

From immobility to realization: the steps of a path of creation¹

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Abstract: This paper describes and analyses the life of a talented painter, following up her path and metamorphosis. We talk about the life of E., who has a severe physical disability that has kept her tied to a hospital bed for 29 years, and how the discovery of her talent as a painter was important to change her existence and make it significant. Through a qualitative case study, we tried to understand how she lives daily and how she deals with both her disability and her talent. Supported by excerpts of Elaine's reports evidencing her changes, we share our reflections and those of the theoreticians who discuss identity, stigma and talent development.

*“If there is a sense of reality, there must also be a sense of possibility. [...] It is reality that awakens possibilities and nothing would be more perverse than to deny it. Even so, it will always be the same possibilities, in sum or on the average, that go on repeating themselves until a man comes along who does not value the actuality above idea. It is he who first gives the new possibilities their meaning, their direction, and he awakens them”. Robert Musil, *The man without qualities*.*

This paper discusses topics such as discrimination, identity, talent and change. It aims at clearing up some aspects – personal and social – which can favor talent development, even under extremely unfavorable conditions.

It describes and analyses a life path, which represents, on one side, the experiences of gifted people in Brazil, a nation where this issue has been overlooked despite some good in-

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tentions. Alencar e Fleith (2001, p.172) state that: "[...] what Pfromm Netto (1979, pp. 25 and 26) has highlighted two decades ago still now remains quite real: problems related to research, identification and suitable education of gifted children and youngsters have drawn governmental authorities and public opinion attention quite limitedly..."

In this report, we will follow-up the dramatic identity changes of one single person, from a physical disability through personal realization, based upon talent in artistic creation.

We will talk about the life of Elaine⁴, who has a severe physical disability that has kept her tied to a hospital bed for 29 years, and how the discovery of her talent was important to change her existence and make it significant. Elaine is 30 years old and has been interned in the University Hospital since she was a child. When she was one year old, she was victimized by poliomyelitis, consequently becoming tetraplegic and losing all her movements; her communication means are only her mouth and eyes. She can move neither her arms nor her legs, and remains all the time laid on the bed. She breathes aided by a respirator, thus requiring the services of an intensive care unit. To leave the hospital, Elaine needs a special bed and a breathing device, as well as an ambulance with a specialized team. There are so many difficulties that she rarely goes out.

Her working environment is quite different from traditional ones: it's not a painting studio, but her own room and her own bed. She doesn't get up to paint. During a few hours a day, this room at the first floor of the Orthopedics Department of São Paulo University Hospital is turned into an Art Studio, the place where Elaine produces the wonderful canvases she paints with her mouth. She has a painting teacher, and hospital volunteers help her, placing the brush between her lips, holding the canvas, taking the paints, and brushes. It's a kind of work that requires effort and perseverance, confirming what Guenther (2000, p.14) states: "*One of the most involving characteristics of human talent is its own permanence*".

⁴ To preserve privacy, the names mentioned by Elaine, as well as her own name were changed.

It is exactly because we think man is made of possibilities that we considered it would be important trying to understand what led Elaine to be what she is and do what she does. *“We are born to start and we are human only because we undergo a “human metamorphosis”, i. e., a progressive and endless historical concretization of becoming human, which is always the overcoming of limitations of the objective conditions existing in certain moments and societies”*. (Ciampa, 2004, p. 60). Recovering her individual path can enlighten certain aspects, which may allow a more deliberate action from other parents or caretakers, in the sense of favoring other talents recognition and development.

In order to do that we carried out a qualitative case study. The qualitative research neither tries to enumerate or measure the events studied, nor employs statistic instruments to analyze data. It departs from wide interest issues or focuses, which are defined as the study develops. It involves the abstraction of the reported data about people, places and interactive processes upon the researcher’s direct contact with the studied situation, trying to understand the phenomenon according to the participants’ perspectives. In turn, case study is defined by Godoy (1995) as the kind of research that seeks the clarification of an environment, situation or individual by the study in depth of a single case.

Two long interviews were carried out with Elaine; they were written down and analyzed, trying to understand how she lives daily and how she deals with both her disability and her talent. We have also tried to know the place her painting talent occupies: how it came to her life and became part of her identity. Supported by excerpts of Elaine’s reports evidencing her changes and the most significant bases of such changes, we will share our reflections and those of the theoreticians who discuss identity, stigma and talent development.

From immobility to realization: Elaine’s path.

Elaine has grown up in the hospital since she was one year old, when she was between life and death. It was only two years ago that she took heart and asked her parents what had happened since she got ill, recovering a story that was into the dark up to now.

