EXPLORATIONS INTO A COMPLICATED STORY – OURS

Voices, experiences and accounts of disability at the University of Bologna

edited by
Nicola Bardasi and Cristiana Natali

translated by
Nicola Bardasi, Yuri Lysenko, Eleonora Perugini,
Zazie Alberta Piva, Gabriele Savioli

reviewed by
Peter Henderson

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www.buponline.com
info@buponline.com

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Introduction

Cristiana Natali

Translated by Gabriele Savioli

Maria Paola has only one hand – the right one.

When she started dancing with us, she told me she had absolutely no experience in any form of movement, claiming she had no talent. Very soon, we found out a musical sensibility in her, together with great imitation skills and an extraordinary smoothness of movement. In the beginning, when she started dancing, Maria Paola used to wear long-sleeved shirts, which re-established an image of symmetry. By the end of the year, she was performing in stage costumes with uncovered arms. When I asked her to write two pages about her experience, I knew I would get emotional reading her words. However, I didn't expect her words to show me unfamiliar sides of her which I didn't know.

The concept of this book takes inspiration from those two pages. The reader can find them here as the second chapter (entitled *How dancing gave me a hand*). Through Maria Paola's story, we can approach an unknown reality and an original way to narrate it. The result is the appearance of greater understanding, granted by those who have generously offered to share their experiences with the reader.

As a matter of fact, Maria Paola stresses the importance of communication and exchange. When I asked her about her expectations with regard to her contribution which we were about to publish, she explained:

> I'm pleased people will read my story […] I hope that it can motivate people who find it difficult to talk about it – don't be afraid.
>
> *In what way?*
>
> Talking about it is useful, establishing communication about it, because one of the things I notice the most is other people's embarrassment in relating to me. Embarrassment for many things for which I, at times, don't even think about […]. Many people have created problems for themselves which I've never even had. On the one hand, it could be a question of upbringing, because some people think they are offensive, and maybe there are people who could even take it badly, differently to me. Of course, it depends on the kind of problem one has. There are many more debilitating problems that my own which can create difficulty. So I'm not judging people who take it badly when someone talks about their disability, I know this kind of person. However, for someone like me, it's embarrassing when someone feels embarrassed, because at that point I don't even know how to react. Instead, if you give me an input and I can answer, or the other way around, then communication is established, we can talk. [This book] is an opportunity to open a door (interview with Maria Paola, the 2nd of January 2018).

How many doors can we open to the world? As many as there are ways to see it, feel it, live it. Through the subjectivity of their words, the authors of this volume give us a surprising point of view.

This book gathers both the texts of people with disability/DSA[1] at the University of Bologna (students, former students, graduates, professors, interns and technicians) and contributions by tutors of those with disabilities. It also contains the story of a student and her experience with the Disability Awareness Laboratory organized by the School of Arts, Humanities, and Cultural Heritage in collaboration with the association "Acca Parlante". As regards Matteo Corvino and Francesco Musolesi's contributions, they preferred interviews, conducted and transcribed by Nicola Bardasi[2].

How where the contributions gathered? Through the Service for Students with Disabilities/DSA, an e-mail was sent inviting them to participate with their own contribution. We have included this invitation here because we would like this book to be just the beginning: in fact, the on-line version could be enhanced with texts by anyone who wishes to participate. We refer to students and in particular, technicians, tutors and teachers with disabilities: since is there is no address book for reference, we had to resort to our personal contacts, which is inevitably limiting.

Just a note of warning to readers: each contribution is autonomous. It is therefore not necessary to read them in order, although we do suggest reading the contributions of Enrico Franceschi, Luca G. De Sandoli and Matteo Corvino in the indicated order, as the references contained may get lost on the reader.

We would like to thank those who believed in this project from day one: Costantino Marmo, President of the School of Arts, Humanities, and Cultural Heritage, all the members – students and teachers – of the Joint Teacher-Student Committee, as well as the administrative personnel of the School vice-presidency (Donatella Alvisi, Antonio Merli, Annarosa Pasi, Nadia Perri, Moira Venanzi). Thanks also to Ilaria Tamburini and Francesco Secchieri for their collaboration and all the personnel working in the Service for Students with Disablities/DSA. Finally, a big thank-you to Brenda Benaglia, Roberta Bonetti and Enrico Franceschi for helping to edit the final draft of the book and for collaborating in the distribution process.

We think this book can be a growing project, so we would very pleased to receive your comments at the following e-mail address: cristiana.natali@unibo.it

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[1] Specific learning difficulties such as dyslexia, dysgraphia, dyscalculia, dysorthography or dyspraxia (see *infra*, p. 35, n.11)

[2] Nicola Bardasi also wrote the editor's notes.

How dancing gave me a hand

Maria Paola Chiaverini
Modern Literature Graduate, University of Bologna

Translated by Gabriele Savioli

A few months after we had first met, a friend of mine confessed he had felt deeply embarrassed for asking me, in the middle of a situation where I was in trouble: “Do you need a hand?”, immediately thinking that he had put his foot in it. I laughed because I had never associated that figure of speech with the fact that I don’t have a hand; it’s like saying to a blind person: “See you tomorrow”. When these situations happen, not only am I not offended but most of the time I don’t even think about: I am the first one to use the expression: “Do you need a hand?”; I was about to write: “Can you please lend me a hand?” and choosing this expression I realize that I have always found it difficult to ask for someone else’s help. I have had to learn to do it when I have a problem – ask for a hand, ask for help when I have been in difficulty.

When you’re born with a different physical structure from most of your peers, you grow up and realize that there are things you are not able to do. In my case, my personal limit concerns a specific aspect: working with your hands. I soon understood that I could never play piano. Then I found out that it’s not always like this for everyone: when you learn to do things, you do so by imitation. They show you how to tie your shoes, you see how everybody ties their shoes, but you can’t do it because you need all your fingers. You can’t tie your shoes like them, you must find another way. I figured out my own way to tie my shoes and realized that limits encourage creativity: find your own path, which can’t be taught, but you need to find it, to reach the same goal.

Even today, my friends are amazed when they see me painting my nails.

Nevertheless, my determination which pushes me to overcome limits has created a new one. Something more difficult than tying my shoes or realizing I would never be a trapeze artist (I loved the circus when I was a child) was learning to ask for help when I was not able to do something. Pride and shame kept me from accepting my shortcomings, which were obvious but became even more real the moment I asked for help.

I learned how to get help when I became a woman. Growing up and becoming a woman is a process that affects your perception of your own body, as well as aesthetically: from this perspective it affected my disability greatly, at least how I saw it. It’s probably not so different from the way teenagers are concerned about having a big nose or being chubby or having braces. Even though it seemed to me that those problems were strictly subjective (OK, not always, but often) while my “problem” was, without doubt, indisputably objective. Furthermore, while other defects were in some ways fixable, mine was unchangeable. Also, although it seems a contradiction, the idea of wearing a prosthetic hand had never even remotely occurred to me. I have always regarded my little hand with possessiveness (it’s mine, it’s me, anyone who touches it will be in trouble) and unavoidable resignation (this is it, there’s nothing I can do about it).

All these thoughts and feelings are not confined to self-reflection but are reflected every day through the faces of people that look at me. It’s not easy to deal with these gazes, because other people’s reactions are out of your control. Sometimes it is not possible to react because people don’t express their feelings directly, trying not to hurt or offend me. For example, children usually ask me immediately what happened to my hand and I answer their questions directly, which is usually funny and surprising. If their parents are around, they usually feel embarrassed by their kids’ questions, because they are worried they are offensive. If I can, I answer them directly, involve them in the conversation: when it happens, it’s good. Most people I meet don’t immediately notice my little hand, it happens during our conversation: this calms me and as a result, calms them too.

Instead, strangers just stare at me and say nothing. If I return the gaze, they turn away: here, facing such stares I feel helpless. For a good portion of my life I tried to protect myself from this by covering up, by avoiding showing myself to strangers. Luckily, circumstances in life force you to open up.

The first of these for me has been love: when you love somebody, you cannot avoid revealing yourself completely naked, both your body and soul. Showing yourself to a person whose “judgement” is extremely important to you. Sometimes it has gone well, sometimes not so well but love teaches.

The second very important thing has been dancing. I discovered it late, during my University period, in the form of passionate African dancing. I will always remember the moment when I heard the rhythm of the drums for the first time: that blew me away and out flowed a stream of joy I didn’t even know existed. I now feel this joy every time I dance. It happily overtakes all my preconceptions and fears and engulfs me every time I dance. It’s exactly like when you fall in love – you are overwhelmed by emotions and you don’t care about anything. It’s such a deep and beautiful feeling I cannot let anything or anybody – least of all my own fear – take it from me. I am no longer afraid to show myself: *I want to show myself.* I wish everybody could share this joy, also because I can’t keep this joy to myself.

When I think about it, I realize how lucky I have been. If you see me dancing, you don’t need to ask me if I’m joyful.

Sensory rediscovery of the world

Rocco Pessolano
Cultural Anthropology and Ethnology student, University of Bologna

Translated by Nicola Bardasi

When an event like the loss of sight occurs in adulthood, it forces you to face a huge challenge that threatens to be overwhelming. Your old world is lost and you have to find a new way to live and organize your reality.

Since childhood, I've always loved travelling. When I decided to leave for the first time after high school and go to England to learn the language and to learn about other ways of living, I remember the endless discussions between my father and my grandfather, with whom I spent most of my childhood, about my choice to leave. My father believed that the cause of my increasing interest in travelling was due to the frequent visits that my grandfather and I made to a small railway museum, where, in addition to vintage steam locomotives, you could also admire photos depicting travellers of the *belle époque* with suitcases and clothes of the time.

There is no doubt that the travel stories which my grandfather told me and the novels by Verne or Salgari which I read in that period of my life strongly shaped my teenage universe and built a symbolic imaginary that in turn led me to embark on a life of discovery and curiosity, oriented towards things different from me, towards "other" cultures.

I still remember my grandfather's old *De Agostini* atlas, on which I tirelessly traced the boundaries of states, until I learned by heart the outlines of nations and continents. That visual memory remains extremely alive even today.

After my adolescence, the desire to travel and get to know different cultures took me to various parts of the world, both for work and for the pure curiosity of discovery.

The job of assistant and tourist guide that I was doing in those years greatly refined my empathic perception, exploiting to the maximum the sense of sight. Having to manage generally quite numerous groups of people and having to pick up within a few moments the mood of the group from their facial expressions and body postures, the sense of sight was undoubtedly the one that helped me most. Over the years I learned a technique to collect even the smallest details in my field of vision in a few minutes and, from a few particular details, memorize people's faces and names.

The numerous trips to distant countries showed me a great variety of landscapes, from the coniferous forests of Scandinavia and the tropical forests of Brazil to the crowded metropolises of New York and London. Moreover, thanks to my passion for cinema and the art museums in every city I visited, an enormous repertoire of images, faces, natural scenarios and architecture was built up. This created a considerable mental database, a library of images in my memory that I would later find a fundamental resource in constructing my "new" mental images.

For the first part of my life, my world had been made up of colours, landscapes, faces, basically through an overwhelming predominance of the hegemonic sense: the sense of sight. My symbolic universe was strongly influenced, constructed and shaped by the perception of the world through images.

My evaluation of the world around me, my judgements about things, scenarios, people and facts, the creation of "pre-opinions" mainly took place through the sensory channel of sight, which somehow dominated and influenced the other parameters which were brought by the other senses. To be more precise, the sense of sight outran the other senses which, for physiological reasons, need more time to bring useful information back to the brain in order to form a judgement (Le Breton 2007). In fact, touch, smell and taste are senses that need physical proximity; only hearing, like sight, does not need physical proximity, but in many ways, it becomes subordinate to sight and strongly conditioned by it when the two senses work simultaneously.

Sight is certainly a more selective sense than hearing: using sight you can concentrate on a point on which to focus attention and bring the information back to the brain. Hearing, by contrast, is a sort of door always open to the world, which captures everything going on around it, making it very difficult to discern information.

Sight, as mentioned before, was not only the fundamental tool of my work but inevitably also influenced my preferences in the construction of social networks and personal acquaintances, which were unconsciously influenced by appearance and image.

Then one day, a day that seems to be exactly like any other day, starting with a morning like any other you have experienced before, you open your eyes and see, as usual, the colours, sunlight, everyday objects, the furnishings of your room, the faces of people and you could never, ever have imagined that this morning would be the last time you would see this performance, that what you were seeing at that moment would be "the last rehearsal", the last representation that the magnificence of sight would grant you.

In fact, on such a day, a serious traumatic accident caused a bilateral retinal detachment with widespread lacerations.

I can only try to describe my immediate sensation. Retinal detachment is a subtle enough event because it doesn't cause physical pain when it happens. The only perception one has is that of slowly seeing an opaque curtain being lowered, the feeling of "seeing through a sea of milk", a very appropriate metaphor, as the Portuguese writer José Saramago wrote in his novel *Blindness*[3].

The curtain that came down before me at that moment turned out to be a veil, a foggy blanket that was going to make a whole world disappear – the world of meanings that over time I had built and shaped through experiences gained throughout my life had been definitively closed forever in a few minutes.

