of love is verified. When the confrontation with sufferance doesn't end in a shipwreck, it transforms itself in an alliance with other people who have been hurt in the same way. The same concept is at the base of the non-profit associations, there where the meeting of different kinds of suffering turns into an scream of love that unites everybody, that gives people the strength to claim their rights and remember their duties".

In her work Silvana offers us a complete description of pain, being the mother of Marco and Luca who both have a rare and devastating illness. No expert, no matter how good they are in interpreting the feelings of those that appeal to them, will ever be able to describe such a feeling.

And the other parents and relatives? This feeling should also be transmitted to them, in all spontaneous or organised occasions of self-help. The first thing to do is to support them in surmounting the approach-towards-disability-phase.

These assertions don't want to diminish the importance of the studies on the motivations that stimulate the family members of people with disability to dedicate their free time and their energy to the protection of their children, and other people's children as well. It is not by chance that one of ANFFAS's slogans, the most important and best organised association of family members in Italy and perhaps in Europe, says: "*every person with disability is our child*!" meaning that our responsibility as parents can't limit itself to the safeguarding of our son or our daughter. But how can all this be realised when a lot of families still close themselves like a hedgehog when they hear their child is disabled, often imprudently communicated in the obstetric and gynaecological hospital wards because there is no adequate communication protocol for these particular circumstances?

There are still a lot of families that are not ready to face the approach with disability, after all it is not something taught at school, and as we often repeat, none of us chose to have a child with disability.

It is difficult, but not impossible. It is a tortuous process that many psycho-sociologists compare to the mourning for the death of a dear person, once this has been overcome one enters the so-called phase of acceptance and, I might add, of inclusion of our children.

In a few words, the process starts with the question "Why did it happen to me?" and goes to the statement "I don't want the others to suffer in the same way as I did after my child was born!"

The personal experience induced me to continue with coherence and determination, a series of initiatives in the logic of favouring the beginning of self-help processes, from 1986 onwards.

But what instruments emerged from this experience? What are the future possibilities?

The aggregation among families is fundamental to "count", not to feel alone when facing daily life of living with a person with disability and most of all to be a force against those that hinder the enjoyment of the human, civil and social rights of our children.

But before getting to this, it is necessary that the relatives, and particularly the parents, learn to open themselves towards the others, that they stop thinking "no one can understand because the others don't live with me". They should learn to say "my experience, the way in which I handled this moment, the way in which I solved and tackled my problem, should be useful for those that have just started to walk along the same road".

Normally this is the spirit that inspires the relatives of people with disability who have decided to give life to initiatives that, in different ways and degrees, can be called help or mutual help initiatives (associations, forum, specific committees, other). I have successfully used some of these aggregation processes in my associative and life experience and I think it is useful to present them to you.

To accept reciprocal help it is necessary that the parents of persons with disability should not only have overcome the various phases of welcoming and accepting their child, but they should also have acquired, in some cases spontaneously, in others by means of training cycles; some of the principles, fundamental according to me, that characterise the "efficient parent"(EP), a conception that is closer to the idea of Erickson's "adult" than to Gordon's homonym "efficient parent".

We will list some of them that are part of the training content of ANFFAS Onlus of Reggio Calabria.

1. One of the most important tasks of the EP for their children is to promote their autonomy and independence to a maximum: disability makes them seem small and defenceless compared to their brothers and sisters, both in their childhood but also in adulthood, above all

when they have an intellectual and/or relational disability. It often happens that we substitute them, we spoil them, and they, smart as they are, adapt themselves to the magnificent affective sluggishness. The unequivocal result is the arrest or delay of their growth, which in turn involuntarily hinders the complex process of social inclusion.

2. The EPs should be aware of the fact that they can and must represent and protect their children and relatives only until their eighteenth birthday; in fact, when they come of age they can start a correct dialogue between parents and child, as in all other families, in full respect of their child's wish and desires. The families of people with an intellectual or relational disability are an exception because the latter probably can't represent themselves. In these cases one should apply to the "Istituto dell'amministratore di sostegno" a kind of tutor.
3. The EP should avoid the "*reverse competition*" of whose son or relative has the most serious condition. We sometimes hear: "but at least your son can hear, mine can't hear and can't walk …", "Yes, but mine also has diabetes…" and so on. We should learn to understand what our children are able to do and what their potentiality is. It is not difficult to discover, if we establish a good collaboration with the therapists that follow them. However, this small talk (regressive escalation) very often is nothing else but the expression of an insignificant self-commiserating behaviour. We should recognise it and consequently avoid it. Finally, there is no such concept as "absolute gravity", except in the medical or assistance sense: probably there are people with disability who will never reach full autonomy, but fortunately these cases are rare. We should take action for those who have the right to a dignified life full of stimuli and affection, in order to guarantee them a life at home or in environments that are similar to family life. In fact, in these cases we need to identify collaborations and synergies, even with the institutions, to favour inclusion processes for the "after us".