When she got ill, her family looked for help, and moreover, looked for someone who could be responsible for Elaine, who bears an incurable disability. She says, “[...] *at that time, when I was between life and death, they used to come more often; **then when I started to stabilize, it was the end**⁵...*” She tries to explain their attitude, “[...] *it doesn't mean they do not want to come, but they live far away...*” But she recognizes that they are not able to deal with the situation, “[...] *you see, **it is hard to deal with such a situation**, it's very hard. Even now I know they feel like that, as I have discovered a little time ago that my father cannot deal with the situation, that's the reason why he does not come frequently. [...] he always has an excuse: he's fishing, or he has back pain, or he cannot travel anymore, and so on, but this is not the reason, it may be all of this, but it's not [...] I know that, even not saying that, he feels quite guilty. And how can you take this away from him? You can't, you can't. [...] My current relationship with him is very distant*”.

For Elaine, it's worse to get in touch with her mother's omission, “[...] *I did not ask anything to my mother, yet. It will be... I noticed that it would be more difficult [...] I don't like to remember, excuse me, but I don't like to remember. I feel I have to give it some time*”.

Considering their daughter was properly cared, her parents left her in the hands of the hospital employees, who became her significant others, helping in her socialization process, “[...] *There were doctors, nursing aids and the occupational therapists, **friends who often came out of nowhere***”. Or otherwise complicating things, “[...] *therefore, sometimes it's difficult to have five hundred mothers, five hundred fathers with different opinions and not knowing whom you shall obey and how to do it. Each one wants to educate you according to*

⁵ Bold type from now on is ours.

her/his own way, and you don't have a real father-and-mother education. It's completely different, completely".

The important bonds were established with the most outstanding people, such as Aunt Leni and Dr. Fábio. Elaine describes these relationships as very tender ones in a touching report, "[...] *but there are some people who left marks on me. There is Leni, who I still call aunt Leni and Dr. Fábio [...] Leni was a nursing aid. When I was a little kid I was that silent child, I only shook my head. She began approaching me closer and closer, and then I began to open my heart, to speak, to talk with her. **That was when I was a little kid, I was about four years old and that encouraged me a lot. Then, for me, she is my... today, she's my real mother.** She's retired, but she comes every Easter, Christmas, New Year's Day, she calls me on my birthday".*

Doctor Fabio is someone who cares for her until now. "*Dr. Fábio is a very handsome person and he is also beautiful inside. He is a real doctor, he's human. We used to play a lot. He didn't retire, he quitted. It was a great loss. But I still call him, he comes to visit me, comes with us in the promenades, because I always need a doctor with me, often several ones. [...] This week, for example, he came all the time, because he gave me a formula to lose weight. I called him because I had some reactions, so I called right to him. **Then I said – Uncle, and he answered: "Is it you Lili? Tell me" and then I speak.*** The affection of those people takes her out of her own isolation, inviting her to open her heart. From the feeling of safety, Elaine can risk looking at herself.

First, she didn't understand her limited condition, "[...] *when I was a child, I couldn't resign", questioning her difference, "Why? Tell me, why someone teach me to write with my mouth while he/she writes with his/her hands? You know, I didn't get it. I didn't understand. When you are a child you don't understand.[...] Why to study? There was another teacher at*

that time, she came... it was so beautiful! She came with a copybook and lots of pencils. Once, I threw everything down to the floor and started crying and screaming".

Elaine recalls the difficulties physical disability have caused, *"First, I thought I could never reach the place where I'm now [...] for example, someone teaching me how to do, teaching me what he/she was doing so easily with his/her hands. I said, Gosh! It's easy for you. You are doing it with your hands, but try doing it with your mouth!"*

She depends completely on other people, *"I don't know what walking is; **I only know what is depending on other people and being humble to ask for everything"**. Dependence takes Elaine's privacy away and exposes her, like in a reality show. *"I told Pedro⁶ that if we go there [to the Big Brother reality show on TV], it would be a piece of cake for us, because **we are watched every moment and it's horrible. We have no privacy"**.**

Reckoning on other people improves her life, *"I like when the nurse takes the bowl and puts my hand into it, specially when it's hot and the water is refreshing; I don't like it too cold, but just cold, and then I wash my sweaty hands".* And that recognition allows her counting on those who surround her, doing what she believes she has to do - painting, *"I began painting on a spiral notebook. Sometimes I preferred the big one, you know, craze for huge things, [...] **I did my best to draw a whole large sheet of paper.** [...] When you're kid, you keep doing that for entertainment. It was also a way of discovering what you can do, because I did not know what I could do".*

Elaine can do her work only when somebody helps her, *"I always depend on somebody, not to help painting, but I need the material and someone has to be there in case I need. To shift the canvas, to bring me more paint, to take another brush, to wash, to change the water, everything. **There always must be someone there, always"**.*

⁶ Pedro is 32 years old, he got poliomyelitis when he was a child, is tetraplegic and lives in the same room as Elaine.