The current use of the concept of "worldview" to define a system of representations or the symbolic system of a certain society reveals the hegemony of sight in our western societies. The strongest message that our society conveys to us is that the world exists when we see it. At that time, I was an "actor" and a "product" of that world, a world that is based on and feeds on images.

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[3] *Blindness* (the original title of the work in Portuguese is *Ensaio sobre a Cegueira*, or *Essay on Blindness*) is a novel by the Portuguese writer and Nobel Prize winner in Literature, José Saramago, published in 1995. With his unique style, characterized by the impetuosity of a prose that transforms dialogues into a flow of thoughts, Saramago gives us a portrait of our world: blind to evil, that which comes from within, from our animal nature, and that which comes from outside and make us suffer more and more. The novel is an invitation to look at our time and its contradictions, to deal with the darkness that grips us and makes us all equal, because we are equally blind. All equal because blindness takes away hope from the world. "Blindness is also this – living in a world where there is no hope" (http://www.connessioni-letterarie.it/recensione-cecita/, last accessed 5th May 2016).

I spent the first period after the accident between hospitals, post-operative hospitalizations and my parents' home. Over a period of eighteen months, I had three operations, so my connection to the world at that time was made up of hospital beds, waiting rooms and medical check-ups. I had been catapulted into a new world, completely different from my own, from that world that I had learned to build with time and the experiences I had lived. My new world was an "in-between world", a kind of limbo, made up of meanings that I used in order to learn about the new universe around me, an unknown universe that I had to get to know through other sensory channels.

I speak of "limbo" because the period of hospitalization was like living in some sort of "non-place." The feeling of that period was as if for a long instant my life before the accident had been "frozen", put on *standby* and, at the same time, as if I was living a parallel life, an "other world", as in a sort of extended dream. In which everything I perceived through the other senses, what I felt, touched, smelled or tasted had very marginal relevance, because they were experiences not supported by the dominant sense: sight.

At that time I realized how much I needed sight, among other things, to give a kind of "certification" to reality – basically the things I was experiencing and perceiving with the other senses didn't seem to me ultimately "true" because they did not have the approval of sight.

As the sociologist David Le Breton states, "the body is a profusion of the sensitive, it is inscribed in the movement of things and mixes with it with all the senses, between the flesh of man and the flesh of the world there is no fracture but an always present sensory continuity, the individual becomes aware of himself only through feeling and experiencing his own existence through sensory resonances that cross it tirelessly" (Le Breton 2007, pp. xi-xii). But when the hegemonic sense of sight fails, a "fracture" takes place with the sensory continuity of the world. The other senses experience an initial moment of bewilderment and then a long period of adaptation.

It's as if the years of the domination of sight had somehow "intimidated" the other senses, making them unable to express concrete judgements, as if sight had deprived the other senses of responsibility and sight was the only credible sensory referent for the brain. This is my way of explaining the feeling of "unreality" that I experienced during the first period of blindness. Undoubtedly the period that I have defined as "limbo" can also be defined in other words as a period of non-acceptance and rejection of the traumatic event, a fact that is normal in almost all cases of changes involving the destruction of the previous world after an accident.

For those who suffer, the body is not simply a physical object or a physiological state: it is an essential part of the self. The body as a "physical object" cannot be clearly distinguished from "states of consciousness". Consciousness itself is inseparable from the conscious body, and therefore the sick body is not simply the object of cognition and knowledge, the object of representation in mental states or the object of work for medical knowledge: it is also a disturbed agent of experience (Good 2006).

In my specific case, the lack of the "comparative sense" represented by sight led me not exactly to a rejection of my situation but rather to feeling that I was living in an unreal world because the "other" senses at my disposal were not yet able to analyse reality autonomously or create a coherent system of decipherable meanings.

The period which I called "limbo" lasted just over a year. This period helped me somehow to begin to understand, with great caution and through empirical experiences, this new world into which, despite myself, I had entered. Slowly the unreality of the "limbo" made way for awareness and for empirical experimentation of the world through my other senses. The "Tyrant" Sight was no longer there, so, after a period of sensory "anarchy", the other senses organized themselves to share the burdensome task of substitutes, expanding to the maximum of their abilities and trying to give the brain, in an "alternative" way, all the information that it needs to process cognitive perceptions. I can say from my experience that the phase of slow sensory replacement began quite early. The slowest and most difficult phase is psychosocial acceptance and self-acceptance.

A world had been lost and there was little to no hope of returning to the old one: this is the thought which is most difficult to metabolize. I felt like a new Gulliver when he survived the shipwreck. He landed in a world completely different from his own and retained the faculties and experience that he had accumulated from the previous world, but he also understood that in the new world he had to learn to use new parameters and perceptions, and trust in them.

The work of rebuilding the world is difficult and placing oneself in it is even more difficult. What I had learned about the world of blindness when I was a sighted person came back to mind.

Social etiquettes that I used without realizing it, because they were part of Western culture, that is, of that culture which had shaped the first part of my life, were still present. "Relationships with others, the organization of individual and social life, all activities implicate sight as a fundamental requirement and make the blind an anomaly and an object that causes anguish for other people. In common opinion, all activities are impossible for a blind person, and their own thoughts organized around visual impressions escape, and all their faculties, wrapped in darkness, are lost or blocked. It seems to many that the blind person is somehow oppressed by his circumstances and that the sources of his personality are as though poisoned" (Le Breton 2007, pp. 43-44). Losing your sight means losing the use of life, staying on its edge. Sociologist and anthropologist David Le Breton has found that the term *blind* and its metaphorical meanings take on a pejorative nature in various languages. Blindness is a closure to any form of lucidity and leads the individual to defeat, with the loss of the ability to discern, to see and understand, to analyse events in a correct manner. Putting on blinkers or closing one's eyes, on the other hand, means not understanding reality, and in all languages "blind" is one who lacks enlightenment and reason, someone who is obtuse, clumsy and so on (Le Breton 2007).

It is not difficult to understand why a blind person is a stigmatized person who creates anguish for other people. When awareness of the loss of vision slowly emerges, the major problem is how to "rebuild" an idea of the "self" in the world and give meaning to the new world in the gradual attempt at rediscovery. The process of reconstruction is slow and at the beginning, also due to the circumstances, full of disappointments; starting the rediscovery of a new world through the four remaining senses can at first be both frustrating and exciting at the same time. Through a sort of anthropopoietic ritual[4],

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[4] Anthropopoiesis is an anthropological concept that has found applications in contemporary French and Italian anthropology. The theoretical framework that forms the background of this concept is the ancient idea of man as an incomplete being, that is, the idea that human behaviour is not widely predetermined by genetic heritage. The human being completes oneself only with the acquisition of culture. Anthropopoiesis is seen both as anthropogenesis and as the "rebirth" of man as a social being by creating "models and fictions of humanity". Social and cultural practices fabricate the man through ritual and institutional constraints. Anthropopoiesis is an updated reprise of the very old idea, at least in the West, of human incompleteness, of man as an organically incomplete being, in particular in the way in which

a rebirth or rather a “second” birth achieved by acquiring new elements – i.e. a cultural reconstruction – I was trying to reshape both my body and my being, penalized by an incompleteness of the biological body, using cultural elements that would allow me to have the right characteristics to be part of this new social scenario. During this slow metamorphosis, even physical posture and its remodelling should not be overlooked. Moving, which in the past was rapid and immediate, dictated by the information provided by sight, inevitably had to be transformed into a slower, more composed action: self-assuredness and speed were replaced by slowness and reflection. The posture of the body certainly became more careful and calculated. The plasticity of movements shaped the body in such a way to be ready to experience the world through touch. A new cultural anthropopoiesis had, in short, led me to an acceptance of myself and at the same time to having an active role in society, or at least beginning to represent and understand a role, a presence, within the social group with which I had to interact.

My apprenticeship period was slowly coming to an end: sensory experimentation and the acquisition of new techniques were strengthening the idea in me of being able to continue on the path that had been interrupted by the accident. Previous experiences and stored images of the world were a valuable aid in the formation of mental images. I was struggling to rebuild my place in the world and trying to redefine myself as an actor in a scenario that was necessarily different.

In a situation of physical coexistence with a sensorially-disabled person, the “user guide” to be followed by other people involved must be changed slightly if you want all such people to be genuinely involved. In the case of a vision-impaired person, it is necessary to use sensory channels that avoid the use of sight and, using the verbal or the tactile channels, it is certainly possible to reach a form of direct inclusion of the blind person in the communicative interaction.

There is no doubt that sight is the sense that dominates over the others in interaction in physical co-presence, dictating and suggesting judgements which then inevitably influence the order of the interaction.

For example, one day I was in a bank office waiting for a clerk to open a bank account. While I was waiting, I had put my white cane in such a way so that it would impossible to notice. The interview with the employee was very straightforward, respecting the canons and interaction that are commonly shared in such communicative situations. However, as soon as I made a move to stand up, saying goodbye and revealing my white cane, the interaction suddenly changed. The clerk, who up until that moment had been kind and friendly, at the sight of the stick, unconsciously began to address the person next to me with phrases such as “Will you sign it?” and explaining the terms of the agreement to the other person, even though a few minutes earlier, he had spoken to me perfectly cordially. In this case, the simple appearance of a “symbol” such as the white cane was enough to change the communicative frame, thereby upsetting the interaction.

Restarting the sensory discovery of the world without sight in a protected environment can certainly be an advantage in the early stages.

I was lucky enough to start experimenting with my new perception of the world through the four remaining senses in a known environment, which gave me some confidence, because I had to try various things several times before acquiring a certain agility. For

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Clifford Geertz (1987) and Francesco Remotti (2013) have recently defined the concept of anthropopoiesis.

example, I started cooking again after losing my sight. Cooking has always been something I love doing. When I started doing it without seeing, it was an experiential “journey” through touch, taste, hearing and smell. The most important thing is organization. Memorizing and having a mental and tactile outline of the positions of ingredients and kitchen items is the most important thing.

As you refine your techniques with touch, you also understand the quality of the food, the degree of ripeness. Sense of smell is the guide in the world of spices and fragrances of food while your hearing makes you discover a world through the “sounds” of cooking. In addition to cooking, little by little I started to rediscover a series of activities that I was able to do and that somehow brought me back to having a sort of contact with the world that I thought was definitively lost. For example, the discovery and use of audiobooks gradually brought me back to the world of reading. Another tool that until then I had considered something linked to the classical iconography of the “sad blind person” was the classic white cane, which has been a fundamental tool for me in the discovery of this new world. Actually, my white cane is an extension of the sense of touch, a tool that touches things and sends back sounds and shapes that can be deciphered as well as being a symbolic element to signal the presence of a blind person to other people.

Through technological aids such as screen readers[5], I started to use the computer again, which gave me access to information through the Internet and allowed me to re-establish contacts with the outside world through the use of e-mail. Little by little, this allowed me to rebuild a social network of relationships. The combination of all these elements was the motivational drive that allowed me to regain full possession of my new life and start a new adventure, trying to live in a world through other perceptions.

This new adventure led me, at the age of forty-six, to want to get a second degree but, this time, as a blind person. My passion for cultural anthropology, which had matured during the years of my frequent trips abroad, was the perfect motivation for the new path. My arrival at the University of Bologna led me to discover a group of people who were both strongly motivated and empathetically prepared to work with people with disabilities.

The staff of the Service for Disabled and Dyslexic Students were an essential support for me during my university years.

Together we developed a system that made the study plan accessible for a blind student, using digital texts, recordings of lessons and the use of assistive technology such as robots, Braille and apps. This perfect synergy led us to build a good working method over the years and I am happy to say that together we have achieved an important result, in terms of breaking down physical and organizational barriers and prejudices.

Unfortunately, all this is thrown into question when bureaucracy prevails over the results obtained and over the experience gained over the years.

The turnover of inadequately-trained staff and untrained managers brings into question the quality of a service that could be a point of excellence for the University of Bologna.

My main interest in these years has been fighting to dismantle stereotypes towards blind people and, where possible, trying to improve access to fundamental rights, including the right to study. My university experience in recent years has helped me undertake a

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[5] A screen reader is a software application that identifies and interprets the text displayed on a computer screen, presenting it via speech synthesis or a Braille display. Screen readers are mainly used by people with (partial or total) sight problems. Visually-impaired people may also use in-screen magnifiers [editor’s note].

profound cognitive journey, both for myself and for the composite interpersonal relationships that are intertwined and still-developing in the situation of my new life.

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A story of deafness: a University experience

Cecilia Bacconi
Nursing student, University of Bologna

Translated by Zazie Alberta Piva

My name is Cecilia Bacconi, I'm a twenty-one-year-old attending my third year of the bachelor degree in Nursing at the University of Bologna.

Like anybody else, I have many character traits, qualities, flaws and virtues, but here I would like to write about one in particular: I'm deaf. I have been since I was born, due to a genetic mutation. In my family, in fact, no one except for my youngest sister – who is more profoundly deaf than me – lives with this condition. What an ironic, absurd thing! This is just to explain that this is a hereditary characteristic. I wear a prosthetic in my right ear and have a cochlear implant[6] in my left, and from an early age I had speech therapy for almost ten years, which helped me develop good language skills, learn how to listen but most importantly how to talk. And today I am very proud of the person I have become thanks to that experience: a deaf person who hears and talks.