4. A family member of a person with disability should perceive the above-described feeling, which will lead him to a feeling of solidarity with other parents. In the waiting rooms of the rehabilitation centres we often see mothers, fathers and grandparents that stare at the floor; they hardly ever greet each other; and rarely talk to each other. No, this is wrong! We, the family, should learn to communicate with each other, exchange experiences, and discuss everything that is happening to us because communication is the first phase of the growing process. And talking about waiting rooms of rehabilitation centres, they should be equipped with computers, notice boards and with services available to the associations of the families so that the waiting time is used positively, giving information on the centre's rehabilitation programmes (obviously only those allowed by the law on privacy), on rights, on new laws, on municipal notices on initiatives of family associations and on parties organised for the children and their families.
5. The EPs have an enormous desire to share with the others who are in the same boat. A propos, I want to remind you of another motto of ANFFAS Onlus, result of a ten year old history and culture: " *one family is not enough for a person with disability!*" This is a further invitation to feel part of one *big family*, linked to a concrete and strong solidarity, focussed on common *need* but also on the *desire of redemption*, and therefore strengthened by the awareness of having to fight together to pursue rights sanctioned by laws.
6. Finally, a family member of a person with disability has a strong desire to know the socio-political reality that surrounds him, to know the world of exclusion, because if today the social policies marginalise drug addicts, the elderly, the new poverty of unemployed youngsters and adults or gay people and lesbians, tomorrow they might turn against the world of disability.

Once the "efficient parent" who has overcome this symbolic test, he will be fit to participate, to be part of, to give part of, and why not, to take part, in one word, "associate" with the aggregation, which according to him expresses and pursues more than the others his values and objectives.

From this moment on the "efficient" parent or family member will become a "competent" parent or family member.

In this sense, the aggregation that receives should have a guidance function, to create roles, to exchange experiences, to obtain knowledge in legislative matters and if necessary to be the base for a possible confrontation with political and administrative representatives.

The more the organisation invests in this area, the better the possibilities to express an efficient and competent management.

But not always the reception in the family associations should be taken for granted. Told like this the acceptance seems simple, almost by the book, but to realise these models a lot of work has to been done!

The mosaic of different associations of family members of people with disability presents a diverse reality. There are very diffused risks that repeat themselves. Some of them are: bureaucratisation, service management, internal and external competition, self- reference, the power that derives from the management of big but also of smaller sums of money, practical exploitation, conditioning by Counsellorships and other powers.

The association of family members should be a place of gathering, of exchange, of growth and development of the political conscience of the parents, family members and of all the people that concretely want to share directly, even if not personally, the emotion of acting together to achieve common goals, democratically and freely choosing strategies, phases, instruments, objectives and so on.

It is important that a very "organised" association of family members doesn't depend only on itself; on the contrary it should open towards a broader network of associations in order to count on a political level that goes beyond the territory. Even an association that is a local branch of a national organisation can't have the pretentiousness to operate without a network of organisations as for example FISH (Federazione Italiana per il Superamento dell'Handicap = Italian Federation for the overcoming of Handicap).

Another fundamental rule is that the associations of family members should never put themselves in a subservient position as regards the institutions. Often the management of services in agreement with public offices leads to subordination and an association of family members can't afford this to happen. It should be able to deal equally with the political and administrative representatives of the local public offices.

Even more important is that the associations of family members don't forget the parents and relatives, the new couples facing the first problems of a child with disability, the elderly couples, the single mothers and fathers, the families that live in the middle of nowhere so that services never reach them, families that don't know their rights, and we can go on and on with this list.

The first self-help starts here: first a correct information initiative should be activated that is able to reach these families and that, beside giving information, counselling and the meeting they need, offers them the warm feeling of solidarity of another "peer" parent.

