

# Becoming disabled in adulthood: a pedagogical reading of life stories

## Diventare disabili in età adulta: uno studio sulle storie di vita

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The article analyses the results of a qualitative Italian piece of research that involved 20 disabled people who became disabled in their adulthood. These were perfectly sane people, successful professionals, mothers and fathers, women and men with lives full of interests, who overnight were subjected to trauma that irreversibly changed their lives.

The stories were collected through semi-structured interviews, and explain emotions, states of mind, thoughts and worries that are experienced after the disability has occurred.

The biographies collected together in the work make you think about disability in adulthood as a tortuous, complex and hard walk of life that gradually led the disabled people to reach different goals, often unthinkable and unexpected.

For many interviewees, the first sensation after the trauma was that of being lost. In fact they felt inadequate, without a way out, useless and defeated, and after an introspective process they found themselves deeply different in both body and mind.

The most frequent stages in this pathway are despair, acceptance and reorganization. In this piece of research we wanted to delve into the role of the professional educator in the path of recovery and in their accompaniment and support for the adult disabled.

**Key-words:** disability in adulthood, resilience, acceptance, reorganization.

abstract

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## 1. Becoming disabled in adulthood

Every year many people find themselves in a changed personal situation following a traumatic event. They might have had a job, a family, commitments and social relations, and have been forced to reorganize their lives because of accidents or severe illness that irreversibly changed their individual condition.

Studies show that a person who has become disabled faces difficulties in accepting the new situation, and sometimes perceives themselves inadequate because he/she thinks this is what others think of them. One piece of research about the building up of a new identity after a traumatic event highlights that in many cases people with disabilities do not accept their condition because they feel they are judged in a negative way by other people (mainly colleagues, friends or acquaintances). What negatively conditions the building up of a new, positive identity is the perception of not being adequate in the following areas: personal independence, sexuality or work. It emerges from the study that these people think they are not able to work, have personal relationships or be independent if compared to before the accident. These restrictions, being physiological and sometimes psychological, inhibit altogether the field of autonomy, and consequently the will of the person to get active and carry out processes aimed at the achievement of a new autonomy (Galvin, 2005).

In 2008 The United Nations Convention on the Rights of Persons with Disabilities was promulgated. The need for such a document arose from such little attention being paid to the difficulties faced by people with disabilities that strongly contrasts with the most elementary human rights. There are several physical and mental barriers that hamper disabled people in their claim to important rights such as those to life, socialization, work and professional education.

Disability in many cases permeates the person's life and clouds all other aspects and qualities. Disability is thus synonymous with inferiority, inadequacy, 'unfitness'. People feel refused, not accepted by others. It is often more a perception of refusal than a real condition, in many cases it is pride that drags the disabled person away from others, they might not want to appear as 'different'. Especially those who became disabled in their adulthood have to reckon with shame and with the idea of appearing different from what they were before.

A study that is quoted several times in the literature clarifies this aspect very well. Daily habits constitute continuous confirmations of the perception of normality. Therefore, when these run out because of the arrival of a disability, one's perception of him/herself is generally distorted (Denzin, 1992). According to this study, a person with disability suffers from a loss of identity because their actions marking the rate of the day change. For example, not being able to autonomously get on a bus or not participating in sport as before the traumatic event affects their general personal perception, thus modifying the sense of belonging to the category of 'sane' people.

A recent study proves that disability arrived in adulthood causes several difficulties, especially in the self perception. People recently affected by disability have trouble seeing themselves as 'different' from the past indeed. This leads them to consider themselves as incapable of carrying out any task (both working,

recreational, and emotional ones) and to deem themselves as completely unable to be independent (Chang, Y. J., Chen F. S., Huang J., 2011)

Studies on the effects of chronic and disabling diseases highlight that the building of one's personal identity is a long process that starts in babyhood and is self-fed throughout all of one's life. A chronic disease stops this development and introduces a contrasting element that usually, at least at the beginning, causes an overall intense upheaval (Shih, 2011). A new and unexpected event such as the loss of the use of limbs undermines personal identity and affects the stability previously consolidated (Robillard, 1999).

