

**FACULTY OF HIGHER EDUCATION SCIENCES  
COURSE IN PSYCHOLOGY OF DISABILITY  
AND INTEGRATION**

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## **The Disability and I: a hidden story**

By Santina Portelli

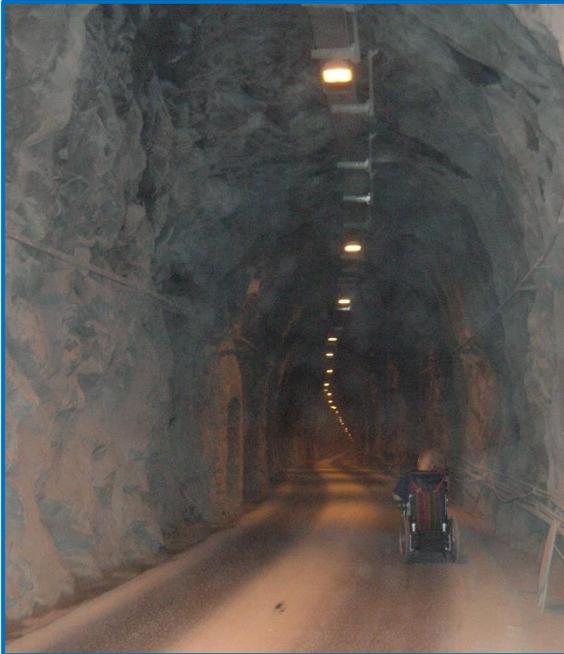
### **Introduction by Ottavia Albanese and Nicoletta Businaro**

Every encounter, every story told is in some way part of our story. "The hidden story of Me and the Disability" is inside every one of us, the objective of the seminar is that everyone mixes their story, to the point of getting to know the disability that everyone has without being afraid or ashamed of it.

References to the book "Convivere con l'handicap" [Living with the disability] by Santina Portelli and the book "Palla al piede, l'handicap o io?" [Ball and chain, the disability or myself?] by Walter Lavacca.

As a psychologist, she has collaborated with universities in Rome and Milan for the training of teachers and psychologists. Affected by spastic quadriplegia, a painter, she is an active member of the V.D.M.F.K. Worldwide association of painters who paint with the mouth and/or foot. [www.vdmfk.com](http://www.vdmfk.com)

## Tuscany, Marble quarries on the Apuan Alps Photo by Marina Ramonda



S. Portelli: "but what's there at the end...?" The artist pushes her wheelchair with her mouth and goes towards the unknown unconcerned about apprehensive friends, worried about the two way street.



Artwork "The hidden story" oil on marble by S. Portelli  
There is no artwork more difficult that to paint the curves, with the paint drips that leave no mark, to leave a face hollowed with a stick, mysteriously wrapped in the unrefined material.  
Completed in 2008 revealed for this seminar

## **INTRODUCTION**

Initially, I wanted to hold a very direct and raw seminar, without frills, entitled “Me and the disability”, I wanted the people coming to this seminar to be intrigued and stimulated, called in to live this experience, this encounter of detailed study.

That “Me” wasn’t addressed only to me, a disabled person, but to everyone, an invitation to confront oneself with disability.

You must be wondering how come there is this inversion of subjects in the title of the seminar that I am proposing, on the other hand, as “The Disability and I”.

I could say that I don’t like being in the center of attention and therefore I put the disability in as a stunt double, but jokes aside, I asked a dear friend of mine who has known me for years for advice, and she told me that the title, as much as it is effective, could leave space for ambiguity, “a hidden story” might seem to be my story, myself being “maybe” a disabled person.

So I fixed it by putting the disability in the foreground and inviting you to relate to it, in other words: “The Disability and I”, where, it is this very relationship that is the protagonist of “a hidden story”.

Together we will see how everyone experiences their own disability and how they relate to it, and furthermore how many different ways there are to relate to one’s own disabilities, and how much of a psychological and project-related influence can the awareness of having a disability have.

Every encounter, every story told is in some way part of our story.

“The hidden story of Me and the Disability” is inside every one of us, the objective of the seminar is that everyone mixes their story, to the point of getting to know the disability that everyone has.

More than anyone, us who work and will work in the educational and clinical sector, we have the task of developing as people before developing as technicians and operators, experts in didactic and clinical strategies.

Technical knowledge should not be a refuge for our limits, therefore let’s not use our role as a shield.

## ***THE INVISIBLE***

**How is disability experienced? diversity? how does it feel upon first contact? Even though there has been continuous talk and study of these topics over the years, we cannot seem to dismantle that invisible barrier which distances the disabled person from himself, from the very first glance.**

**I, myself, in years of research and training future psychologists and teachers, have come across this difficulty, and that's when I insist on what I consider to be a focal, fundamental point: how is the disability experienced intimately, in deeply, by a healthy person, more specifically by an operator.**

**In this seminar, I am proposing a step beyond: how do we experience our own disability?**

**In some cases *the invisible barrier* is palpable, ma neither the healthy nor the disabled person manage to chip away at it, in others the awareness of having it, has activated mechanisms to modify oneself and render it almost imperceptible.**

**But the disabled person can tell if this barrier has only been dealt with culturally, if “he is not his disability”, at the same time this is a condition which is an integral part of one's own life, which one lives with in every moment.**

**Often it is this particular condition of the person to provide him with new instruments of knowledge in human relationships, as will be deduced from life stories as well.**

## ***THE DISABILITY AND I***

Reading, studying stories through a method of emotional listening and introspection is, in fact, what THE INSTRUMENT of this seminar is meant to be... On this journey, we will be helped by the protagonists of my book "Convivere con l'handicap" [Living with the disability] and others such as, for example, a friend, Walter Lavacca, who, in his recent book "La palla al piede, io o l'handicap" [Ball and chain, myself or the disability], defines himself as: "Ball and chain. That's what my friends call me... I was born in 1953: the year of the first football match in TV, of the war in Algeria, of Pinochet at the height of his power, of the Italian expedition that conquers K2... a year learning about... the frenetic use of arms and legs, a year that could not be more different from me!