Besides offering a good independent social secretary service, an association of family members should realise that it cannot delegate a group of counsellors with the responsibility to intervene in the tangle of problems they have to face. Certainly, every member is called to participate actively in all the activities of the association and not only in the assembly meetings. Advocacy allows to put together people with common problems and the association offers them the necessary training, technological and methodological instrument to pursue autonomously a common goal, if necessary even by using the association's name. Usually a family member who has already attended a self-help training coordinates the committee that is formed like this.

A perfect experience of self-help informatics was represented by the Forum of the A.GE.DI[34], published on their web site, but unfortunately in disuse because there is no moderator to continue the job. This forum, if used by means of an internal browser, can show how much it has meant for the millions of people that visited it, and what it might represent if it were put in use again.

Finally, an association of family members should invest a large amount of its resources and energy in training. The desire to know can never be satisfied. The association of family members often succeeds in catching the interest of outstanding experts in every field of knowledge. This favours and partly economises (sorry for my frankness but all this is the merit of the experts that collaborate with our associations) the association intervention and gives it quality.

To all this an important element is added: WE, with our experience and if

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[34] For further information visit the website www.agedi.it link forum.

it's there, with our expertise, can teach the other family members to be "competent", even without joining the association.
As regards training, at the ANFFAS of Reggio Calabria the project "Crist*Al"* was carried out from 2003 to 2005". ANFFAS is still preparing its conclusive conference and the elaboration of the final documentation. It was a cycle of seminars on themes such as bioethics, the "after us", sexuality, social communication and many others. It was formulated in training weekends addressed to family members of people with disability who, in turn, engaged themselves in training other family members.
Of the twenty subscribed, fifteen family members concluded their training cycle, attending at least three seminars and relative inter-seminar meetings.

In conclusion. We can't pretend to describe in these few lines the parents association's 21 year experience.
In fact, it all started in the spring of 1985, when, following my initiative, a committee of parents made its first steps in the ex AIAS centre of Reggio Calabria and founded the A.GE.DI. in September 1986 and subsequently a branch of ANFFAS (a daughter branch of A.GE.DI.) in 1990. The latter evolved into ANFFAS Onlus in 2002.
Processes that seem to be of no importance but that hide sufferance and sacrifice, as well as a lot of satisfaction for their accomplished success.
To conclude my reflection, just back from a meeting with the promoting committee of the ANFFAS of Bagnara, an interesting and joyful group of families and sympathisers, that, in spite of its various problems, is ready to face for the first time another group of families from Gioia Tauro, I ask myself "when is it our turn"! ?
And therefore I'd like to finish with an appeal: it is fundamental that more and more parents accept training, it is necessary that the family associations promote the latter but even more important is that the organisations of the world of disability, which have already worked out avant-garde training processes and funding procedures for European projects, spur us to get starting. Obviously we'll do the rest together!

CHAPTER 10.

A HUNGARIAN EXPERIENCE.
INDEPENDENT LIVING - PERSONAL ASSISTANCE AND PEER COUNSELLING.
WHAT DOES INDEPENDENT LIVING MEAN TO US?*

The principles of Independent Living:

- People with serious disabilities can live independently. This means that they have control over their lives. To obtain this objective they need: personal assistance, general assistance devices and services and an inclusive society.
- The people with disability have the unalienable right to take their lives in hand, make decisions and take on responsibilities that regard them, as any other adult, in order to participate fully in the social life on every level.
- People with disability know better than anyone else what they need and they are able to solve efficiently the difficulties they meet.
- The needs of the people with disability can only be satisfied efficiently by the services supplied by the organisations they run themselves.
- The people with disability should be involved in the decision-making process, in the project designing, in the development and research on all levels and for all aspects that regard their lives.
- The people with disability should be encouraged to respect themselves, to think independently and to fight for their independent living.
- The community should guarantee people with

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*This chapter was written by Margit Nász and Eva Caesar (IMPULZUS, Association MEOSZ - National Federation of Disabled Persons' Associations).

disability all the necessary conditions to be able to live independently:

- Appropriate healthcare
- The necessary rehabilitation
- Appropriate technical assistance
- Accessible homes
- Adequate income
- Financial Resources to promote independent living
- Freedom of movement
- Inclusive Education
- Appropriate job training
- Inclusion on the labour market
- Personal assistance
- Peer support

IMPULZUS is an association that works together with other associations in the Civil House.
It organises:

- Public round tables on issues regarding disability
- Basic training on sign language for women that work as "home carers", realised thanks to the women's programme KRISTÁLY
- Counselling on legal issues and issues linked to rehabilitation, in the field of the Job Counselling Office.