Rather than talk about myself, in this account I'd like to talk about how deafness is still, in the twenty-first century, underestimated and ignored, especially in the university environment.

In the nursing bachelor degree course study plan, it is compulsory to carry out several internships during which students are supported by tutors who teach them practical knowledge related to the health profession. In April two years ago, 2015, during my first year of nursing school, I started my first fateful internship. I was already very anxious just at the thought of trying out the completely new, different experience of being in a working environment. But above all I had a lot of questions concerning my condition: "Will I be able to hear everything?", "Will deafness be a problem for my tutor?", "And what about the patients? Will they trust me?". In short, my head was full of doubts and I knew the answers would arrive only at the end of my internship.

At the beginning of the internship, I had imagined I was not going to hear the buzzers, that it was going to be tough to follow fast-talking doctors during patient rounds, to understand the names of the medicine, to check blood pressure while using a stethoscope[7]… This is what I thought, but I was wrong. I won't deny I encountered some difficulties, but I have to recognize it was all a lot easier than I had expected. The greatest difficulty I encountered was my personal relationship with my tutor, the person who should have been my point of reference but instead turned out to be someone completely different. In fact, from the moment she became aware of my deafness, she behaved very distantly towards me: she didn't oversee me or explain things to me; when I asked her to not to talk so fast, she would talk even faster; when I asked her to face me when talking to me, she would turn her back; when I begged her to repeat because I hadn't heard her (which, by the way, only happened a few times), she would huff in my

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[6] A cochlear implant is an electronic device which is surgically implanted and constitutes a sort of "artificial ear" that allows to re-establish completely or partially auditory perception [editor's note].

[7] A stethoscope is a tool used by doctors to listen to sounds or noises produced by the functional activity of a patient's deep organs, such as lungs, heart, intestines, blood vessels [editor's note].

face. Basically, she wasn't open towards me and treated me as if I was inadequate to carry out the internship and, in the future, a career as a nurse.

In this respect I would like to tell an anecdote that to some may not seem very significant, but has great relevance to me. We were in the room where all the medicine is kept and while I was reorganizing it, there was a very loud drilling noise, one of those noises that you could hear as if it were two metres away even if your head were under a pillow. In all likelihood there was construction work going on near the hospital and this was the reason for such noise. At that moment my tutor faced me and asked: "Do you hear that?". As soon as I heard this question, I got so mad I still don't know how I was able to contain myself and just reply: "Yes, I hear it".

Right after that I left the room and went to the bathroom to catch my breath. I was purple with rage. I was outraged by her stupid question, outraged by how she treated me, outraged by all the incomprehension she constantly demonstrated. I had thousands of thoughts swirling in my head: "Is that really something someone should ask?", "Why does she think I wear a prosthetic? To look beautiful?!".

This cold, insensitive situation reached its peak on one of the last days of my internship, when one of the people I'd become friends with in the ward told me another fact that made me realize the opinion my tutor had of me. This person told me: "Cecilia, one day while I was drinking coffee in the kitchen, your tutor arrived. We began chatting and she told me you couldn't become a nurse because you're deaf". There – that's what hurt me the most: to be seen only for what I look like and not for who I am, to be evaluated only based on what I have in my ear and not for what I can do, say and think.

I wasn't being treated for who I actually am, that is Cecilia, a trainee who wants to become a nurse, but only as "the deaf girl".

Personally, I don't think there's a worst attitude than one that makes people focus solely on others' problems, flaws and failures. I believe this way of thinking and behaving is wrong primarily because if we all focused only on others' flaws, then nobody would have a role in society and nobody would be seen for who they really are, but only for what they project on the outside.

During my internship I never asked my tutor to make things easier for me, just to listen. In fact, in my opinion, whatever the job you're doing it's essential to show willingness, be a fast learner and be conscientious in carrying out your tasks, but it's also important – I'd say especially important – to know how to listen. I'm probably not the right person to be telling you this, but it's knowing how to listen that can help others: knowing how to listen to doctors when they talk to you, knowing how to listen for noises such as buzzers, knowing how to listen when your colleague needs you, knowing how to listen to patients when they need pain medication or just need to vent, cry or laugh.

I believe this ability to listen is the core principle of our job and I, as a deaf student, think I was able to listen. I'm not saying this to brag about it, but because in my life – and, therefore, during my internship as well – I have learnt not to focus solely on someone's difficulties but to look beyond them. I have learnt that on encountering a disability we have to understand that there is always a person behind it: a person with dreams, ambitions, desires and skills.

I'm deaf, not by choice but due to a fact. I did, however, choose to face my disability, not let myself be impeded by my limits but, rather, overcome them. I'm deaf and I chose to learn to speak like everyone else. I chose to listen, and to do so in order to follow my dreams and ambitions. Hence, I can tell you that we are defined a lot more by our choices than by facts that happen to us. I, for example, am deaf, but thanks to my choices, I can hear and talk. Maybe sometimes even too much!

Equality and difference

Francesco Nurra
History and Oriental Studies student, University of Bologna

Translated by Yuri Lysenko

My experience as a person with disabilities accessing the field of education in Bologna has been a complex journey with both positive aspects and shortcomings.

I have recently started to take an interest in the field of Gender Studies and Disability Studies, which is why I will be putting into words something almost unorthodox, even though the two subjects are quite distinguishable. Having said that, Disability Studies are often offered within the Department of Gender Studies in many universities around the globe.

I would like to present as a comparison – as well as applying it to the world of disability – the distinction between the so-called feminism of equality and that of difference. This means that there are two types of claims made by people with disabilities: one is concerned with equality, while the other regards the differences among people with disabilities and involves a stronger identity characterisation.

In my humble opinion, these last two schools of thought need not be divergent, they can be complementary and can fuse together, as they should.

Allow me to explain: as a person with disabilities, I demand – indeed, right now I demand – the same breadth of access to education, movement, independence, housing and employment other people enjoy. Admittedly, for many people with disabilities – myself included – this is not the reality we find ourselves in.

Ableism, i.e. discrimination against people with disabilities, does not correspond to a lack of inclusion, but to what exclusion from social and economic spheres of life across most of the globe has fashioned, i.e. the lack of and the disparity in access to certain rights, rights desired or taken for granted by the rest of humanity.

This brings us to the disability of difference: the social context produces largely economic disparities and, being disabled myself, I know that I have some different needs which, if met, would allow me to achieve the political goals I have set for myself. This holds true when the statement “to each according to their needs” is considered.

One of these goals, in my case, is independent living, that is to say, that marvellous concept developed during the Civil Rights movement in Berkeley by Ed Roberts. As someone who is severely disabled, I require countless hours of personal assistance, which is something I am not currently being offered completely. At the moment, I find myself in a position of living in Sardinia, a region which, according to official data, is the poorest in Europe but which currently seems to provide fertile ground for an attempt – hopefully – to devise an ever-improving system that would support personal assistance. This is made possible by a fair share of funds allocated by Decree n.

162/1998[8], which amounts to about 150 million Euros. Regardless of the decree, however, I would still not be able to go and live alone. And the cost of living with a disability would not allow me to do so anyway.

The reason behind the divergence lies in the city of Bologna itself. The inability to become independent, despite assistance and supplementary services, was one of the reasons why I decided to leave Bologna one year before graduating. Thanks to the availability of the teaching staff, though, I was able to finish my studies by distance learning. At present, I am writing my dissertation under the supervision of a professor whose guidance is, in fact, provided through distance learning.

Ultimately, the only reason why I was unable to remain in Bologna was that it was not financially feasible. This is what it was like: even with my disability pension and benefits, as well as a healthcare allowance provided by AUSL [the local health authority, editor's note] in Bologna, after some time, I was unable to maintain a decent standard of living. It goes without saying that, for some expenses, I also received assistance from my parents. However, when their support could no longer be guaranteed, I was forced to leave. I had also looked for a job, but at a job centre I was told: "You either study or you work! You can't possibly work and study at the same time". Would a "biped" or a so-called "normally-skilled" person have been addressed in this way?

All these economic reasons are closely related to the right to study. Unfortunately, I find myself in a position of not being destitute, while not being well-off either. Let me explain: to access regional funding – with the ISEE (National Income Indicator) threshold of about 19,000 Euros in place at the time – you had to come from a truly poor household to benefit from it, while if you were a little richer, you were out. The ISEE threshold is the national threshold, so there was nothing I could do to have my name on the list of those who could receive a disability allowance.

If taken seriously (something I did not do), such expenses related to a severe disability, which would amount to some 2,000-3,000 Euros per month, have to be paid by the person with disabilities and their family. This means that you either need to be the son of an oil tycoon, to rob banks or sell drugs at the highest levels of criminal proficiency, or you bankrupt yourself and your family. I believe, in most cases, people with disabilities are forced to stay at home jobless.

When a learner is disabled, access to higher education is also determined by economic factors. The lack of financial support can also raise issues of psychological well-being. When you are always on the alert, when your life depends on getting funding and – in many cases – on the good will of volunteers, friends and social workers, life is constantly beset with the anxiety of not being able to go to the toilet, not being able to feed yourself, or not being able to get out of the house. Moments of informal assistance sometimes occur, and these are obviously down to chance and necessity. The precariousness already felt is fuelled by a failing welfare state whose backbone is more often than not the so-called "family caregivers", i.e. those relatives or spouses who care for the person with a disability. That same disability may severely affect others, as, in the long run, the daily workload might cause psychophysical problems in those who bear the full brunt of it, paid or unpaid.

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[8] This refers to Law 162/1998 which, by supplementing previous legislation, establishes additional support measures in favour of persons with severe disabilities. To date, the extent of these measures and the sum of economic resources allocated to them are defined on a regional basis [editor's note].

But then, is a Western government which sees itself as progressive, competent, a guarantor of civil rights and suppressor of economic obstacles to ensure that everyone has the same opportunities at fault towards people with disabilities? I think the answer is quite obvious if we look at the facts. Of all the paradoxes the West has to offer, this is one of the most side-splitting. Sometimes, even universities are deficient, due to a lack of funds, it would seem. From day one, I was told that not enough funds had been provided to guarantee transport to every class, and that it was because the university did not allocate enough.

I would like to take this opportunity to touch on the issue, so that people with disabilities who require the same type of service will in future receive the support they need.

However, this complaint notwithstanding, I would also like to commend the University of Bologna.

It is no small matter to have ensured that facilities and classrooms are accessible. Such a positive achievement does need to be commended. I must also mention that all the teaching staff I have met have always been very helpful. It is because of the cultural tools they provided me with that I could learn how to analyse situations from a critical point of view and write this piece.

Another quite wise choice the university has made – and continues to make – is to allow Bologna Prison convicts and former convicts to study at university, should they wish to do so. One of the people who used this service was my flatmate at the Student House. For privacy reasons, I cannot disclose his name. However, being bound by ties of friendship, mutual respect and trust, I would like to take this opportunity to thank him. I owe him a lot: he contributed to me being able to continue my university education. My future plans? I would like to try doing a PhD at the University of Bologna.

I did not mean to make this piece sound argumentative, but I did want to pinpoint situations, contradictions and circumstances that could be changed or improved.

I hope it will serve a cause.

The secret club

Anonymous
Veterinary Medicine student, University of Bologna

Translated by Zazie Alberta Piva

At university, and in the rest of the world as well, there exists a sort of secret club. The members don't have a membership card, nor did they voluntarily choose to become part of if: they simply just found themselves in it. One of the features of this club is that its members are under the impression of being the only ones registered, or at least the only ones with regards to the local branch. In principle they know other participants exist, but they don't know them and don't know who they are. For this reason, they feel alone and separate from others, namely those who were not compelled to sign up. Every once in a while, one member is lucky enough to meet another one. Sometimes they recognize each other at a glance, other times it's necessary to go beyond a first superficial approach, but there's almost always a sign, which allows a member to recognize in the other an equal and find in them a sense of affiliation and understanding.

The above-mentioned club is the disabled club. And I am part of it.

My disability is mental and not physical, and because of this I'm both luckier and unluckier. I can call myself lucky because I don't live the hardship people with physical disabilities face. I'm unlucky because I face other hardships that are often underestimated, unrecognized or socially stigmatized.

This is exactly the reason why I decided to contribute to this project: its goal is in fact to raise awareness about different disability conditions and sensitize people to these themes. As far as I'm concerned, I believe that if my essay leads to even one person feeling less misunderstood and alone, then I can say that I'm satisfied.

I suffer from depression and anxiety, two monsters that feed off each other, and if I could wear the marks from the suffering they cause me on my face then I too would be a monster. As with all mental illnesses, one must be diagnosed by a specialist, a psychologist or a psychiatrist. The fact that people often self-diagnose themselves with these diseases without really suffering from them and that the expressions "I'm depressed" or "I have anxiety" are used so easily and frequently, are two reasons that have contributed to belittling proper anxiety and depression. Therefore I will immediately clarify something that is often misunderstood: being anxious is different from suffering from anxiety, and depression doesn't merely correspond to being sad. The nervousness prior to an exam, for example, and sadness itself are moods and as such are important – far be it for me to belittle them – but they are something different and non-pathological.