The need for reorganization their lives is particularly felt on the professional front. Many people with disability, for instance, would like to restart work after disease or an accident, but they cannot carry out previously achievable tasks and they do not always feel ready to fill new roles nor to attend new training courses for a requalification.

The process of reorganization means acceptance and then the process is long and complex. Not everyone achieves the same goals in terms of overcoming trauma. Only the most resilient succeed in not being overcome by the traumatic event and in facing with determination the difficulties presented by the new condition (Dettori, 2011).

## 2. Resilience and Disability

The word resilience was originally used in physics to indicate the capability of a metal to get back to its shape after a stroke not strong enough to break it. Since the 80s, this term has been used in social sciences to indicate the capability of an individual to positively handle traumatic events and to reorganize their own lives in the face of difficulties. Resilient people are those who, despite being immersed in adverse circumstances, manage to face them efficiently. They manage to revive elements of their existence and to achieve important goals at work and in social and affective areas, sometimes against expectations (Cyrułnik, 2002).

Resilience is therefore the capability to tackle difficulties with grit, and to use the same difficulties to reinforce one's own personality. It is the person's ability to get back on their feet facing the obstacles they meet along the way, whether ordinary (such as in relationships with parents, at school, at work or in interpersonal relationships) or extraordinary, such as in the occurrence of a disease or disability.

At the end of the Second World War, scholars tried to detect identify the resources that had allowed some people to have good psychological adaptability in view of the many post traumatic disorders that affected veterans. Although several people were irreversibly injured and traumatized, they showed the ability to positively reorganize themselves more than others. They did not let the new situation (e.g. a severe disability) prevent them from having a life full of interests.

Several people with disabilities, despite the initial trauma, applied extraordinary resources in reorganizing themselves and in achieving a satisfying social role. (Martin, 2015)

The paraplegic Hawking, for instance, is today famous for his mathematical

theories. He draws on his disease the strength to carry out his studies and, with the help of computers, he puts forward theories acknowledged as brilliant.

From the first studies on resilience, it emerged that this is not a personal, continuous ability that a person puts into practice every time aversive situations occur. Clinical observations revealed that people in different situations and at different times may react to stress in negative ways. Sometimes they were shown to be highly resilient, while at other times they weren't at all and plunged into depression and crisis (Rutter 1987). Thus, resilience is the process of readjustment that leads those who develop a disability in their adulthood to rally and recover, to reorganize their days and make plans for the future.

We find from an etymological analysis of the term that it comes from Latin *resalio*, which means jumping, bouncing, and also the attempt to get back on an overturned boat. This is what happens to a person with a disability who, after a trauma, finds the strength not to sink and finds a new meaning to their life, getting back on the boat of life with new goals and a renewed motivation. The resilient person manages to activate psychological processes that allow him/her to face new, difficult situations, without being overwhelmed. He/she feels a new capacity to control their life, and perceives this inner strength to master situations and not to surrender to despair and depression.

The following research maintains that sudden changes in the state of health affecting personal autonomy are 'only partially accepted'. In this case, such a person will be able to accept the new condition only in part, in a sort of cohabitation, rather than a real acceptance. However, studies show that as time goes by the feeling of trust in life grows in people in such a situation, as does the ability to see oneself as more socially able (Magrin, Scignaro, Viganò 2006).

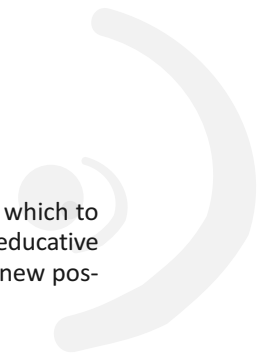
It is clear that not all people developing disability in adulthood manage to reorganize their life positively. Many, especially in cases of severe disability, do not succeed in overcoming a sense of inadequacy, and sometimes get lost in a process that leads them to losing control and self esteem.

People with disabilities will become more or less resilient according to their personal abilities as well as to environmental spurs. The reorganization and acceptance process can be fostered by the support of people likely to activate resilience processes. Educators, for instance, can have a crucial role in terms of care and support of people with disabilities.