And work allows her becoming aware of the way her talent flows, ***"I didn't know I have such thing. Then I began to discover it through the flowers, the little girls and boys, the child's gift came to me."***

She appreciates the encouragement of those who surround her since she discovered she could draw, *"Everything began with a drawing pad; everything began there. There was such thing of beginners, how to do things with the mouth and be useful someway [...] everybody said my first flower was wonderful, except me, but I knew that even it wasn't beautiful for other people, it was a way of encouraging me: go on, you will succeed, you know..."*

Her ability began consolidating: ***"I discovered that I liked that even more, it was not just a hobby, it was not just entertainment, and it was not just to earn money [...] ...and now I see Art in my life is a challenge, every single painting is a challenge, and the more difficult the better, the more detailed the better; I love details, tiny details"***.

She looks for new updating ways and possibilities, *"[...] then, you look for adjustments [...] she has a technique with her hands; there are certain movements you need to perform on the canvas that were impossible to me. I managed to do them, but it's very hard. For example, water reflections require head swinging and the paint dries too fast. You have to melt one [brushstroke] to each other to obtain the nuance, to perceive that it's really reflecting the tree, the sky, the sundown on the water, so... It's also too nice. In the beginning, it was a little frustrating"*. She recognizes the pleasure of performing something that seemed to be a challenge, and this makes she move ahead, leaving frustration in the past.

Elaine has decided to write a book on her life as a way of recovering her identity. She realizes it's important to know who she is, *"It took me a long time to get used to the idea of going after my story. Because I think I was not curious about or, if I was, I had not the nerve to ask. Now I think different, I'm trying to examine some facts"*.

Today, she recognizes herself as an artist and she is proud of being considered as such rather than a disabled person, *"It's quite cool to see people valuing (me) not just for being a disabled person who paints, but for being Elaine, a human being, a sensible Elaine, a quarrelsome Elaine, a stubborn Elaine. You know, it's not the disabled Elaine"*.

Elaine recognizes that she is growing professionally, *"I have noted that I'm really growing in such part of Art, I see I'm growing day after day. Who would imagine I would have a painting at the São Paulo Museum of Art, or six paintings in Switzerland!"*

Her universe was enlarged together with her will to expand her contacts. Today, the Internet is the channel of Elaine - the girl who depended on aunt Leni to talk - into the world. She wants to participate and do things like any other person, and along this process, she comes back to be a child and has to learn again, *"[...] I discover that in the Internet. I was screwed out in the Internet and, at the same time, the Internet has opened new horizons to me [...] I'm in the world, within a hospital, but in the world. I have to learn."*

Elaine could be whatever she wished on the Web, but she prefers to advocate for the identity she had conquered as a disabled artist, *"[...] last week I was chatting with another person in the Internet and she/he didn't believe that I was writing with my mouth, that I live in a hospital, that I'm a disabled person. The Internet puts the world in your hands to do whatever you wish. People are so used to lies that when somebody tells the truth, they think you are kidding. I do not know who I must be in the Internet"*.

Elaine knows people are curious, and she bravely faces the fact of being twice "different", causing surprise: *"Some time ago, I used to be like a "wild animal". If I did not like some person, I gave an oblique glance, I tried to brazen that person out, make her/him feel uncomfortable. You know, it was like, 'Ah, she/he just came here for curiosity, she/he came just to see the endangered species', like many people do even now. Many people come here to see if it does exist, if there are poliomyelitis cases in Brazil, survivors, practically the only ones, I*

*don't know, in the world". A difference that seems to disappear when she is with sincere friends, "[...] **those who are real friends see me as a normal person, a human being with faults and qualities, who dreams, cries, feels, plays and fights**".*

She clearly identifies the diversity of reactions she causes, also for being twice different, *"Strangers can even see me as a painter, but there is such thing of 'poor girl'. So, there are some people who see me as a poor thing or otherwise, who think, 'fortunately it wasn't me'. I notice this in the mall, where there is a lot of movement. A stretcher is quite a weird thing. People look at me in a strange way, other ones do not look, they collide with the stretcher and I apologize, but **the person doesn't look at all. They do not want to see, it's strange. [...]** And there are those who recognize me. **"Look! Oh my, it's that painter. The one I saw on TV, or in the newspaper"**.*