Since depression and anxiety come in various shapes and nuances, it would be impossible for me to provide a complete and exhaustive description, so I will talk about my experience, even though I imagine it will be impossible to do so thoroughly. The only way I'll be able to give you a "user guide" is if I provide you with guidelines to understand what we, the mentally disabled, go through. In order to do so I must tell you how I have felt, how I still sometimes feel, how this disease works and why it's incapacitating.

There's still so much unknown about these pathologies: for example, they don't know why some people get sick and others don't, neither why some get sick after external events, while for others it's due to internal ones. As far as I'm concerned, I fit somewhere between the two.

I was always an emotional and sensitive kid, I've always felt pressure to do well, I've always lived certain events – such as group games and written tests – with apprehension, but these are situations that I have more or less always been able to cope with.

The real problems began at university. A faculty with a very selective entrance test, big exams, limits on the advancement to successive years, a commuter life which left little room for rest and leisure, and my demanding and perfectionist disposition made me feel worse and worse.

It all started so slowly. I don't even know when it actually began. At first, it only had to do with the academic life, but then it began to affect everything else. The anxiety I suffered from became more and more generalized and it came with the unwanted guest of depression.

I started being more and more agitated about exams and my sleep cycle was the first thing to be affected by it. At the beginning you tell yourself it'll go away and you ignore it, while scolding yourself for being that way, since everyone else seems to be doing everything so well, so easily, but you aren't. You spend sleepless nights and stare at books for entire days without being able to do anything, paralyzed by anxiety and by negative and repetitive thoughts: "Come on, what does it take to study? All you got to do is read and repeat, come on… Why are you in a cold sweat? Why do you have vertigo? You're a real idiot, a failure, you're worthless".

The high grades you're able to get, despite having had to postpone exams, stop satisfying you, because inside you know you could have done more, because you wasted entire days, wasted days that keep mounting. You feel time going by, lost time, time that you'll never make up, it doesn't matter what you do, how much commitment you devote to it, by now it's too late, your peers keep up, apparently without any struggle. You start to feel different from those who, in your eyes, have everything that you are missing. You start to feel alone, isolated, empty. You wear a mask and keep behaving normally with other people, creating even more distance between you and them. And this becomes your way of reasoning: there is you and there is them.

By now you've almost lost your memory and concentration, you're not able to take exams anymore and pretend nothing is bothering you. Therefore disguising everything becomes more difficult and more exhausting: even the easiest things require tremendous effort. Even running an errand triggers an anxiety attack and, as you're realizing it, embarrassment and fear of getting caught increase, because who would ever understand you? How can one understand that everything is so painful and fatiguing? Surely they would judge you, so you continue faking your emotions, while realizing more and more how great the gap between you and the others is, and meanwhile the sense of emptiness and loneliness keeps growing. In fact, the mask you wear becomes heavier and heavier, it's increasingly tiring to keep up appearances every day, so you start to drift voluntarily apart from people, friends, family and acquaintances.

Every night anxiety wakes you up, reminding you how tired you'll be the next day, as depression repeats to you negative and repetitive thoughts: telling you how wrong you are, how much of a mistake and failure you are, telling you the pain will never stop, making you feel you have your back to the wall, trapped inside yourself.

Days become dense, dragging themselves slowly along, becoming indistinguishable. What used to give you joy stops having that effect on you. You see your friends thrilled for things that would have interested you too and that now leave you cold. Sometimes you're unmanageable, because depression makes you think and feel negative things, so you pull away even from people you hadn't distanced yourself from before. Everything feels worthless and meaningless: to what end should you keep fighting if you know it's no use, that you'll never be happy and that, after all, you don't deserve it?

So you stop trying, because you've exhausted every fibre of strength, you stop making plans you know you should want to carry out, but that you no longer have even the slightest desire to carry them out anymore. You don't feel joy, you feel annihilated, alternating between states of apathy and excruciating suffering. Your low self-esteem and lack of purpose become unbearable. Anxiety and depression keep you imprisoned inside your own home, your own room, your own bed. You're more and more convinced you'll never be happy again.

Suicidal thoughts come up – they were already there, but now they have a more defined shape. In your worst and lowest moments, those kinds of thoughts are very present and the suffering feels overwhelming for one person. You think that, after all, other people will be better off without you. However, most of these suicidal thoughts are passive: it means you will never kill yourself, but if a car ran you over and you died on impact, you wouldn't complain.

This is, more or less, what was going – and sometimes, still goes – through my head, although I don't think I've been able to put down on paper the intensity of the emotions I'm talking about.

At that point I found the strength to ask for help. With my parents' support, I dropped out of school for a couple of years and focused on getting back on my feet, as well as trying to understand what I really wanted to do in my life: whether I really wanted to quit studying or if it was only the disease talking. This is one of the greatest problems: sometimes it's hard to understand if what we think is what we really believe or if it's the disease putting those ideas in our heads. Hence, you start doubting your own thoughts.

The real breakthrough was beginning therapy with a psychotherapist (psychologist). The truth is that it was really hard to admit I needed an expert's help, but it was even harder accepting it. In Italy, the negative idea that "only crazy people go to shrinks" is still widespread, contrary to what happens for example in the United States, where there's a different culture and approach that allows everyone who can afford it to go to their therapist weekly.

Even more socially stigmatized is going to a psychiatrist, something I had to do at one point, since in my case it became clear there was a genetic or paraphysiological component. I had to work on myself a lot in order to accept that I needed medication, again because it's a common idea that psychotropic drugs will change you or that if you have to take them, there is something seriously wrong with you.

Reality is a bit different. Psychotropic drugs are used to create a more optimal environment in the brain, enabling it to function as a healthily and allowing the nerves, in my case damaged by the constant presence of cortisol and adrenaline circulating from years of anxiety, to regenerate (recent studies have demonstrated this, albeit slow, capacity). In short, psychotropic drugs are not happiness pills and are nothing like cocaine, just to name a drug; this is something that I particularly wanted to explain and emphasize. Moreover, on the subject of therapy, another thing I'd like to point out is that it's a process and doesn't work like a magic wand. Anxiety and depression, like other mental illnesses, don't miraculously disappear from one day to the next. It requires a lot of effort and, most importantly, you need to learn how to live and manage, understand and embrace your illness. It's not a straightforward process, but rather cyclical. I had many relapses and I was scolded for taking backward steps, even though the relapses were out of my control. Please remember never to tell a depressed person while he or she is at their worst that they are taking backward steps. There are at least two good reasons not to do so. In the first place, trust me, that person is already aware of it and you will do nothing but aggravate the situation. Secondly, because it's not true. In fact, forward steps are not measured by the disappearance of relapses but by the reduction of the relapses' duration and intensity and by the ability of people to live with them. There will be relapses that are worse than others: be encouraging and point out that they're temporary, because the person going through them doesn't realize it.

All of this translates in different ways in the university environment. For example, I often need more time to prepare for exams. The reason is that, aside from the actual study time, I need to consider crisis times (whether they are depression or anxiety crises, due to university exams or to their inherent cyclicality). The cycle isn't always the same. I say this because lately, with only a few exceptions, I can manage myself a lot better. There are, however, some elements that tend to repeat themselves.

It takes me a long time to start studying. For the first few days I'm in a crisis and it turns into a staring contest between myself and the books. Before I start to study, I have to fight against paralyzing anxiety and myself. Anxiety keeps telling me I won't make it, that I don't have enough time and that I should postpone the exam – something I don't accept since I'm already behind and if I put it off I will just delay it again – and then comes the sense of failure and depression. Sometimes, once I've overcome this phase, I actually start studying and keep going until the exam, other times the crisis wins and I postpone the exam or start studying for another one, thinking I might have a better shot, while tormenting myself for not being able to fulfil plan A.

Sometimes this feeling of not having enough time to study is due to an underestimation of my capacities ("I'm never going to make it"), other times anxiety has dictated a study plan that is too strict because I want to make up everything right away. When I realize the plan I had developed is unachievable, I go into crisis again and I am able to come out of it only through the (re)acceptance of the time I need. Sometimes it's merely the depression reappearing to whisper and convince me that I'm doing everything wrong and that I'm a failure.

I always doubt myself, my decision-making, I often fear I've overestimated myself by not taking enough days to study for exam X. At other times, instead, I fear I've underestimated myself and that, in that time frame, I could have taken exam X and exam Y. I also have these doubts and fears because, if I only consider the actual study days, I'm actually very quick at studying and verifying this makes me hate myself and my disease even more. Anyhow, most of the time, I live these fears simultaneously, and their coexistence is the reason why I constantly falter.

I always question every one of my decisions. At times, I even feel like deciding what to have for lunch is a decision that makes me waste time: "A sandwich would be quicker", "Or should I cook so I can take a break and relax?", "If I take a long lunch break I won't be able to study enough today, but if I don't, I'll struggle anyway and be less productive…".

The university initially helped by assigning me a tutor who helped me lay out my study plan. It was really helpful because by relying on an external "authority" with the decision about which exam to take and when to take it, I freed myself of responsibility and eliminated one of my anxiety sources. Every time I had doubts regarding the exam plans, I could turn to her and immediately erase my source of stress.

Another reason why having a tutor was helpful was learning to think about one exam at a time, because contrary to others, I cannot establish a long and detailed study plan without feeling the weight of the following exams, which leads me to study for it with a greater load of responsibility.

The real help came from the possibility of taking exams even just a day or a week after the official date or taking exams that should have been on the same day on separate days (with a day between one another, for anxiety reasons). Having a tutor officially assigned to me enabled me to contact professors with an external validation – it was clear I wasn't making anything up – and this helped me open up to them and explain my situation in order to make my request. And to be honest, the professors – even those who had a reputation of being less helpful – turned out to be understanding, available and most of all – something I wasn't expecting – human. All of them met me halfway and helped me and I can't express my gratitude enough to them.

However, all of this – i.e. the fact that I needed a tutor and the help I was given – is a secret that, aside from a few exceptions, I guard jealously. Firstly, because I was embarrassed, I was ashamed I needed these tools (I have now come to terms with it). Secondly, because I fear other people's judgment and jealousy. If it was known that a student took exams not on the official dates, others would complain and protest before asking themselves if there was a reason behind it.

When reading this, someone may think I'm being dramatic and that I should give people the possibility to react, but to that someone I answer that I've seen it happen, not to me, but to an acquaintance of mine. This girl suffered from serious and frequent panic attacks that prevented her from carrying out her entire internship during the shifts assigned to her. The professors decided to have her make up the days she missed with other shifts, on her terms, which unleashed an uprising in her classmates "It's not fair", "But then I should… too", "It's easy that way", etcetera.

This is the reason why we stay in the shadows and belong to a secret club. We're not that concerned with people's opinions, but with the consequences of their judgements: feeling isolated, wrong, misunderstood and judged for something that is not our fault. So, allow me to be explicit: the help those of us belonging to the disabled club get doesn't favour us and is not a privilege. They are compensatory tools that put us on the same level as others, whether it means taking a written exam instead of an oral one for an anxious person or an oral instead of a written exam for a visually impaired person. This is the difference between equality and equity: equality consists in giving everyone the same exact tools while equity consists in giving different tools to different people so that they can obtain the same result.

Every one of us would immediately give up the special exam dates and the other compensatory tools if it meant being able to quit the disabled club membership. We can swap whenever you want.

At the same time, though, I have to say that since I started hiding less and expressing my distress more explicitly, I have found not only more sympathy but also other members of the club, though perhaps unaware of it. I "discovered" many people who suffer – some more, some less – and this has allowed me to feel less alone. The really nice thing though, beyond the mutual sense of belonging, is giving others the possibility to finally open up to someone because, as I was saying, one of the most common things is keeping everything inside and pretending that everything is okay.

So, I would like to end with an appeal, the real user guide, but to get to it I needed to tell you all of the above. Nobody knows how much impact they have on others' lives and you can never know what another person is going through. So, don't judge others' academic or life paths, but open up, communicate your feelings. You have no idea of the resonance you could create.

The long journey

Michela Ricci Malerbi
Pharmacy student, University of Bologna

Translated by Nicola Bardasi

I'm Michela, I have Ehlers-Danlos syndrome[9] and I think I've always been a fighter. My story is a little long and rough, but I want to tell you about it.

It all started at the age of eleven, when I was diagnosed with apparently trivial scoliosis. However, the doctors had immediately noticed the anomalous characteristics of my back. The first of these doctors was one I remember with the greatest affection: Dr. C. (a great doctor and a great man), who had treated me since childhood for a form of asthma which, with the passage of time, would become chronic. One day, during a check-up, he began to evaluate my back not as a pulmonologist, but as an "improvised orthopaedist": a slight curvature had alarmed him.

A short time later, there I was promptly in the office of dear Dr. V., a paediatrician and friend who had seen me growing up and who loved his beautiful "pretty lady" (as he sweetly called me) so much. I remember his words, which, as he is no longer with me today, make me feel his absence even more strongly: "Don't worry, pretty lady," he said hugging me tightly, first with his little blue eyes and then with his reassuring arms, "it's only the beginning of scoliosis, but it's a good idea to be seen immediately by an orthopaedist." So, that's what we did.