Vanistendael and Lecomte claim that operators working with people affected by trauma may promote the resilience process by helping people with disabilities. Such people identify some useful resources, even drawing from past experiences. According to their perspective, 'resilient people are a mix of frailty and strength. Frailty comes from the ordeal suffered, strength comes from the ordeal overcome' (Vanistendael, Lecomte, 2000, p. 188).

Feuerstein pinpoints as *mediators* those who put themselves as *helpers* by providing support through their means of recovery. His saying 'do not accept me as I am' means it is one of the educators' tasks to detect spurs aimed at taking the person in difficulty to overcome the impasse and to positively reorganize their own cognitive, emotional and social life (Feuerstein, 1988).

Education here is meant as supporting the person with a disability to find new strategies to give meaning to life after the negative event. The point is not to suggest or propose alternative models, but to support and walk together with



the person with disability, so as to lead them to find new horizons in which to invest in the future. The choice will always have to be personal and the educative accompaniment is a mediation process to foster the encounter with new possibilities.

### 3. Giving meaning to others' words

Studies and pedagogical research methods that delve into the complexity of situations have several times drawn from the principles of the phenomenological method and have applied it to educational research. As everybody knows, phenomenology proceeds from data and moves towards processes of description and analysis that enhance each specificity (Mortari 2007).

Qualitative researchers study reality giving voice to the protagonists. Thus, they try to enhance individual experiences to come to more general principles that come from analysis of the account and from consideration of implicit and explicit meanings. The researcher has the hard task of gathering experiences and processing them through meticulous analysis. By doing this stories from trustworthy witnesses are exploited to better understand reality and facts subject of the study (Lackey, Sosa 2006).

When they are carefully listened to and interpreted, personal experiences represent an invaluable source of information that allow researchers to investigate complex topics that sometimes are not captured by qualitative analysis (Hennink, Hutter, Bailey, 2011). By giving a voice to adults who experienced singular events and reflected on them, the understanding of complex social events can be promoted (Formenti 2006). The researcher has the difficult job of creating a relationship of trust with people involved in the study, so that the piece of research is a meaningful experience for them, too (Mortari 2010).

Talking about adults with disabilities, meeting a competent researcher who is willing to listen to suffering, difficulties and achieved goals has a twofold advantage: this promotes the research evolution and at the same time it allows the person with the disability to retrace his/her experience one more time with a hermeneutic perspective. Studies found in the autobiographical narrative a possible process of identity rebuilding. Through the narrative, the adult with the disability therefore has the chance to psychologically process the physical trauma, and is thus led towards a gradual awareness of the new condition and to a progressive acceptance (Penning 2012).

This is the reason why, when discussing the epistemology of research, narration is not only meant as a report, but also as the reasoning on issues when the researcher is confronted with the person involved in the study.

Through the narration the individual puts in use mental processes that drive him to a deep meaning analysis by investigating reasons, intentions and possible explanations. Spoken facts are not examined one by one, but they are linked to one another so as to build a system of meanings (Clandinin, 2007). The researcher is interested in this system because it creates knowledge and through its analysis it is possible to understand social events lingering over cause-effect relations and give meanings culturally acknowledged and acknowledgeable.

## 4. The research

The aim of this piece of research was to understand the mental processes of a person who has been affected by disability in their adulthood. From this analysis researchers tried to find out which educative processes may promote the acceptance of a new condition after a trauma. By analyzing each case it was possible to study:

- The initial reaction to the disability and the adaptation processes executed by the person with the disability;
- Procedures that lead the person with the disability to co-exist with a new condition that deeply modified their previous life conditions;
- The role of the educator in the recovery of autonomy and in the support of the person who encountered disability in their adulthood.

A theoretical sampling was used for the study, thanks to the invaluable collaboration from the managers of the association for people with disability and veterans, who sensitized the members to take part into the study.

Thus, a sample of 20 units was determined. It was heterogeneous in gender (12 males and 8 females), age (some of them were very young: 28, 30, 32 years old, others were older than sixty years old), work and social rank (nurses, teachers, factory workers, unemployed people, temporary employees, doctors and managers), qualifications (from elementary certificate school leavers to graduates) e disability typology (blind people, paraplegics, affected by disablement to the upper limbs).