We were saying that everything began with that damned forceps that has left permanent marks on my body: I am all broken.

Do you know those big olive tree that seem to crumble, bend around themselves but stay around for centuries? There, that is me.

Do you prefer the official definition? I am affected by spastic quadriplegia. Others such as Alice Sturiale present themselves and write:

***"I"***

I am happy with what I am.

My name is Alice, my relatives call me "snake", but I am not offended, because I am quite happy with my mischievous personality.

I am of medium build, I have long legs, I am not very fat, but I'm not thin either. I have dark green, big, expressive eyes, my face is slightly sprayed with freckles, I have a small mouth and two big protruding teeth like White Fang.

I have something that I maybe brag about too much which is very long, blond hair that is straight as an arrow.

I have many virtues but I admit I also have many flaws, such as a sensitive, irritable personality.

Among my virtues, on the other hand, there is the fact that I am an extrovert, I fit in with friends quite well and I like everyone's company. I always have a joke ready and I like food, I am very untidy and I am very lazy about household chores. I don't like being alone for too long and I complain a lot if I don't do something.

**I am easily offended but I don't dwell over a bad situation. I am very attached to my family.**

**I am good at abstract drawing and organizing mischievous plans, I am always dreaming about becoming famous among other things, I have my head in the clouds, sometimes I even try to make some small dreams come true such as establish a tiny company of young investigators.**

**I always want to joke around, maybe too much.**

**I have a passion for sports even though it is not possible to practice them all, because I have some issues with motor skills which don't allow me to walk, but I go skiing nonetheless and I am very happy about that because it is my favourite sport.**

**... I am nosey, I always meddle in other people's business and I always try to know their secrets.**

**... I can keep secrets very well and I am very rigid about my ideas.**

**(January 26th 1993, 4th year of elementary school)**

## *Santina*

I have heard people talk about disability ever since I was a little girl, I remember that at the time it seemed “normal” to me to hear talk of children like myself, because we were seen not as children who had a problem, but as children who were a problem.

The word “problem” dominated the word “child”, child was an adjective and “problem” or its synonyms were a noun.

The majority of disabled people, over the course of their existential path, tend to subvert this barrier, that is, that they are not the problem, but rather they have a problem.

*For your mother you are a guilty conscience*

*For your father you are a child that always has to be re-born*

*For the society you are an economic burden*

*For a doctor you are a body to cure*

*For the school you are a “special case”*

*For the caregiver you are a job*

*For the other person you are not there...*

*For yourself you are a limit or in other words... a problem*

*Therefore..... The barrier exists in every one of us.*

### **Note 11 to the poem “Disability”**

This was written on night, after painful observations, accompanied by crying, of the difficulty to relate with adolescent friends who, between joy and hassle, flaunted the first mini skirts and tights shirts, impossible for Alice, in the immature game of seduction.

And the fear of whether or not there would ever be a boy by her side in her life. Suddenly, she asked for a pen and some paper, she wrote, and finally she fell back asleep, calm.

Some time later she came to the conclusion that in order to experience a true equality in a romantic relationship, maybe she would prefer a boy in a wheelchair just like her, at the same height of the eyes and the heart.

## **HANDICAP**

**Maybe without the four wheels  
it is easier.  
It is easier to have fun.  
It is easier to move,  
it is easier  
it is also easier to  
win over boys.  
But I believe  
the four wheels  
serve to get to know  
all of life  
and know how to face it  
and win.**

(Alice Sturiale, 12 years old)

## ***EVEN THE CLOUDS HAVE A DISABILITY***

**In the silence of the fresh morning air  
I look at the sky as if I wanted to go inside it,  
Immerse myself in it, as if it were ...the sea.  
I observe it and all of a sudden lightning strikes  
"Marina, Marina did you know the clouds have a disability?"  
You look at me confused and you are one big question mark,  
You ask me, why?  
"Because even the clouds need the wind to walk".  
The clouds, my beloved clouds, all of a sudden are my travel companions.  
I have always loved the wind!**

**Santina Portelli**

## **Topics covered during the seminar**

- **The Disability and I, in other words, an invitation to introspection with one's own disability**
- **The invisible**
- **The disability and I, using life stories**
- **Introducing oneself**
- **Becoming aware of the handicap**
- **Short evolutionary path on the forming of the identity**
- **Family**
- **Relationship with one's own disability**
- **Adolescence**
- **Relationship outside the family**
- **With peers**
- **Repercussions of the disability on personal development**
- **Special life events, enough to overpower an exceptional event such as the presence of a disability.**
- **Positive and negative diversity**
- **Do you still feel healthy after the seminar?**
- **Reciprocity**
- **Educational stubbornness, potentials of the disabled student , inversion of the roles**