I remember those moments very well. A long wait in a waiting room crowded with people, on a sad and gloomy autumn afternoon, always accompanied by my mum, my tireless companion on these "journeys". Around us there were many people, seated and standing, attentive to the anonymous and slightly crackling voice of a loudspeaker that called numbers and indicated clinics. Everyone listening, so as not to lose their turn after such a long wait. We were new to this kind of "pilgrimage", it was the first time we had faced a problem of this kind. Unfortunately, for us the long trips from hospital to hospital, from doctor to doctor, was just beginning.

After the X-ray was done (the first of many), we went back to the clinic and Dr. So-and-so, whose name still dredges up old moments of pain and a complete lack of sensitivity, urgently prescribed a Lyonnaise back brace, for twenty hours a day for the years to come (presumably until the age of eighteen).

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[9] Ehlers-Danlos syndrome is a set of hereditary connective tissue diseases. There is wide clinical variability: the patient can go from an almost imperceptible expression of the disease to a much more serious symptomatic case, which significantly limits the patient's life. Specifically, the hypermobile subtype to which I refer in this paper is characterized by hyper-mobile joints, mild skin hyper-extensivity, tissue fragility and extra-muscular-skeletal symptoms. The main symptoms are accentuated joint instability (which is the most intense and relevant symptom) and dislocation. This condition is accompanied by widespread chronic pain in most joints. It is also characterized by a hyperextension of the skin and may also include cardiac disorders involving, in particular, the mitral valve. Complications include asthenia, fatigue, sleep disorders, osteoarthritis and early osteoporosis, and cardiovascular symptoms (chest pain, palpitations, postural instability). The hypermobile subtype of Ehlers-Danlos syndrome is hereditary, but unfortunately the cause of this disease is not yet well known. Worldwide, research is underway with the aim of understanding the genetic basis.

"Until the age of eighteen." It sounded like a prison sentence!

With the naivety which often characterizes children, I began to wear that back brace (which at the time a good friend of mine nicknamed "schlub") with perseverance and determination. I seemed to respond very well to the therapy, which also included regular attendance of a gym where postural gymnastics was practiced. That's how seven years passed, in which my back continued to deteriorate gradually but without major twists and turns.

At one point, however, the deterioration was clear. In three months, my curve had increased to twice the size and so my family and I were forced to look for a possible vertebral surgeon, a search that proved to be extremely difficult right from the start. I remember perfectly the return journey after a long and tiring day: we were sitting again in the car and the silence made room for a thousand thoughts and a thousand doubts. That morning, too, we had left with the intention of "being relaxed and living the day calmly", but I knew very well that, like the other days of "research", going home would be very tiring.

Milan had been the destination that day: we had heard about one of the best doctors in the field of vertebral surgery but, of course, we could not have imagined that we would meet yet another detached and superficial doctor. "I don't feel like operating on you right away. I'll prescribe you a year and a half of a plaster back brace, then we'll re-evaluate," he said.

He hadn't even made an effort to look at any of the many radiographies we had brought to him, which showed a clear worsening of my back curve; he hadn't even read any of the reports that underlined the presence of circulatory problems and the beginning of a reduction of left lung capacity, precisely because of the excessive curvature... nothing. Two hundred kilometres to get a summary and hasty advice. I felt invisible, it made me feel almost "capricious", as if I wanted to have surgery on a whim. His *iPhone* appeared to be more important to him than I was. The *iPhone* with the pink cover that he continuously took out of his pocket, unlocking and relocking the keyboard without any reason, perhaps checking how long it was taking. I cordially said goodbye to the owner of the pink *iPhone*, vowing in my heart that I would never return to him again. A judgement, perhaps the easiest, was the quickest.

The search for the perfect surgeon was not yet over. I was looking, in fact, for the person to whom I could say with serenity "I trust you totally, you can open my back in half, I'm not afraid. With you, I'll go into the operating room with a smiley face." My family and I found him in Schio, in the province of Vicenza. It was not long before the date of the surgery, scheduled for February 4th, 2010. We were missing some tests and the last blood deposit. Because of the snow, we decided to leave our car at home and travel by train.

The journey was particularly long: two train changes and about four hours, or a little more, of travel. I wasn't scared, I couldn't wait to put an end to this. I wanted and dreamed of the surgery not as a nightmare, but as liberation... and, fortunately, the countdown was now ending.

Mum and I left the house in the afternoon and big snowflakes accompanied our arrival at the central station of Bologna. Platform 1, *Freccia Rossa*, in the direction of Padua. "Have you validated the ticket?", "Yes! Run, Mi, we're going to be late."

Finally, sat down! I put my legs on the suitcase, looked at my mother, now hypnotically absorbed in a book, and I realized the importance of having her close to me in this journey.

“Tickets, please.” The ticket inspector had arrived.

My mum showed him the ticket, still partially absorbed in the story, which by now, she had made her own.

“There’s a problem, Madam. The ticket is for only one person”.

“Are you sure?”.

“Take a look... See? The ticket is a round-trip Bologna-Padua. Number of people: 1.”

When she realized the mistake, my mother apologized several times to the ticket inspector, who inevitably, made us pay the second ticket and the additional fine. “This trip is very expensive” said Mum, joking. At the time, we didn’t take anything seriously, we tried to downplay everything that happened, and we started laughing.

After the problem with the ticket, we carried on to Padua, where there was a quick connection onto a train to Vicenza. That winter was really an exception: it kept snowing constantly and our train slowed down more and more, accumulating delay after delay. Timetables of the trains in hand, we watched the connections fall through one after the other: we did not have much time, we would have to run to catch the second connection and hope to be able to catch the last train to Schio. I started to worry. It was already late, and the next day I would have all the appointments in the hospital that had been booked a long time ago. Meanwhile, another feared word began to spread among the passengers: “Strike”. We kept laughing.

When we arrived at Padua station, we got off the train to check the departure boards: all the trains scheduled for the evening were gradually being cancelled, but one was still scheduled before 8 p.m. We ran to the ticket office on the other side of the station, which was obviously and irremediably closed, so without a ticket, we boarded the last train available. We looked at each other and kept laughing. The few desperate and badly organized people who were in the same situation as us were inevitably infected by our laughter and by the beauty of the sight of mother and daughter who were having fun together. If they only knew the rest of our story...

This train would take us to Vicenza, but our journey would only end when we reached Schio, and there was no train at that moment.

We needed a plan B: thanks to word-of-mouth from heartfelt friends, a Salesian from Schio came to pick us up directly from the deserted station of Vicenza. In his red Panda, with a day’s work on his shoulders and the classic but effective lie, “I was on the road”, he took us directly to the hotel wishing us the best for everything that awaited us.

“Didn’t you book a room for next week?”. Needless to say, we started laughing again. In fact, the room was no longer available: due to the owner’s mistake, it had just been given to a family. They already knew us, we had been guests there when we had been to Schio for other check-ups and they knew my situation; within an hour they had moved the family to a hotel a little further away and gave us the long-awaited keys to our room. I remember we were hungry, and the kitchen had closed a long time ago. There were no sandwiches or fruit, nothing at all. There were only two brioches left over from that morning’s breakfast. I assure you they were the best brioches I’ve ever eaten.

After the endless odyssey, Dr. B. operated on me with thoracolumbar arthrodesis on February 4th, 2010. Eight hours of surgery, fourteen pins and two titanium bars, but I can say that I faced all this with a big smile because before entering the operating room, they told me that it would be “the last big step”.

The recovery was gradual, and paradoxically the hospital stay seemed peaceful and relaxing to me. The nurses, who I have always called “angels in white uniforms”, helped me with all their sweetness and humanity. My back was a real masterpiece.

In a short time, I regained my life completely and went back to climbing. Everything seemed to be going well and, for three years, I enjoyed my wonderful life with a new and very straight back.

Problems, however, as you well know, are always around the corner.

After about three years from my first surgery, serious pain began. My entire back was painful and inflamed both to the touch and to movement. Moreover, around each screw, reactive bursitis had emerged that caused strong cramps and made movement impossible. Just think that it was impossible for me to comb my hair and I could not bear even a bra hook. After many attempts to alleviate the pain using mesotherapy, infiltration, massage and acupuncture, we unfortunately reached the second operation on January 10th, 2013.

The doctors hypothesized a rejection but without defining the cause: it was explained to me that normally, the problem of rejection should appear immediately, not after three years as in my case. One thing was certain: all fixation devices had to be eliminated to alleviate the pains that I had been suffering for months by then. Before entering the operating theatre, I heard a familiar phrase which I listened to and welcomed with hope, but with a slightly weaker smile than the first time: “You’ll see, after this we’ll have finished, it will be an operation without problems”.

Despite the promises, however, it was very invasive surgery: to remove everything, the surgery involved fracturing the donated bone – inserted during the first operation – which had fused over the entire operated area. The pain I suffered, they explained, in addition to the incision of forty centimetres for the length of the spinal column and the muscles underneath, was like that of a fracture.

My mom used to say, “Grit your teeth and be brave. Fight, but with a smile” and so I did.

I recovered from the second operation on my rachis with a little more fatigue than the first, but with a great desire to close that chapter of my life and think about my future, graduating from one surgery to another and starting my university career with grit and determination.

Unfortunately, however, the problems were not over yet. In the space of a few months, my back had begun to “ease down”, regaining its curve. Compared to the masterpiece three years earlier, it was changing, with great disbelief from the same doctors. My back, theoretically, had been firmly fixed and should not have deteriorated in such a way. At the same time, violent neurological symptoms appeared: continuous tremors, sudden nausea, visual auras, headaches, insensitivity to touch and lack of perception of limbs.

I started worrying and scaring myself. I was not able to understand what was happening to me. My family and I didn’t know where to turn and at a certain point, one of the many doctors who was treating me advised me to do an MRI of the spine and the brain. We found a condition that, until then, had never been considered: Chiari malformation affecting the cerebellum and a significant syringomyelia at chest level. The path to “finding the right doctor” was long and tortuous in this case too, but fortunately we found a centre that dealt exactly with this neurological field related to scoliosis.

We flew to Barcelona. There I was diagnosed with a malformation of the “filum terminale”: the marrow, due to a malformation (of unknown origin), had remained anchored to the sacrum and with growth, continued to exert traction over the entire marrow. This seemed to explain perfectly the appearance of scoliosis, its otherwise inexplicable subsequent worsening, the syringomyelia and even the Chiari malformation.

Had it finally come to an end? Maybe we had really found an explanation for everything? In Italian that sounded somewhat Spanish, Dr. R. of Barcelona made me sit in his luxurious, maniacally furnished office and after listing all of his discoveries in the medical field and his first-ever scientific study, he said to me: “After this you can breathe a sigh of relief, it’s done!”.

I had a resection of the “filum terminale” in Barcelona in September 2013. When I woke up, all the neurological symptoms that had marked previous months had suddenly disappeared. I had freed myself from a huge burden with minimally invasive surgery.

It really did sound like a godsend. The only flaw? At the time, the surgery was only performed in that clinic in Barcelona and unfortunately had a very high cost. The next day I managed to get on the plane back to Bologna, extraordinarily happy at the result but all bruised, with fresh stitches from the operating room and my mother pushing the wheelchair, laughing and breathing her first real sigh of relief.

One thing did not seem to be entirely convincing: the therapy that I had been prescribed at the time of my discharge. It was a drug for Parkinson’s disease. I am very curious by nature: I always look for the reasons behind doctors’ choices, not to criticize them, but to understand and learn new things. I did not find a convincing reason to justify the administration of that drug and, above all, the dosage indicated (three times the recommended dose in the case of Parkinson’s). In addition, they told me to go and pick up the six-month prescription (which came to about 400 euros) in the pharmacy near the clinic, declaring that in Italy I would never find it. Back in Italy I discovered that it was found in any pharmacy and was, moreover, reimbursable.

Anyway, I tried to be trusting and took this medicine for a few weeks, but several side effects immediately appeared. I mustered up courage and spoke to my professor of Organic Chemistry (of the second year of Pharmacy) who, very kindly, took my situation to heart and talked about it with the professor of Pharmacology and Pharmacotherapy, who called me for a chat. I explained my concerns to him, and he scrupulously listed all the reasons why he was advising me to immediately suspend the drug and finished up by saying:

“They gave you a horse’s dose of a drug which you didn’t need at all. The pharmacist must have promised a cruise to the doctor’s wife. I’ll see you for my exam.” Disheartened, but satisfied with my tenacity and curiosity, I returned home. This time I had had the last word, and I was convinced it was the final one. But the scoliosis kept getting worse and worse.

To keep my back steady, there were few possibilities. It was an adult back and had been operated on twice, so the orthopaedists in Bologna and Vicenza sent me to Sheffield in England to try a new back brace, but today I can say that it was yet another painful, expensive bust. Meanwhile, my general health left something to be desired: physical inactivity had led me to have generalized muscular hypotonia, my joints suffered continuously until they started to come out of their axis. At first, it only began with frequent dislocations of the shoulders (without pain) then the mandible, hips, knees, ankles, wrists and fingers followed, with widespread, stabbing pain. I had been treating the pain for a long time with opiates and any possible painkillers, but the pain continued, became unbearable and severely limited my life.

Finally, now I can say it. We have reached a “conclusion”, eleven years after the start of my story: I have Ehlers Danlos syndrome, the Hypermobile subtype, a rare genetic disease. The cause is not known and, at the very least for now, there is no known cure for this syndrome, but now I know that it was the actual cause of my journey. The only therapy I can hope for at this point is to learn to live with it.