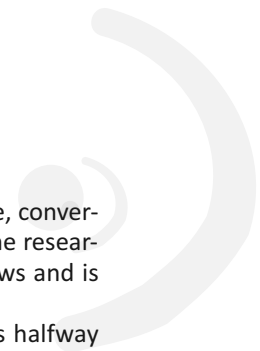
Also the types of disabilities were different from one another. However, the majority of those interviewed were had vision impairment or had lost the use of their lower limbs.

They were asked to be engaged in semi-structured interviews, which were recorded entirely, transcribed and analyzed using Atlas.ti software, which helped in the detection of categories for an analysis of implicit and explicit meanings (De Gregorio, Lattanzi, 2011).

### 4.1 The use of semi-structured, qualitative interviews

More than any other research tool, the qualitative interview allows researchers to investigate in depth social reality and points out aspects which could be missed out by a quantitative approach. In the dialogue with the interviewee, the researcher has the chance to 'enter in depth' into the situations, getting to know the emotions, feelings and moods that the same interviewee reports. As they can be complex and take a long time, the qualitative interview is usually addressed to a limited number of subjects. They are asked to talk about their experiences freely, but also to answer to precise questions that the researcher considers important for the study (Outwaite, Turner 2007).

The qualitative interview, also known as "autobiographical", allows the researcher to access the perspective of the studied subject, and to catch their mental categories and the tacit theories they have built over the years.



Unlike surveys, which use the same questions for each interviewee, conversations carried out in the qualitative interviews are unique because the researcher calibrates the questions according to what the interviewee knows and is willing to reveal.

The *semi-structured* qualitative interview, as the title indicates, is halfway between a free interview and a structured one. It is conducted by following a draft that was previously arranged and allows the interviewer to deal with the issues concerning the study. Since it is not a strictly structured conversation, the interviewee can talk about some aspects the researcher had not foreseen but turn out to be helpful for the research.

## 4. 2 The research results

While retracing their stories, the interviewees admitted to have felt *lost* right after the traumatic event. After that, thanks to paths of growth, introspection and the support of others, they found themselves deeply different from the past, sometimes even better.

From the analysis of the interviews, it is possible to pinpoint three stages that interested all the people with disabilities, even if in different ways and at different times.

The first stage is that of *despair*, which is sometimes accompanied by rage or depression. Usually, this is the stage that comes immediately after the news that the person will be disabled forever and that their physiological problems, which were considered temporary, will be permanent.

The second stage is *acceptance*, and as we will see later on, it is a slow process that not everyone achieves completely, even after years.

The third stage is that of *reorganization*, in which the person with the disability has more or less deeply processed the initial shock. They regain their lives and get engaged at work, in recreational and sport activities, and in interpersonal relationships.

The majority of the interviewees acknowledged that illness, pain and suffering have changed their lives deeply and modified their beliefs and convictions. Changes affected the emotional and value area above all, and today many of the people with disabilities feel enriched, more sensible and more grateful in life for the opportunities they have daily.

To almost all of them, throughout the path of acceptance and reorganization, it was of great importance to maintain a relationship with one or more people that represented an incentive to react and re-appropriate important areas of autonomy. In some cases it was an educator who gave support, care and acceptance.

The following paragraph reports considerations gathered from the research. Words in *italics* are expressions taken exactly from the interviewees that may give the reader for a better understanding of the theme.

#### 4.2.1 *The first stage: despair and rage*

From the analysis of the life stories of people who took part in this study, rage and initial despair emerge as a common factor. Immediately after the traumatic event, the neo-disabled had to face dismay, a sense of helplessness and fear of the future.

The first days were hard and distressing; crying, rage, silence and discouragement often permeated the hours throughout the day and the sleepless nights.

The person with the disability had difficulties in metabolizing the event and in reckoning with the state of health change that disrupted their way of living.

A young woman recalls the thoughts that troubled her after the loss of her sight:

*Thoughts tormented me, they were like beats with a stick that left me out of breath and extinguished my will to live. I went from a bad thought to a worse one; I was down in the dumps. I felt alone, sad and wretched. I was really beside myself. When I think about it now, it seems impossible to me that I sank into such a profound depression, because I had always been an optimistic and positive person. In those moments I was overwhelmed with despair.*

In some cases, rage took over despair. A very strong rage sent in several directions: to the ineffective doctors, to the unfair God, to the little sympathetic parents.