Besides the difficulties and prejudices, Elaine tries to get in touch with life and take profit of those rare moments when she can go out: *"So, it's like that, **trying to figure out ways of living, of amusing myself, besides the difficulties**. When I was a child, I had such kind of revolt, because I did not understand what was happening, why such long time in the hospital, why there were so many children leaving and I stayed..."*

In short, a tragic event in Elaine's life has turned her into a disabled person, requiring special care and determining her physical confinement. Due to the seriousness of the situation, she couldn't live with her parents and family, she couldn't have a "normal" life at home, as other children did. Her parents were impaired by the situation, and could not manage to be part of her day-by-day, could not be present to take care of and nurture her. However, Elaine had significant persons who effectively took part of her life into the hospital, with whom Elaine has developed strong emotional bonds. When she realized that she was different, she was revolted. Looking for an activity, she discovered she was a talented and recognized painter. Her ability allowed her to identify another Elaine, who is productive, creative. Mov-

ing between both conditions has allowed her to recognize herself in both of them, appropriating a wider life, out of the existential confinement.

She has learnt how to face her physical disability through Art, alleviating stress and frustrations. In this process, while she creates her own world and herself, Elaine constitutes her own identity. She has discovered that she likes painting, and she expresses herself through painting. In her paintings, she creates, she reveals herself. She reconnects herself to the world, to other people who respect and admire her because of her talent.

Her capacity to think and live creatively every day is a daily conquest through which she can feel and create opportunities for herself. Creating is not a magical, but a subjective process, made of changes, development and inner life organization.

Self-discovering is not simple, discovering one's own creative self means following a path, and as a continuous process, creativity unblocks obstacles, providing the possibility of reconstructing one's own identity.

Identity as a metamorphosis

One of the most outstanding characteristics of human beings is there are not two identical persons; every individual is unique. As Ciampa (2004, p.58) says, *"one produces the world and oneself within an ongoing socialization process, when identity is formed. However, talking about identity is talking about oneself not forgetting the other and how this other helps me to be what I am and to recognize myself as someone different from her or him"*.

Even being unique, people are not identical to themselves along their own whole life, *"identity is movement, it's the development of the concrete, it's metamorphosis, it's change"*. *It is neither permanence nor stability. There are possibilities of different configurations. It's by doing and acting that one becomes something. We are our own actions"* (Ciampa, *idem*, p. 60).

It's within this perspective that we will try to explain Elaine's conquests in assuming and updating her talent, configuring, from the disabled person's image assigned to her, another way of being and being considered, fighting against crystallization, which works "*[...] as if, once the individual was identified, the production of his/her identity would exhaust together with the product. [...] Thus the general expectation is that one shall act according to his/her predications and, consequently, be treated like that*" (Ciampa, 2001, p.163).

Identity is not a static trait. It is constituted in the action, in work, in the human capacity of not giving up and making projects, dreaming, "*They are characters mutually engendering upon acting and saying [...] characters mutually constituting themselves and, at the same time, constituting the universe of meaning constituting them*" (Ciampa, *idem*, p.154). In facing and overcoming objective difficulties and socially attributed representations one can see the greatness of some human beings, always being born and reborn within the task of living.

Identity and stigma

The word stigma was created in Ancient Greece. At that time, and still now, it was a resource used to discriminate people: signs were cut or burnt into the body to advertise that those people were traitors, criminals, slaves, etc. Stigma is an eminently depreciative word. The stigmatized person became the prototype of the socially banished individual. It's the one left outside the society by those who need to feel "normal".

According to Goffman (1982, p. 80), "*the term stigma, then, will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed. An attribute that stigmatizes one type of possessor can confirm the usualness of another*".

Whenever the word stigma comes to the mind, we think such stigmatized person is condemned to a sad existence, to be unhappy and carry his/her hard life forever, that is, a poor

creature. Goffman (*op. cit*) also said that, *"the attitudes we normals have towards a person with a stigma, and the actions we take in regard to him, are well known, since these responses are what benevolent social action is designed to soften and ameliorate. By definition, of course, we believe the person with a stigma is not quite human"*. (p. 82).