The greatest difficulty is its invisibility: from the outside I don't seem to be suffering. Pain-relieving therapy, a constant smile and the right amount of makeup help me not to show it. I discovered, unfortunately at my expense, that this aspect can be a double-edged sword: I've found myself not being believed, being criticized, mortified and all too often humiliated.

My greatest achievement is that I have never put my life on hold: I have always continued my studies and I have always tried to cultivate my passions. Today I need just two exams to graduate and become a pharmacist and soon I will go on stage to act and sing in two musicals. I admit, however, that behind the facade of a cheerful girl who "takes on the world", there was fatigue, suffering, disappointment and tenacity.

Student life – first at school and then at university – has been a lot of effort. After half an hour of study, my back pain is already unbearable, diplopia prevents the best definition of words or formulas, and demotivation makes its way through the cracks. A break is necessary. And it goes on, during all the hours of study that follow.

It has been the same for all the hospitalizations I've had to go through during my studies. I started with great willpower, with all the books necessary to prepare for an exam that I would have to take on my return but, every time, the pain and the necessity of visits prevented me from preparing for the exam at my best, as I would have liked.

I remember it as if it were yesterday: during the hospitalization for my second operation, I was waiting for the results of one of the first written exams taken for Pharmacy. I had prepared for the Mathematics exam in a difficult period, marked by terrible pain, daily mesotherapy, busts and various therapies up until the operation to remove the fixation devices. The exam results came and it was a 26, which I called "disappointing" at the time. I remember the bitterness with which I read the grade on Almaesami (the university's online exam result system, when I was still completely inexperienced with such electronic portals) and I also remember the reaction of my mother, who brought me back to reality by making me understand that, at that time, any positive grade should be considered a reason to be proud.

Even today – with two exams to do before graduation – I have not been able to accept this point of view. I can't accept not getting top grades but, unfortunately, I've always struggled to reach them. I don't want it to be considered a sort of excuse, but I think that everybody else with disabilities can admit that pain is limiting in every aspect of life. It also limits sleep and any other activity, let alone studying eight hours a day.

With some friends and study companions, I used to study at the library of the CNR in Bologna at 9.30 am (when, of course, there were no lessons in the faculty) and we stayed in the library until 6 pm. There were also some moments of difficulty and pain, so I would lie down to rest on the CNR tables (with the complicity of the librarians), with a few drops of Contramal as needed and sweet friends who have never left my side. After a little rest, I always started studying again until the end of the day. I tried not to give up, ever.

The most painful part of my university career was the compulsory attendance that some lessons required. Days on which I had the most pain limited any activity, but even on those days I had to be present at any cost. However, I met many professors who were willing to understand my condition and showed empathy for my situation, which at times moved me.

But unfortunately, I also had to establish a relationship with teachers who thought exactly the opposite, probably biased because of my invisible disability or from past experiences with people who pretended to have a disability. I'll never understand the reasoning by which I was treated with such bitterness and disregard, but sometimes I think that maybe they don't know why either.

I will tell you one of the many times – obviously without mentioning the name or surname of the person concerned. In order to take that exam, 80% attendance was absolutely necessary and, unfortunately, exactly at that time, a hospitalization for washout[10] had been set up for me at the Niguarda hospital in Milan. It was a precarious situation: I needed to do the washout as soon as possible.

Disheartened by the unfortunate concomitance of events but aware of the importance of hospitalization, I plucked up the nerve to speak to the professor and explained my need to be absent, asking, however, his consent to take the exam anyway even if I already knew that my absences would be more than those allowed. I'll remember her answer forever: "For me it's as if you've had a trip to the Maldives. I'm not a reader of medical certificates so don't bother to bring any". I was petrified.

It was at that moment that I asked for help and I was subsequently sent to the Service for Disabled and Dyslexic Students of the University of Bologna: the Service mediated with all the most problematic professors, helping me to establish precisely that dialogue that I could not obtain alone. Thanks to this service, I was also able to make the professor understand the need to use a stool to sit on during laboratory sessions: not all teachers immediately accepted my request because, according to the regulation, the use of a stool is not allowed in laboratories. Our afternoon sessions in the laboratory, however, could take four or five hours and you can easily understand the difficulty it could create for me.

My last great personal disappointment is the fatigue with which in this period I am facing my internship in Pharmacy: I hoped to do my best, to show everyone my great desire to do it and to get involved, but I must honestly admit that, unfortunately, I can't take more than half a day.

I can't bear more than four hours standing, advising, uncovering the world that awaits me and smiling to "my" patients. On these occasions, I understand that I must lower my expectations of myself, even if I must admit that I am also starting to get tired of having to do so.

I cannot mention all the events that have marked my university career, but I can say with certainty that my encounter with the Service for Disabled and Dyslexic students was a great help for me and I believe that the only downside was the fact that I only discovered its existence in the fourth year of the course. If I had known about this service before, my university life would certainly have been a little easier.

I am aware that life is not easy for a disabled student. I'm talking about myself, of course, but I think I can also speak for many other people. I know I won't be able to get top grades for my degree – a goal I've always tried to achieve – but I can guarantee that it will still be my greatest success and a great source of pride, despite everything.

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[10] Washout is a treatment to detoxify the body from opioids taken for a long time as painkillers [editor's note].

When disability is invisible

Jennifer Pallotta
Biodiversity and Evolution student, University of Bologna

Translated by Nicola Bardasi

I have just read a short story written by an adult dyspraxic[11] who wanted to remain anonymous. I totally saw myself in it. In a few lines he described in such a perfect way the anxiety and difficulties that people, such as me, with this "disorder" that you can't see live.

We dyspraxic people perceive the words that are addressed to us in an "amplified" way. Then the anxiety grows endlessly and to let off steam, we can't stand still: we have to jump and run, often uncontrollably, and people can actually think we're crazy.

As far as I am concerned, I can say that I have always had this condition, probably caused by cerebral hypoxia at birth. Dyspraxia, however, was only diagnosed when I was already twenty-five years old, under the name of "evolutionary deficit of motor coordination". This deficit leads to a constant delay in the acquisition of skills that characterize the normal stages of motor development: I walked at two years of age and still today, at thirty, I do not know how to ride a bike. Often, in addition to this delay, there are also visual and spatial orientation difficulties, problems in the recognition of physiognomy and dysgraphia. For me the main problem, however, is hypersensitivity to various stimuli: not only to audible and tactile ones but to all types of stimuli. Sometimes I perceive the words of others much "worse" than they may be and this throws me into total discouragement. I think dyspraxics might call themselves hypersensitive people. Dyspraxia is not considered a pathology, but it is very present in every aspect of the everyday life of those who live it.

For me, in addition to the delays and problems already mentioned, my dyspraxia has also caused a lot of teasing from peers, lack of friendship and earfuls from adults who considered me slow, lazy and messy. Anyway, I was able to finish school and then I enrolled in university. After two "wrong" years in Pharmacy, I enrolled in Natural Sciences, where I got on very well. Right there, during the third year of my First Cycle

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[11] The term dyspraxia derives from the Greek *dys* (a prefix indicating difficulty, malfunction) and *praxis* ("acting") and indicates an alteration in the development of gestural learning. It can be defined as a sensory integration disorder that originates in the brain. It is, in fact, a disturbance - and not a pathology - very widespread but little known, which often presents itself accompanied by other diseases related to the autistic spectrum or other disorders such as, for example, dyslexia. In many cases it is found in premature babies who at birth had a lower body weight than normal. Different types of dyspraxia can be differentiated: motor dyspraxia, verbal dyspraxia and oculo-motor dyspraxia, which may also be present together in the same subject. Only in the last few years has this disorder become better known, at least with regard to children and adolescents. Dyspraxia, however, can improve but not be cured and stays with those who suffer this condition for life. Adults also find it very difficult to be employed or to maintain stable employment and, unfortunately, there are still no structured forms of support for their integration into the world of work. For information about dyspraxia, it's possible to visit the following websites: www.aidee.it (Italian Association for Dyspraxia of the Evolutionary Age) and the page http://www.stateofmind.it/2017/01/disprassia-evolutiva-riabilitazione/ which also contains a bibliography on medical and psychological matters linked to dyspraxia.

Degree, the Physics professor advised me to go to the Service for Disabled and Dyslexic students at the University of Bologna, whose operators sent me to the Centre for Linguistic and Cognitive Disabilities, where it was finally possible to diagnose me with dyspraxia and so at last everything was clear. As far as my university experience is concerned, I didn't have any particular problems. Professors have usually been helpful.

I believe, however, that the main difficulty lies in the fact that dyspraxia is not considered in the Law on Specific Disorders of Learning, within which are included dyslexia, dysgraphia, dyscalculia and dysorthography, although a dyspraxic person may sometimes have these disorders, as well as many others.

Another problem is that, not being visible, people often think that dyspraxia does not exist. I must say, however, that my relationships with my fellow students at university have been mostly good and I have had no problems, apart from the fact that sometimes I did not know how to approach them. I was afraid to feel outside the group and so I was looking for protection from the professors with whom I had become more familiar – perhaps because one of them paid attention and followed me a little more and I liked this kind of relationship.

In fact, dyspraxia can be associated with disorders linked to the autistic spectrum. I also look for the help that I need and that was not given to me during compulsory education because the disorder had not yet been diagnosed and there was a lack of empathy and desire to help me by teachers, especially during secondary school.

Now I have a Master's degree in Biodiversity and Evolution with a bio-anthropological curriculum. I took me a lot longer compared to my peers, even to figure out "what to do when I grow up" and I would say I figured it out – I hope so! – now that I'm in my early 30s. Now I am studying for a second Master's degree in Quaternary, Prehistory and Archaeology at the University of Ferrara. I would like to become an archaeologist and anthropologist, and I hope to be able to work on archaeological excavations. However, the most serious problem in this regard remains the fact that for a dyspraxic person, it is much more difficult to be constant and maintain a job for a long period. I am also subject to depressive crises that, especially when they are strong, keep me in bed. I am registered within the protected categories but, unfortunately, in my case the seriousness to which paragraph 3 of Law 104/92 refers has not been recognized (it is only inserted within paragraph 1). In other words, dyspraxics are often not fully recognized as disabled.

I also think that it would be important to create a greater link between the university and the job market: this would be beneficial for all students and in particular for people with disabilities, who undoubtedly have greater difficulty getting involved in it.

More generally speaking, with regard to the "user guide" which I can suggest based on my personal experience as a student, it seems important to me that teachers who find themselves with a dyspraxic student recognize some characteristics: first of all, the tendency to be always moving. Even just sitting, a dyspraxic person will have to move, so they will make involuntary movements with their arms and/or legs, especially if they are in a stressful situation, such as during an exam. Often it is better to take oral exams behind closed doors, i.e. in the absence of other people taking the exam. It is also useful for the dyspraxic person to take the test first, as during the waiting time, anxiety rises, and performance may be affected.

Based on what I have experienced in person, I believe that the best results are achieved when professors show compassion and talk calmly and "softly". As I said before, dyspraxic people tend to be hypersensitive to sounds and lights, it takes very little for them to be disorientated and they often perceive the words of others as “amplified” in tone and meaning. For example, it has happened several times that I have perceived a simple observation by someone as criticism. That, of course, doesn’t mean not holding back when it’s necessary.

Since dyspraxia is often also associated with visual disturbances (ocular-motor dyspraxia) and, as a consequence, with dysgraphia caused by the difficulty of hand-eye coordination, I think it’s important to advise students with dyspraxia to use a computer with speech synthesis (a system that allows the person using it to dictate what they would like to write) or to ask for the help of a tutor. For example, when I wrote my thesis, I had the help of a tutor who correctly edited the text I was dictating to her.

Relationships with a student with dyspraxia can be easier if one considers the fact that dyspraxics tend to be more “immature” than their peers and that, usually, they reach the various stages of development later than others. A twenty-five-year-old student with this condition could still be totally dependent on the help of the professors to get themselves organized. In this regard, it is useful to point out (however trivial it may seem) that as soon as a correct diagnosis is obtained, strategies can be implemented which help and can also have a huge impact on personal growth. In my case, as I said above, the absence of a diagnosis caused me problems during compulsory education.

Regarding inclusion, I believe that in order to achieve it more effectively, it could also be useful to start suitable sports activities. Even if it is not often noticed, a dyspraxic person is to a greater of lesser extent in a disadvantaged situation and encounters considerable difficulties in carrying out ordinary activities such as socialization.

People with this condition may not know how to behave with other people (for example: just say “hello” or hug them?) and have high physiognomic difficulties, which means that it takes a long time before you recognize people even if you have already seen them before. Dressing can also be a problem because wearing and matching clothes properly can be difficult. I think that some workshop or theatre activities could help a lot in this regard.

I would like to stress that these suggestions do not consider all forms of dyspraxia and, therefore, not all people with dyspraxia. What I have written refers to my personal experience of ocular-motor dyspraxia, but there are forms of verbal dyspraxia with severe impairment in spoken and written language. In such cases, there is a need for even more targeted instruments to help and compensate, and these instruments should be implemented on a case-by-case basis.