Starting from these premises the association created in the little region of Szolnok, more precisely in the county of Nagykun-Szolnok in Hungary, three support services: KRISTÁLY, SZÉCHENYI and FÜZFA.

The support service in general

The Support Service, offered by the association, sustains people with disability until they are able to participate fully, guaranteeing them the conditions to accomplish this.
The main activity of the Support Service involves services that answer the needs of all individuals.

The first service is Peer Counselling, which aims to support people with disability until they achieve their independent living, following the philosophy of the Independent Living Movement.
The other service prepares the conditions that allow people with disability to put in practice the principles of Independent Living, making them become reality.
The association has developed a flexible system of personal assistance service offering different solutions, depending on age; its aim is to guarantee people with disability equal opportunities. Its actions are essentially based on the principle according to which all services should be modified and focussed on the client's needs.

Objectives
The objective of the Support Service is to enable self-determined living by offering people the possibility to have access to public services both in cities and in small villages, offering home assistance, and assuring independence.

Target groups
These services are offered to people with serious disabilities- defined as such by the Laws nr. 141/2000 (09.08.) and nr. 21/2003 (25.02.) – who in their daily lives need the help or advice (in case of mental disability) offered by another person. These people need assistance to wash, dress, eat, and use the toilet or to move around in their houses with the help of support devices.

Tasks of the Support Service
According to the Law nr. 1/2000 (07.01.) on the professional tasks of the social institutions that supply personal care and the conditions for the person's functioning, Support Services must perform three basic tasks:

- Personal Assistance
- Transport Service
- Information and Counselling

Other services are:

- Home assistance
- Legal Advising
- Counselling for job inclusion
- Peer Counselling and Information on Rehabilitation
- Family Support

Personal Assistance

With personal assistance the disabled people are given the instruments that allow them to participate fully in community life on all levels. Thus the person with disability can take care of his personal hygiene, communicate, take care of his house, have access to education and job services and do other activities such as going shopping or participate in cultural initiatives. Personal assistance is supplied to people with serious disabilities or orientation difficulties.

Transport Service

The transport service allows people with disability to reach several public, health, social, cultural and other kinds of services.

Counselling, Information Service

People with disability and their family members are given support to encourage their independence, safety, ability and rehabilitation as well as their full participation in community life.

- **Peer Counselling** means that the counsellor, a person with disability, helps the service's clients, also people with disability, by means of active listening and problem solving techniques. This method is based on the principle of the common life experience of the counsellor and his client, i.e. the experience of disability and everything linked to it.
- The task of the **Social Assistant** is to identify and solve conflict situations that arise between the client (person with disability) and his/her family members.
- **Mental care, counselling** focuses its attention on the character, the individuality and on possible psychological damages to the disabled person. The colleagues that supply this service participate in meetings to discuss the different cases.

Programmes, training and services are organised for people with disability to promote their social integration. The young disabled people and their parents can meet and discuss in **clubs**. The aim of the training is to prepare them for the following jobs:

- Peer Counsellor
- Guide
- Community Informer

The biggest success of our programme is the inter-professional work developed with the help of experts and volunteers to promote the Independent Living of people with disability, besides this well-structured support, services have been created that can only practice when authorised and only to supply support to people with disability. The Support Service is able to create a new kind of community and employment system. It promotes professional policies, collects data and information, works out proposals, prepares and presents advice on work methods.

The results of the Support Service

- New opportunities were created for people with disability, who previously lived between four walls and who are now more motivated to start working or to participate in community life.
- The Service can also supply assistance during holidays, for other leisure time activities or to help with school, depending on the needs of the people with disability.
- Also for the family members that take care of the people with disability, there are more opportunities to return to work, even if it's only part time.
- To develop our knowledge and to train experts we asked the HEFOP (Human Resource Development Operative Programme) for funding and we received 17,8 million Hungarian Francs (HUF)

Our Support Service participates in professional forums and meetings and in each and every place where it is possible to draw the attention to the condition of people with disability, on the importance of their fight against segregation in all fields, such as education, employment, mobility, rehabilitation and social assistance. We will continue to show the rest of society the challenges, the difficulties, the different forms of discrimination people with disabilities have to face daily. We hope to find new solutions, to continue exchanging experiences and good practices with our partners and to develop cooperation.