A man who became paraplegic tells us of the rage he feels for the doctors:

*I was angry with the doctors. I considered them shifty, hasty, superficial and sometimes contradictory. In my opinion, they did not do everything they could; I thought they were uninterested in my condition. Many times I insulted them and told them they were incompetent.*

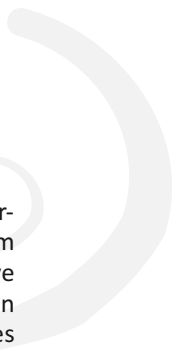
A young woman who lost one arm lashed out at God, by whom she felt abandoned and betrayed. She perceived what happened to her as unjust:

*After the accident, I did not go to church for many years. My rage to God was enormous, I couldn't bear that he did this to me. I had never done anything bad and had always been a believer and practicing.*

In some cases, the receivers of this anger were relatives. Ironically, those who were closer, and did their best to help, bore the worst of the abuse. They were the most exposed to insults and outbursts. A man who became paraplegic describes what happened in his family:

*I was being raving lunatic with my family. They couldn't say anything right; I attacked them and sent them to hell. If they tried to comfort me I insulted and cursed them. I needed to work my explosive rage off and they tried to hold me back. I'm using this expression, 'holding me back', because in certain moments I was really out of my mind. I once threw the remote control to my father who was trying to comfort me.*





In many cases the people with the disability will shy away and isolate his/herself. The comparison with the others is hard, they can't bear consolations from friends and parents who play down the accident and tell them 'it could have been worse'. Staying on their own helped many people with disabilities reckon with themselves, process the grief and accept themselves. Each case testifies that there is a time of introspection necessary for reaching acceptance. This is eloquently phrased in the reflections of a middle-aged woman who became visually handicapped:

*Loneliness seemed to me the only chance to survive, I did not want to meet anybody. I wanted to stay on my own; I was bothered even by my husband and children. I could not bear my mother, or my brothers, who tried to be close to me and comfort me. I searched for solitude to strive with grief and inflict sorrow to myself. Today, after years, I think it was necessary. You can't escape from it; you have to be on your own, to experience sorrow at first hand. Being desperate and crying all the time alone was necessary for me to accept the situation. I believe you have to reckon with yourself before rebuilding relationships with others.*

#### 4.2.2 The stage of acceptance

After the initial stages, the hard times in which the person with disability despairs, sink into depression and picks on the whole world, the acceptance of the new condition gradually starts.

Not everybody achieves the same degree of acceptance; after some months someone begins to live with the new situation, while others are never able to accept it, even after years.

A young woman who lost the use of her legs tells of her experience:

*I spent hours crying, despairing and looking for someone to cast my rage on. Later on, after hitting rock bottom and running out of negativity, I thought I could not go on like that. I decided I had to restart and change direction. It was no use at all behaving like that, and my attitude was creating problems for my two children, who were always sad. They gave me the strength to say 'stop'. I realized I had to stop crying, I was alive and therefore I had to regain control of my life.*

A young man who became visually handicapped admits that even though many years have passed, he cannot accept the situation. He says he lives with the disability, but it is a kind of constrained co-living.

*I am not resigned to living as a blind man, I don't like it, and I don't feel I am myself. Every day I hope scientific research finds the cure for my disability, I trust testing on stem cells, and it seems they are giving promising results.*

Time helps the process, allows a person to accept and find solutions to give sense to their existence. Studied stories confirm the ones who better accepted their condition usually walk down a path of interior growth.

A woman who partially lost the use of her lower limbs tells about her experience:

*Acceptance has come slowly. I felt rage and confusion throughout the first two years. I went on questioning the sense of my life and what would be my future. Then, I started accepting the situation and began thinking that, even though I had a disability, I could live with dignity.*

In some cases the comparison with other people who had experienced the same problems was very important. Sharing stories with other people with disabilities, especially in rehabilitation centers, helped people taking part into this study find the courage to go on.