Patience and irony

Luca Mozzachiodi
Literary and Philological Cultures PhD candidate, University of Bologna

Translated by Nicola Bardasi

I come from a small provincial town and I was born into a fairly large family with limited economic and social possibilities. It was therefore immediately clear to me that, in addition to the exemption from tuition fees which people with disabilities have by law, to study at university I needed to get a scholarship. This was therefore the first factor in my choice of university location, together, of course, with an assessment of the services for assisting disabled students which the various universities provided. I visited some of them and these visits gave to me a substantially negative impression: some universities were deprived of means and only enabled by the voluntary work of some employees, others required a contribution from me for the expenses. The only one I saw that gave me the impression of working well was Bologna, the city where I then did my university studies after getting a scholarship at the *Collegio superiore*.

I can't generalize by saying "when a person with disability goes to study" but, rather, I have to say, "when I went to study". Naturally, the first issue was getting used to doing the actions of daily life such as tidying up, cleaning, cooking, shopping, a little bit of DIY, etc., as well as obviously getting around. Initially I tended to do everything, perhaps as a sort of demonstration of autonomy to myself, but having to move with a tetrapod[12] and often carrying out many actions with one hand, I risked exhausting myself even on the most ordinary day, and I had to learn to ration myself wisely. Over long distances, which means practically every time I went outside, I moved accompanied by a person who holds my hand and this is how I got to class, but the first problem was specifically related to attendance of classes: the houses where the *Collegio superiore* provided accommodation for students was located in the inner suburbs and the Service for Disabled and Dyslexic Students could not employ volunteers and tutors for mobility assistance and so I immediately had to seek an alternative solution.

Fortunately, the other students at the *Collegio superiore*, or at least a good number of them, immediately turned out to be really sympathetic and very helpful by organizing an informal chaperone service for which several people took charge weekly to help me get around, according to their schedules and I must say right now that if it weren't for this great gesture of human solidarity, I really would not have been able to attend university. On my own, I tried as much as possible to be courteous, to adapt to the circumstances and to make that sacrifice pleasant. So, chatting on the way, I made my first friends in Bologna.

At the *Collegio superiore* we all lived together in a student residence and this, together with the lessons and courses in common, encouraged sharing and mutual understanding. P., my first roommate, was very friendly and fraternal from the beginning – we really

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[12] The tetrapod is an aid for walking. It has an adjustable height and is similar to a common crutch; however, it differs substantially in that it has four legs. The aim of this is to widen the base of support and, therefore, to improve the stability of the subject in an upright position, making walking easier.

created a good relationship and he was also my first intermediary in meeting people outside the *Collegio superiore*. Living in the suburbs and having to organize my trips week by week, my visits to the centre were, in fact, rare and often with long stops in the same place to wait for the next chaperone (it was also my choice, in part. not to weigh more than necessary on a service, taking time from those I imagined needed it more at that time). For this reason, as well, as for the frequent classroom changes and the great number of electives in Humanities, at least at first, I was strengthening most of my ties outside the environment of the degree course.

In the second year, the *Collegio superiore* was transferred to Borgo Panigale, eight kilometres from the centre, and my problems of displacement became even more acute. It was no longer conceivable to make two trips a day, since with the bus it took almost an hour on days of heavy traffic. In the evening, it was rarely possible to go out and sometimes I had to adapt to the schedules of other people and so maybe get up at 6:30 am to have a lift at 8 am for an appointment at 5 pm. I endured it with good spirits, in part knowing full well that life for a person with a disability is never comfortable, and partly recognizing that those who offered to give me a lift were not in any way required to do so and so I had to be grateful, but I must admit that over time it was a bit of a stressful situation.

Sometimes things got better because the Service for Disabled and Dyslexic Students stipulated an agreement with *Auser* [an association for social assistance and solidarity] which escorted me by car at times that I had indicated. The previous point about indication is very important because of course the volunteers accompanied me on foot, often over long distances and with a backpack, and so trips were physically very tiring. The problem was that the mobility-assisted trips were fixed weekly and the car journeys were fixed even bi-annually, based only on the lesson schedule, which made it impossible to attend office hours, go to conferences or study in the university library. As you can see, this is difficult to reconcile with university life in which, among other things, the lessons are frequently postponed or cancelled. In addition, it is obvious that there is nobody in the world who is able to predict exactly what they will do from one week to another at an exact time and for how long; even more so, nobody knows what they will be doing in the space of six months.

Such an approach, unfortunately, naturally causes you to plan all your commitments according to those that can be foreseen and sometimes means giving up something because you can't find suitable mobility assistance or because you cannot foresee it with certainty. Naturally, this too is accepted and tolerated, but one cannot avoid noticing that it represents a considerable obstacle to the integration of people and to the possibility of a full and free life. I personally began to conflict with these needs more noticeably from the second year of my degree course, because, through P. and another friend, I had joined an association of social promotion that works in schools. It was probably one of the most important moments in my political and social education. I worked for three years in an after-school programme for second-generation immigrants. For a year, I did remedial courses for high school students, organized a lot of meetings and public debates and took part in self-training seminars. It was a great opportunity for growth and comparison, for collaboration in order to reach common goals and objectives and for collective maturation. Together, and not with rose-tinted glasses or in continuously idyllic relationships, we became aware of social and political implications linked to our actions; among other things, also familiarizing children with the presence of a disabled adult was important, even if I only understood it over time.

Doing these activities took a lot of time and energy. Sometimes you had to meet several days a week but it certainly gave substance to my thoughts and experience to my analysis, which also allowed me to meet many people from all over Italy (the association is part of a national network) and made us a very united group.

It was in this period that I really began to visit Bologna and live the city to its fullest, with clubs, theatres and cinemas, and often it was these partners who accompanied me in turn, and of course it must be said that my participation in those activities is also greatly due to their efforts. For example, those of M. (the only one who still lived in the old student residence) who had convinced me to participate in these activities and who, every Saturday morning, got up at 6:30 to escort me on foot with three further bus changes, and never complained once in three years.

At about the same time, I had started to attend some of Bologna's literary circles more frequently – those that were less "self-restrained" and, so to speak, less self-proclaimed "mainstream", preferring instead the suburbs, taverns or the homes of friends. I have a strong interest in literature and art and having my creativity merged into books and essays gave shape to much of my work in the city. It placed me within a different environment from that typically attended by a university student. Almost immediately I had conversations and established bonds of friendship with people of very different ages and social backgrounds. The most typical circumstances in which I was involved were book presentations, readings, theatrical or musical evenings and conferences, but often everything tended to be more relaxed and convivial. For this reason, I loved some places in Bologna and I took root there, making it my city and probably bringing something to the urban context and society: sometimes as a result of literary evenings and readings, I am recognized by strangers on the street.

Certainly even in this type of experience, disability has its own importance: not only, of course, for the difficulty of movement and presence that sometimes relegates you a bit to the edge of the action or is misinterpreted as disregard for the work of others, but especially for the continuous and frequent reaction of those who tend to look at you with benevolent condescension and treat you as a child. I'm referring to the chronic impossibility of being treated politely, the use of childish language, the excessively paternal or maternal attitudes, the misunderstanding and morbid curiosity nourished by retrograde and melodramatic cultural representations about the disabled boy who, however, writes poems as, or rather better than, "normal people" – but, in the end, in a different way – and who can't participate in our status. I can't avoid mentioning the violent forms of denial of mental independence and awareness such as giving me toys and trinkets at business meetings or talking in front of me, about me, using the third person. Obviously these are fundamentally issues of culture and courtesy and generally do not provoke conflicted reactions but rational understanding, at least from me, but anyway, because of their frequency, these situations show a serious social and cultural gap in our (and other) countries, and become very dangerous when they happen in the workplace. On average, in fact, I have to work harder than a non-disabled person to get attention and respect, especially the kind of attention and respect that I am not owed as a disabled person but as a superior, a fellow colleague in the same field (or in some cases simply as a human being). Finding the exact point between understanding and firmness to respond to this kind of behaviour is difficult because of my shy character, because it is frequently interpreted as a temporary tantrum or as resentment.

Going back to the facts, I must say that compared to the early days of my arrival in Bologna, the increasing number of commitments and the active life I led were increasingly in contrast with my physical limitations and with the need to plan my day as schematically as possible. At first, I tried to overcome this by reaching compromises with some of the mobility assistants appointed by the Service for Disabled and Dyslexic Students, such as S., with whom we arranged things each time in person for more than a year (with compromises on my part as well) and whom I would then have as a dear friend, knowing that often problems of this type are solved with common sense more than with the presumption that everything should go strictly according to your plans. I must say that, with great wisdom and willingness, the Service for Disabled and Dyslexic Students, which undoubtedly understood the value of my autonomy, allowed me to complete my schedule by myself.

In the meantime, I had to move to the centre to be able to access the libraries to draft my thesis more easily, which was impossible for me from Borgo Panigale. This meant that I had to pay rent, after winning a scholarship which had until then given me the right to free accommodation, and I must consider it an injustice and a substantial financial loss suffered by the School, which should have guaranteed me accommodation and appropriate conditions for studying.

After all, when I visited universities to check the fundamental practicability of the spaces, only in the most prestigious university in Italy was this possibility denied to me, with rare obtuseness and lack of respect for an elementary right, but certainly, according to my concrete experience, academic and civilized cultures of ways, prestige, progress and real collective utility have never necessarily gone hand in hand, as unfortunately people would always want the situation to be presented.

At this point, it is important to make a small digression linked to what has been written so far: writing about disability in general and about one's own disability in particular is difficult not so much due to a sense of modesty, lack of will or pleasure in talking about some things nor, as is sometimes said, for the difficulty for others to understand the sense of what you are saying. All these things have some importance, even if in a secondary sense, but I think the real factor is probably the number of stereotypes and expectations related to disability. These expectations enjoy the complicity of certain types of journalism or cinema that almost always represent Paralympic athletes, geniuses in wheelchairs, people who paint with their feet in a fairy-tale atmosphere, with inevitable interviews that recall the patience, the strength, the importance of pursuing one's dreams, even the contempt for the doubts of others about one's own abilities, or, conversely, describe abandoned, bitter people, perhaps grumpy and unsociable, left on the margins of society and sometimes with animal traits, who will be humanized and brought back to civilization only by the charity of some silent, magnanimous heroes. Nothing could be more hypocritical and far from the truth, but we rarely denounce the violence of this language and the falsity of this representation.

Hence the difficulty of giving an objective account that is not designed to shock, such as "I'll let you know how ugly it is because you don't know", or an uplifting tale such as "I'll show you what it's possible to do anyway and what I've done so far, despite everything." It is never all sacrifice, deprivation and humiliation, nor all wisdom, patience and goodness. As the quiet person I am, I have more than once been told that I did not suffer and that I lived a good life, precisely because on average people expect a disabled person to cry and tear his hair out or go around peacefully as a graced hero, content with the beauty of the world.

One thing that is hard to understand is that you never fully realize what your condition implies (contrary to what others generally think about you) and that you aren't born with an instruction manual that tells you what you can and cannot do. The world is, rather, essentially a discovery, often in a negative sense. You gradually discover or understand how things are going and how to deal with them, although the difference is that as a disabled person, you more often discover your limits than your possibilities, the difficulties of the world on a human scale that's not your scale, and the insufficiency of your strengths, which remain more or less the same while the difficulties of life and its complexity increase with the passing of the years. You know that it will be difficult but you often don't know how, how much or in what way. This sometimes leads to a feeling of being in permanent struggle and continual fatigue, the sense of gradual suffocation which no one had warned you about before and the feeling that the world is not taken away from you all at once, but piece by piece. It's also because of this that you have trouble imagining your future.

You don't realize immediately that you're not going to heal. For me it was a late and sudden discovery, and certainly when you think about the fact that your condition is for life, every day, with no interruption, it is, not to mince my words, a great pain, which in addition you know you have to carry in all its entirety alone, while also knowing that this situation sometimes causes pain or involves other people, because they have to assist you and make changes according to your needs or because they are unable to act. So you are often doubtful about your chances of facing life because you feel weak, you are uncertain because you ask yourself when the physical forces on which you can count will start lacking, you are not even sure that your moral and mental forces are enough to build a decent life for decades, you ask yourself if you have a breaking point or if the discouragement, the powerlessness, even the envy you feel when you look at the lives of other people which seem – and luckily sometimes are – easier than yours can overwhelm your patience and reasonableness.

I write this because obviously all this has repercussions on the relational aspects of life. You get tired easily because every day some of your physical and mental energies are imprinted in coping with problems and living your condition. You are not always sociable, pleasant or joyful, and you have to be tolerated; other times, instead, you use many resources to be up to your best and not humiliate, sadden or worry other people, to respect their space, their rights and make them feel good and comfortable, or help them, listen to them and understand them. Frequently I have to make this effort, sometimes succeeding and sometimes not; my vision of life is probably more similar to an unknown war front where the more we go forward together, the more chance there is to get to the end without being mowed down than to a group trip where it's the more the merrier, although I also recognize that there is a right to happiness.

Thinking about all this – since I moved to the centre where I lived with G., an old schoolmate of mine who had set up a two-room apartment for me as much as he could and who, compatible with his very tiring life as a working student (he was a barman in the evening), tried to help me and take care of my needs like a brother – I had acquired a certain wisdom, if I may say so, about myself and I had understood something important: I was not a passive subject who had to be helped by law or by kind-hearted people, but with my presence and my conduct in life, I could be an example and an important support, not only for my disability or for my nature and my actions, but also for the concrete fact that I faced difficulties every day, that I rarely complained but I didn't pretend to be always happy and for the fact that I always tried to preserve a kind of dignity. All this was not without importance and was certainly also a sort of exchange.