Physical disabled are stigmatized persons. There are limitations in their life that will bring serious difficulties at every moment. It's a person like anyone else, but it's a rare and uncommon human being, always calling the attention, and often causing fear and surprise. Many times, they lack self-confidence and live anxiously, concerned with their exceptionality. They need to learn about themselves; to adjust to the situation; to understand what is important and must be reached. The problem is how to accept limitations without succumbing to them, to accept their own disability and even themselves. To believe that, even being "different" persons, they are human beings made of possibilities and can make choices.

"Persons who have a particular stigma tend to have similar learning experiences and similar changes in conception of self – a similar "moral career" that is both cause and effect of commitment to a similar sequence of personal adjustments. One phase of this socialization process is that through which the stigmatized person learns and incorporates the standpoint of the normal, acquiring thereby the identity beliefs of the wider society and a general idea of what it would be like to possess a particular stigma. Another phase is that through which he learns that he possesses a particular stigma and, this time in detail, the consequence of possessing it. The timing and interplay of these two initial phases of the moral career form important patterns, establishing the foundation for later development, and providing a means of distinguishing among the moral careers available to the stigmatized." (Goffman, *op. cit.*, p.92).

Those people having physical handicaps may develop special methods to avoid the distance and the reserved treatment they probably will receive. They may try to reach a more

personal plane where their defects will not be such a dramatic fact, a hard process anymore, but a new opening.

According to Seligmann (1994, p.76), *"the notion of identity allows understanding its changes, mediated by labor experiences during lifetime. These changes can be positive, i. e., they can happen during the identity enrichment to its maximum potentials, having the connotation of vitalization, that is, an equally positive increase to health"*. The contrary may also be true: *"Labor experiences may also lead to the opposite: to identity-related losses which will correspond to an impoverishment of personality and, consequently, of sociability. Impoverishment here means the loss of plenitude or a development degree which had been already attained in a personal path"*. (Samsaulieu, *apud* Seligmann, *op. cit*, p.84).

Artistic creation as a way to reach alterity.

Through the Art, man creates, becomes sensitive, expresses himself, communicates with each other, and humanizes himself. He manages to retrieve the world, other men, things, himself within a harmonic reunion.

According to Giles (1989, p. 126), *"Art is neither beauty nor creation in the first place, it's the revelation of the Human Being"*. Hence, art should not be understood here in the traditional aesthetic sense, but as Man's way of being: art as a way of existence. By being able to apprehend virtuality, Man is a dreamer. He imagines something, waits for things, wishes and shapes it. Human beings are capable of abstracting through memory and symbols; they are capable of linking past and present, generating associations, which gradually enrich consciousness, imagination, thoughts. While expressing their internal images, people shape them and change themselves. Painting, drawing and every graphic or artistic expression, as well as music and dance, are part of a valuable set of instruments which help human beings to organize their internal order, allowing them to reconstruct the reality around them.

Specifically approaching Art as an expression of disabled persons, Lowenfeld (1961, p. 540) says, *"Art creation may be a great encouragement to physically dominate a hard situation and may also be a means of emotional relief for many disabled person's frustrations"*.

Giftedness and personal adequacy

We borrow this subtitle from our colleague Zenita Guenther's book entitled "Developing Capacities and Talents" to end this paper discussing some personal aspects that favor talent appropriation and development. She says, *"An usual fact in our daily common life is that when we look around and watch people living their own lives, we verify that certain persons are noticeably more "adjusted" than others, i. e., they manage to better capture, perceive and place the problems they have to face, approach life situations more effectively and efficiently, and reach improved satisfaction and success levels, both in solving the problems they face, and guiding their own life"*. (2000, pp. 99-100).

It's impossible to read this excerpt without remembering the path Elaine has gone through towards self-actualization from the most adverse conditions one could face. The notion of **adequacy**, developed within the Humanistic Psychology, is quite pertinent here, after observing how Elaine has gradually expanded her world, her relationships, her existential horizon upon the recognition and development of her abilities. From the angry and shy girl, and after being a child revolted with her own destiny, we were able to follow-up a newborn whole person, aware of her limitations, but not condemned to let them annihilating herself, who is prepared to grow and mature, assuming the task and pleasure of her professional realization and the expansion of her access to the world, previously restricted.

To end our argumentation, we use again Guenther's words, *"The results of such a way of being and living are a positive self-concept; self-confidence and trust in his/her basic condition as a human being; effective knowledge of his/her characteristics, qualities and failures,*

integrated in a wide life project where his/her own improvement as a person is present, at every moment, in the interactions and dynamic exchanges within his/her physical and social world, in every process of being, living and living together" (p. 101).

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