The following personal story from a man with a walking deficit is clear in this sense:

*In this path of personal growth meeting other people with disabilities was of great importance, it made me feel not alone. I spent hours talking with the other patients at the rehabilitation centre, we comforted and confided in one another.*

Sometimes the relationship with the educator promotes acceptance. Unlike friends and relatives, who were emotionally involved, the educator is a professional figure who listens, supports and gives direction without personal involvement.

A person who became paraplegic tells of his experience with an educator who, at first, he refused and who, with time, turned out very useful in the path towards acceptance:

*Thanks to the educator I managed to give sense to my life again. I believe without him I couldn't make it. The most important virtue I acknowledge in him is the ability to listen and to support me without imposing anything. When we first met each other, I was strongly opposed against everybody. I said 'no' because of preconceived ideas. He learnt to know this mechanism and did not get affected by it. He worked with patience and, little by little, I started trusting him.*

As these personal stories tell, the stage of acceptance is very 'personal'. Everybody walked their own way, though it was often painful and difficult.

Acceptance promotes reorganization, and this is realized when the person with the disability commits to achieving new goals. In some cases the people interviewed changed job, habits and friends. It was sometimes a real 'revolution' in their life, and not necessarily a negative one. In many cases disability opened doors to new possibilities and unexpected horizons.

#### 4.2.3 The reorganization stage

After varying lengths of time spent in despair, rage and suffering, the majority of the interviewees reached what we call the reorganization stage. All the inter-

viewees agree on the necessity of effort and strength of will to regain new areas of independence after the illness or the traumatic event.

From analysis of the interviews some activities that promote the social reintegration of the person with disability emerged. These were work resumption or change, commitment to sport, going back to live on their own and support from professional educators.

Returning to work was of great importance to almost all the interviewees because it made them economically independent and helped them feel part of help them feel productive and integrated.

Here is one interesting account by a woman who had one arm amputated:

*I went to the office on the appointed day. I was nervous, didn't know how to behave, I was ashamed especially with some colleagues, I was upset because I thought I had to give explanations. But things went on better than expected. Everyone was kind and I wasn't asked many questions. I still remember the first day at the counter: I didn't know what customers would think of me, without my arm. My job gave me the strength to recover. I now believe that working gives meaning to your days, and my place is among paperwork in a provincial office.*

Other interviewees changed job and had to find a new motivation from inside themselves. In many cases the new job provided them with much satisfaction, which they hadn't had in the past, as a woman who had a leg mutilated:

*After my leg was amputated I had to change job as I couldn't work at the family bar anymore because of the many stairs. So I decided to invest part of the compensation into attending a two year hairdressing course. I took over a salon near my house. Today I feel fulfilled, have lots of customers, love my job and I think I am good at it. I definitely earn more than before.*

Sport opened the doors to new perspectives to many people with disabilities, as we can see from the victories and successes of a young champion tennis player who uses a wheelchair:

*Reorganization started shortly after the accident, when I decided to play tennis competitively. I trained regularly and started to see the first results. Little by little I achieved goals I had never imagined before. I started travelling around the world. I've been the Italian champion of tennis on wheelchair since 2004, and have won several tournaments. I participated in the World Championships in South Africa, Brazil and other places. I joined the Paralympics in Beijing, I didn't win anything but I'm proud I did it. It was very satisfying; The Olympics are every athlete's dream.*

Interviewees without their own family, after living for some time with their parents, decided to live on their own even against the will of their family of origin, who would have preferred to look after them. In many cases the people with disabilities had to adjust their house to their new physiological condition, at times they had to sell the old house or make important renovations. The story of a young man in wheelchair describes the importance of a tailor-made house very well:

*My house was very pretty, I took care of it in every particular and had been living there with my girlfriend for some years. After the accident I was forced to leave it reluctantly because it was uncomfortable and too small for my movements on the wheelchair. Selling it has been very hard; I had affection for it and had invested lots of money and energy into it. Above all it reminded me of my girlfriend who died in the accident. However, I couldn't stay there anymore, so I took an apartment on the first floor of a detached house. There I can drive into the garden with my car and reach the house without problems. It is convenient, I can move around easily and do anything on my own.*

Autonomy is a personal process that demands a lot of effort from the person with a disability. The interviewees admit that sometimes parents (especially mothers) were always there, in an excessive way that could be overbearing and clipped the wings of one of the interviewees.