The services in detail

The personal assistants must carry out the following tasks:

- Look after the nutrition (cook and serve the meals, feed if necessary, do the washing up, etc)
- Help with personal hygiene (bathe or shower, wash hair, clip nails, use sanitary towel, etc.)
- Help to get dressed
- Help to go to the toilet
- Help to move or to go from one place to another, help with the use of support devices
- Take care of the household (clean, wash and iron clothes, heating, gardening, etc.)
- Supply pre-cooked food coming from the common kitchen or restaurant
- Help with the shopping
- Substitute the family in the care taking
- Help with administrative and bureaucratic questions
- Accompany on walks or while using public transport
- Help with child care
- Accompany, teach the way

Transport Service

People with disability are offered a taxi service, which is different from all the other services. It is never used as an ambulance but mostly to accompany children and adults to school, to work, to different event, on trips, to the hairdresser's, to do sports or other leisure time activities, to training courses, etc. Driving a client to rehabilitation is a priority. We insist that our clients use this vehicle for the above-mentioned reasons instead of considering it as a service for ill people.

The most frequent itineraries are:

- Public offices (the Major's office, Guardianship Office, employment office, court, police, etc.)
- Health and social services (family doctor, National Medical Consultation Institute, physiotherapy, institutes that supply daily care, family assistance services, paediatric services, psychological or gynaecological counselling, etc.)
- Cultural services or other kinds of services such as schools, museums, library, buildings for sports or cultural events, defence offices, hairdresser's, post office, bank, shopping centres and other shops, churches, cemetery, etc.)

Counselling, information

The service continuously collects information and data regarding disability issues in order to transmit them to people with disability, their family or assistants. It gives social and rehabilitation support providing the necessary documentation. It gives information on training courses and job opportunities.

Mental care and counselling

- Attention to the character, individuality and possible psychological disorder, with a special attention to women with disability.
- Support for those that live in close contact with people with a mental disability
- Prevention of attacks
- Avoid the danger of isolation
- Promotion of self-organisation
- Mental Counselling
- Prepare the client to support himself and to be autonomous
- Help to analyse circumstances that hinder the disabled client and his family in conducting a normal life.

Peer Counselling

Means that the counsellor, a person with disability, helps the clients of the service (a person with disability) by listening to him attentively and by using methods that allow the solution of the problems. The key element of this activity is the common life experience of the counsellor and his client.

The fundamental concept is that most people are capable of resolving everyday difficulties if they are given the opportunity to do so. The counsellor's task is not so much to resolve the client's problems, but rather to help him in finding his solutions. They are not told what to do, nor are they given any advice, but the peer counsellor helps the client to find solutions all by himself by listening to him attentively, exchanging experiences and by showing possible solutions.

Ways and conditions to use the services

One can use the services upon request, by means of a formal request sent to the person in charge of these services. If the applicant is unable to apply, his legal representative will apply in his name.

Personal Assistance Service

Depending on the kind of application and on the preliminary simplified care, the person in charge will decide for the provision of the service. Before establishing the legal institutional relationship, the person in charge will make sure to:

- Register the request according to the date of arrival
- Inform the applicant about the registration, the preliminary care, the duration of the service and its conditions, the costs, the place and methods of payment.
- Carry out the preliminary care
- Sign the contract
- Send a copy of the contract to who (Head of Maintainer) will take on the service within 15 days.

The Client's Condition

The condition of disability must be verified with a medical document.

The cost of the service is fixed (200-400 Huf, about 1/1,5 euro an hour), and is established in every town based on the regulations of the Head of the Maintainer and depending on the instructions of the person in charge of these services. The total of the payment must be approved by the persons in charge. By law the total payment should not exceed 20% of the income. In case the monthly income is low nothing is charged.

Use of the Transport Service

This service can be used either after stipulating a contract with the institution or in case there is no contract, by sending a written request at least three days before. The sum to pay is regulated in the same way as explained above. The current cost is 50 Huf a km, one third of the price of an ordinary taxi.