*My mother was always with me, she looked after me like a two years old child. She tormented me asking if I needed anything or if I was ok. She followed me and did everything in my place even when I regained some autonomy by means of the wheelchair. I thwarted her and asked to be left alone, I didn't want to be smothered by her cares.*

#### 4.2.4 *The educator's role in the path for the autonomy recovery*

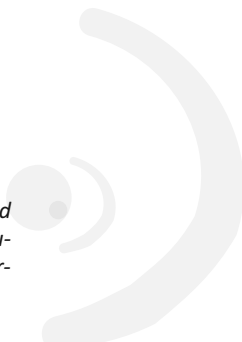
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While telling about their path for identity repossession after the traumatic event, some interviewees (five out of twenty) recalled positive experiences with the educator, who managed to support and back them especially in the acceptance of their new condition. In three stories in particular, the educator more than the family succeeded in leading the person with disability towards a path for the appreciation of their own personal, working and social skills. A 34 year old young man, who became paraplegic at the age of 28, explains very well the good relationship he began with the educator, and the support the latter gave to him during the stage of rearrangement:

*Thanks to the educator, I succeeded in getting up again after months of refusal and escape from the world of the so-called healthy ones, which seemed so far away from me. I started making new plans for my future. The educator was able to push me into starting again with friends, work, relationships and relatives. By means of determination, exceptional sensitivity and patience as well, he encouraged me to make new plans for my future, partially different from what I had done in the past, as my state of health changed extremely after the accident.*

The presence of the educator in many cases represented both a support and a spur during the reorganization stage. A person with a sight impairment started reading thanks to the Braille method that he was taught by the educator:

*I only read the newspaper before, while now I know how beautiful it is to read Russian and French novels. The educator made me fond of these works that fill my days. At the beginning it was he who read; then I pur-*



*chased some talking books. Today reading is my company, I can read Braille and I don't know what I'd do if I didn't know how to read. My educator has the full merit of my discovery of reading; he was able to understand my needs.*

Educators proved very useful especially in the rehabilitation centers. They were capable of listening to the people with disabilities, to support, take care of them and give direction. They knew how to push them towards autonomy without taking over, as the relative who was emotionally involved could. The following account explains the role of the educator in the process of reorganization well:

*By living at home, many people with disabilities are suffocated by their parents' attention. In the centre I was constantly pushed by the educators to move, to do things and to be autonomous. They are experienced and know how to motivate the person with a disability, who otherwise would feel confused, scared and useless. At the beginning it is an out-and-out accompaniment that leads the people with disabilities to gain important areas of autonomy.*

#### 4.2.5 *The awareness that disability can make you better*

All the people with disabilities who told their stories admitted they felt different from 'before the disability'. They report that suffering, pain, sorrow and comparisons with other people in analogous conditions changed their lifestyle and their way of thinking. Being different in body determined important changes in mind, and this led to a reappraisal of goals, beliefs and priorities.

The majority of the interviewees maintain they appreciate life more and they came to the conclusion you can't take anything for granted, and you have to be thankful for the beautiful things you have every single day.

The account of a woman who became paraplegic is exhaustive:

*In the past I was always dissatisfied, I was always looking for more that I had, while today I am more serene. I enjoy small things, like an excursion on a sunny day. Once I considered these things to be normal and thought only extraordinary facts like being famous or rich were important. I've realized that the good things are close at hand and we sometimes cannot see them because we are so busy and we always want more. I can't explain it, but it seems to me the disability changed my spirit more than my body. It may seem strange but today, despite being in a wheelchair, I feel more serene, satisfied and less obsessed by doing and having more.*

Becoming disabled in adulthood often sets psychological mechanisms in motion, and the person is led to question the sense of life. They ask themselves what the value of their existence and sorrow is. They often get closer to religion because they find in God answers that science, reason and logic do not have.

A girl who suffered from severe difficulty walking after an accident, efficiently recounts her experience:

*The illness made me closer to church not because I was looking for a miracle, but because I became more sensitive and available. I know a person who travelled to Medjugorie, so I decided to join them and I've been there six times so far. I think this helps me, I'm interested in prophets and what the Virgin Mary tells them. I sometimes wonder why I don't recover or why this happened to me, but at the same time I tell myself that maybe illness has meaning in my life. The disability gave me a greater sensitivity and a greater belief in God.*

## Conclusive considerations

In the study, biographies from people with disabilities allowed the researcher to analyze the long and tiring paths these people must follow. As we have seen, three stages are detected: initial despair, gradual acceptance, and the demanding of reorganization. Some pedagogical considerations that have arisen from the analysis of the stories of the interviewees are stated below.

### *Uniqueness of the experience.*

The first consideration is that each experience is unique; therefore it is difficult to find analogies, comparisons or similarities between the stories. Even though the people with disabilities nearly always went through the three stages (despair, acceptance, reorganization), timeframes and modalities were different. Some reacted quickly and found resources within themselves to give meaning to their days, while others lingered in rage and non-acceptance for months or even years. Studies highlight that even the most structured psychological systems are profoundly shaken when physiological conditions are modified. Shortly after a negative event, each person facing their disability reacts in a personal way, according to their sense of self-efficacy (Bandura, 1991), which affects the acceptance of the new condition. According to scholars, depression, rage and despair are not to be considered negative, since they allow the people experiencing disabilities to revise their projects and weigh their goals under a new light (Marks 1999). The changeover to the acceptance stage happens when the individual overcomes stress through processes of coping, which make him able to make new plans for the future.

### *The disability represents an opportunity for growth and maturation.*

Almost all of the examined stories point out a pedagogically relevant aspect: the disability, which unexpectedly occurred, forced each person to take stock of their lives and to think about priorities for reorganization. People who took part in the research report lingered, sometimes for the first time, on the meaning of their activities, people they loved and their goals. Many of them acknowledged that the disability obliged them to reconsider their rigid positions and to question their plans for the future. The introspective process of reassessment in their lives was, in many cases, facilitated by an educator, who supported disabled people replace rage with acceptance and promote more rational reasoning.

The environmental context can promote or slow down the reorganization.

Another relevant aspect recalled by the interviews is the person's relationship with a disability-environment. As ICF of the OMS points out, the disability is not

an individual problem, but something of a social interest. From this perspective, a health condition becomes more invalidating if it meets a hostile environment. Several of the disabled reported that they had to move house because there were no lifts in their buildings; moreover, some of them had to leave their jobs because work premises were not adequately equipped or there were no means of transport to reach them. The stories underline how the environmental context may promote the reorganization process by paying attention to the specific needs of each person with a disability. An environment that promotes 'real and not fictional' integration, as an interviewed woman remarked, is that where people feel equal and not different. It emerges from the stories that the people with disabilities most want to feel 'normal'. They are not in search of sympathy, over-protection or overwhelming cares, but they wish to live their daily routine actively, depending on nobody, away from compassionate gazes.

#### *The important role of the educator.*

Many interviewees stated they needed support from educators, and that these were able to take care of them, that is 'to take on' their sufferings. Educators were nearly always the key element for change: they helped the person with the disability to step out of depression and apathy, to find new interests and to be happy again. Educators were highly professional and their focus was on listening, authenticity and congruence (Rogers, 2007); they managed to establish a relationship that became little by little a shared experience and a chance to grow. Accounts show that relatives, as far as they try, cannot offer what the disabled person needs; rather on the contrary, they clip their wings for fear of making them suffer. The educator, being less involved in the situation, manages to create a more authentic relationship, to investigate the personality of the ones he takes care of better and to arrange a personalized educative plan with clear goals to pursue. The educator was revealed to be very useful in rehabilitation centers, because he taught the disabled to gain a new type of autonomy, especially those who had lost the use of legs or sight. It is clear that the person with the disability has to share this plan and has to feel the protagonist of the changing process.

In conclusion, we can say that the first feeling immediately after the trauma was to get lost. People felt inadequate, useless and defeated; but then, after an introspective process, sometimes with the help of an educator, they found themselves deeply changed in body and mind. Disability is an event that upsets one's life and puts to the test even those who have a strong psychological structure. Acceptance and reorganization depend on the capability to predispose oneself positively towards the future, with new targets and goals different from those of the past.

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