There are still a lot of people who need support, but don't know anything about these services, that is why we will continue to diffuse information about our activities. We would like to inform as many people with disability as possible in the city of Szolnok and in the little region that surrounds it, so that they can count on our services. We are ready to help them and to enable them to live independently.

We would like to underline that the whole system of support services is financed by the Government and is regulated by the above-mentioned laws; the clients only have to pay a small sum to contribute to some expenses. Support services exist in many Hungarian cities, but a lot more are necessary to satisfy the needs.

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In 1994 she obtained her qualification as Project Analyser of Vocational Training, at the Region of Basilicata. In Basilicata she was responsible for the evaluation of projects presented for the " EU initiatives: ADAPT and Occupation and Enhancing the value of Human Resources". She attended a training course on Bioenergetics Analysis for four years.
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Giampiero Emilio Aristide Griffo, since 1972 he has been working in the field of promotion and protection of the human and civil rights of people with disabilities, he is on the board of various local, regional, national and international associations. He wrote researches and publications regarding the world of people with disabilities, he collaborated in magazines, university courses, television and radio programmes. He carries out counselling and training on a national and international level. He was European chairman of Disabled Peoples' International; at present he is member of its World Council. He represents the Italian National Council on Disability in the European Disability Forum. He is part of the scientific committee of the university course "Human Rights and disability", at the university of Padua. He works at the National Library *Vittorio Emanuele III* in Naples, where he is in charge of the department on diversity.

Emilia Napolitano, psychologist since 1991 and integrated psychotherapist since 1996. She exercises in the field of disability as peer counsellor and tutor at the S.A.A.D. (Service of Athenaeum for the activities of students with disability) of the University Institute *Suor Orsola Benincasa* in Naples. She participates in projects on the promotion of the diversity culture and enhancement of the value of disability. She is chair of DPI Italia.
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Children and Adults Onlus; *Una possibile autonomia: itinerari di donne con disabilità tra empowerment ed advocacy*, written by Marina Galati, Rita Barbuto, Nunzia Coppedè, Maria Meduri, Emilia Napoletano, Rubbettino, Soveria Mannelli 2003.

Giovanna Spinuso is an elementary school teacher, graduated in pedagogies, at present librarian at a secondary school. She lives and works in Rome At a very early age she became disabled, due to one of the last poliomyelitis epidemics in the South of Italy, she decided to "live anyway" and since the end of the nineties she actively fights in associations to promote laws, services and culture necessary to implement human and civil rights. Among which: the "League for the disabled people's right to work" and the "Italian Federation for the overcoming of Handicap" (FISH). In 1990 she went to Berkeley and San Francisco to study the Californian Independent Living Centres (ILC); since then she has been involved in the promotion of analogous services and policies in Italy. In 1994 she was one of the co-founders of D.P.I. (Disabled Peoples' International) Italy, of which she was the first Chair until 1997. In the same year she promoted the project for the training of peer counsellors in Italy. At present she is Chair of the A.V.I. (Agency for Independent Living), it manages support services for the personal assistance and autonomy of people with disability.

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The starting paradigm of the work of D.P.I. (Disabled Peoples' International) Italia Onlus states that non-discrimination and equal opportunities are at the base of the respect for the Human Rights of people with disability. In its job of cultural promotion, it wants to enhance the value of disability as an ordinary human diversity, it also wants to favour the relationship of inter-independence and reciprocity, typical in the development processes of every individual on various levels: natural, human, civil, cultural and environmental. For this reason it focuses its attention on people with disability as individuals and on their empowerment process, through which they are "strengthened" in their abilities and possibilities to regain their personal resources and take hold of their lives again. After having verified the necessity to develop empowerment processes, D.P.I. Italy structured a methodology and gave life to a new practice: the individual and/or group *Peer Counselling*. This is a method based on the support relationship between two or more people with disability that allows, those that want to undertake or strengthen their emancipation process from disadvantage, to face fear and personal limitations, as well as objective problems, identifying the best solutions and attitudes to achieve their personal life projects.

This handbook, result of a project, was written by several authors and dedicated to women with disability. The title itself *From victims of history to protagonists of life wants* to transmit to its readers the desire and the determination of women, and of all people with disability, to get rid of their age-old reclusion in order to activate a self-awareness process of what they really are and not of an identity made of acquired inabilities.

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