I have seen so many people in difficulty because they were not morally able to deal with hardship or deprivation, because something was not going according to their plans or because they had grown up thinking they could achieve anything with commitment and will, when not due to a sense of omnipotence. I, however, have learned that the fact that it has always been evident to me that my possibilities were reduced, that I had to face my powerlessness every day and that I knew that life would certainly not go as I wanted, regardless of what I would have done or not, has protected me from these illusions, fragility and pretensions, and often put me in a position to help those who were victims of such problems, and allowed me to think seriously – and not from hearing others say so, since every hope and every possession (even that of your physical faculties) can be taken away from you – that the most valuable thing of all is your good disposition towards yourself and others, because of course even that is conditioned, and you can also be deprived of it, but you can put up a more founded resistance and so this disposition is more durable in its fruits. I don't know how much all this was revealed over the years in my way of dealing with relationships, but it was certainly evident because when I decided to live permanently in the centre, the quality of my life clearly improved: being able to go around the city (always accompanied, of course), I could finally live it fully, give myself more distractions, more hangouts, more pure and simple entertainment such as drinking a glass in company. I could invite friends home or be more present at literary meetings, debates and political demonstrations. I began to think about my life in a slightly different way. I have made several journeys both for reasons related to my work as a writer (in 2013 I published a book[13]) and as a trainer in associations or as a volunteer (Belgium, Bosnia, Puglia, Friuli, Campania, France, Sicily).

I probably fell in love for the first time in a different way, not that before or after there were no other opportunities for relationships, but before I tended to see them more as something indefinite or compensatory, a kind of Sunday on which to rest, a sort of flower in the desert. Later I saw them in a less enchanted but also less involved way, in which case I began instead to plan and want to build a relationship. I began to think about the future, even with all the difficulties that in my case this would imply. In essence, in that case as in others, however, I kept a substantially passive attitude. I humanly realized – and still realize – that having to regulate one's practical and affective life at the age of twenty by adapting it to a disabled person can be a choice but certainly not an expectation. Ultimately, when you really love someone, you really wish them to have different, more varied experiences in youth, and every choice is never followed by resentment or malice. On the other hand, she was always sweet and rarely rude. Other occasions have not been so, but I was not too worried about it. When you think of someone you love pushing you in a wheelchair so early, as silly and irrational the thought is, as irrational and naive are all thoughts of this kind, you really think that something in the "natural order of things" went wrong, and that it's an injustice. On a general level and less tied to this occasion, also in this type of relationship and ties, different experience and more information would be useful, since it still happens that I have to explain that my disability is not infectious or, in my case, degenerative. All these things are naturally unpleasant, as are the ostentatious and excessive modesty or morbid curiosity to which you are sometimes subject.

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[13] *Le strade di Gerico* (Serra Tarantola, 2013) [editor's note].

With a bachelor in Humanities, several years now of university experience and a vast network of contacts and friends in various environments, well rooted in the community, I have devoted more time in recent years to associative and literary commitments, to which I have added political militancy in circles linked to the left-wing tradition, initially as a student supporter of the workers of a service cooperative linked to the university, which conducted a campaign to ensure that the renewal of their contract would not result in a drastic worsening of working conditions and wages.

Then I carried out activities of information, picketing, participation in assemblies and organized meetings in support of strikers. Later I approached political groups formed in support of left-wing lists for the European elections and it was a moment of fervour, applying myself to new commitments linked to the conduct of social enquiry, and with different acquaintances, obviously very varied but never or almost never including students (the intermediary in that case was R., who had done civil service years before). I took part in the foundation of a mutual aid society and in the inauguration of a *Casa del popolo*, which carries out various kind of political and social activities, and I collaborated with the *Circolo del Manifesto*. I have always got on well in all these circumstances and I have encountered an absolutely open and welcoming environment, although to some extent not exempt from the worst behaviour and attitudes regarding disability that I might find in literary circles and in general outside the university. However, openness, curiosity and sometimes interest prevailed, also because the symbolic and political meaning of my participation was perceived, however little I could do, both because of my difficulty in moving and because of my physical weakness and precarious condition as a student, all of which, in the end, made me useless or unreliable for most of the activities which were carried out. I have often felt that I am a source of motivation and hope for others, also because of my young age.

I finally moved into another apartment in the city centre which would be my home for the rest of my university years, where I lived with E. and M., two university students younger than me, whom I hadn’t met before. Actually, it was the first time that I had to live with unknown people, not my peers and not coming from a restricted environment such as the *Collegio superiore*, but there were no major problems. I was very well received and indeed I became a point of reference for them and introduced a family lifestyle among us that was previously lacking. I quickly bonded with their friends and they bonded with many of mine.

It was this pleasant climate and the approaching end of my university career with my master’s degree that made me slow down my pace and rhythm of life: in the last year I practically gave up attending lessons, limiting myself to sometimes going to the library or to office hours because the system of accompaniment on foot, although it had become much easier than in the early years, began to be a fatigue not justified by the lessons, which often seemed to me to be too superficial, generic or repetitive – I preferred to devote myself to my thesis and to work.

I have practically been a non-attending student in the last year. I have gradually abandoned most of the activities in the association and several in the *Casa del Popolo*, even if I have long maintained a role on the board of directors in both. Although I am present and in contact with many more active members, in a word I have become lazy. Feeling at home in my environment and feeling that I had led, and still live, a tiring life gained inch by inch had on the one hand undoubtedly exhausted me, but on the other hand induced me to think that I could also allow myself a different pace of life and more leisure, even if there were experiences of collaboration and individual volunteering with other networks and organizations.

The only area in which I have significantly increased my work has been the literary one. I met a very bright professional publisher who was interested in my work and luckily did not fall into the usual discrimination and clichés and with whom I worked positively first as a reviewer, then as a proof-reader and finally as the author of an anthology and then my second book[14]. I also started to collaborate with a second publisher whom I met during one of my journeys as a volunteer. I have been an assistant in several book fairs and for this publishing house, I also direct a series of poetry publications, although I must say that in this second case, undervaluation due to age, lack of competence of other people in the field, and especially to disability, have not been lacking.

We also have to take into account the fact that the headquarters of the publishing house is not in Bologna and that any working relationship in the literary field requires considerable mobility, also at a national level, to meet authors, participate in events and organize meetings, and obviously my disability penalizes me in activities of this kind.

In March 2017, I graduated and after a short time, I started the paperwork for a change of residence and to be taken care of by the municipal social services, with which I have some difficulty in understanding, perhaps due to it being a new contact but which I expect to solve in the future, even if the mobility problem remains and risks becoming significantly disabling for work (which is not offered to you if you can’t go to the workplace, obviously), and my network of friends and relationships is likely to become one based on dependency. In the end, I had the opportunity to talk to the Rector about the difficulties encountered in my path, which I had certainly not forgotten despite everything and which left me bitter and angry on hearing the self-celebration of the university bureaucracy and the hypocritical praise of merit, while being classified in the imaginary (and horrible) category of “deserving disabled”. I protested about the lack of attention, the bureaucratization and the lack of means given to the Service for Disabled and Dyslexic Students, having learned over the years the difficulties of other students and the difficult, stressful working conditions faced with great professionality by the Service workers.

My goal is above all to make my university experience useful in improving the conditions for students with disabilities, something that has so far made ground through contact with the Rector’s delegate on the subject, and which I hope to continue positively. Having to draw my own conclusion and make some final considerations, I can say that my experience from a relational point of view has been more than satisfactory, even though I realize that this is due to a series of favourable contexts, fortunate encounters and good relationships, because every individual life is also a collective work, besides the fact that I have invested a great deal of time and energy in relationships over the years, probably above average and almost certainly at the expense of my career, professional position and material interests.

I have faced, and I still face today, material difficulties and moments of uncertainty and suffering thanks to a good attitude to reasoning and to a capacity of endurance that has developed over a long time, but often also to laughing at my ineptitude, which I do not hide from myself. If you will allow me to make a joke, Lenin said that the virtues of a Bolshevik are patience and irony – even for disabled people they are probably not bad attitudes, and they are certainly perfect for disabled Bolsheviks.

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[14] *L’arte della sconfitta* (Qudulibri, 2017) [editor’s note].

Speaking seriously and without wishing to lecture about virtue, we must however remember, as I have absolutely had the opportunity to experience in recent years, that problems related to disability and integration are also cultural, social and political problems: good feelings and tolerance are never free and they are never the result of an individual action. There are still many battles to be fought because the difficulties are real, as are the impairments. Ignorance is very widespread and rights are not always protected, as mine have not always been. In fact, they will probably be less and less protected. The proportional tendency towards privatizing public education and considering disabled people as a cost item is strong. I think that maybe the first step in establishing relationships and creating healthy contexts for a disabled person is not accepting to be considered either anything less than a man among men or anything more.

Disability and University

Enrico Franceschi
Cultural Anthropology and Ethnology graduate and current employee, University of Bologna

Translated by Nicola Bardasi

Let me introduce myself: I am Enrico Franceschi, I was born in Bentivoglio on the 24th of September 1971 and I am here to write this piece as a tutor for people with disabilities at the University of Bologna. I have been working as an administrative technician at the University of Bologna since 1997, and for several years now I have been working in the university warehouse services. I have about six years of experience as a tutor and I can say that it has given me great satisfaction, even if only for the fact that I have felt useful, but especially for the positive relationships that I have been able to establish with people.

Before I start to talk about my experience as a tutor, I think it's worth recounting when and how I met "disability" and what it meant to me.

My first significant contact with a person with disability occurred in my very early childhood, in a small village in the province of Bologna where my grandparents lived, and where I spent a lot of time. Orlando, a deaf person, lived there too. I remember Orlando with fondness. I believe he liked children and spent time with me. He taught me several things. I'm talking about the early '70s and a very small village in the extreme outskirts in the periphery of the city. Orlando, as I recall, was well rooted in society. He lived there, in his own house next to his parents' and sister's house. Basically, it was an evolution of the extended family, an institution that in that territory had a long history due to the practice of sharecropping[15].

My second significant contact with a disabled person took place in first grade. In the class I attended, Claudio, a boy of my age with Down's syndrome[16], was a schoolmate. It was 1977 and from the few memories I can recall, I can say that the experience was not particularly happy, especially for Claudio. His stay in the class was quite short. All I remember is the teacher complained about him a lot. She said that with such a large class, she had absolutely no time to dedicate to him. So it was that after the teacher had a severe quarrel with Claudio's parents, they took the decision to change schools.

My next significant encounter with a person with a disability took place at the end of the 1980s, when I was nineteen. I had decided to go for civil service instead of military service. It was in this period that I found myself, absolutely unprepared, carrying out the task of accompanying Sonia during her last year of middle school. Sonia was a little girl with Down's syndrome. She was 14 years old and in the eighth grade. I had no expertise in assisting any children, but because of the limited resources available to the school (at least, as I was told), I was put in charge of her. I accepted because working in a school with children seemed much more tempting (and socially useful, or in any case more

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[15] Sharecropping is an agricultural contract under which settlers (sharecroppers) cultivate the property of another, then shares the products and profits of the crop in half with the owner and retain for themselves only the products necessary for their livelihood. In Italy sharecropping was abolished in 1964.

[16] Down's syndrome, more properly trisomy 21, is a chromosomal condition caused by the presence of a third copy (or part thereof) of chromosome 21.

coherent with my choice of a civil counter argument to military service) than staying all day within the four walls of an office doing bureaucratic paperwork, if even just duplicating documents. So, it was then that I began to go every day at eight in the morning to wait for Sonia, who arrived accompanied by her parents. I have to say, it wasn't as easy as that. We had at our disposal a small room in the school, equipped with some toys and some children's books with drawings. Sonia had an intense "developmental delay", she had a very limited vocabulary (about a hundred words), she was afflicted with psychosis, a disease that hardly allowed her to continue an activity for more than twenty minutes and led her to express excesses of anger that nobody could understand. She was avoided by many children, but not by all of them. Those who knew her best (for example, who had been to primary school with her) seemed less suspicious and would spend a few moments playing with her. Our shared experience, however, lasted only a few months. When we returned from the Christmas holidays she had "become a woman": she had started to menstruate for the first time.

Just a week later, I was told that she had been "institutionalized" in a centre in the *riviera romagnola* (where she still resides). At the time, I was quite ill, even if on the one hand the amount of work assigned to me had been greatly reduced. In fact, it wasn't at all easy to accompany a person for five hours a day who expressed themselves with great difficulty, who was able to remain engaged in one activity for only about twenty minutes, who had frequent outbursts of violent anger during which they became a danger to themselves and others, and it was especially difficult to manage situations for which I was not prepared at all. But what bothered me most were the bad thoughts that began to circulate through my mind. The child came from a family that was itself rather problematic, at a rather low social and economic level and it seems that, especially in the past, they beat the child (it was said that sometimes she came to school with abrasions due to ropes with which she must have been tied). Maybe if she were institutionalized it wouldn't be so bad, but what I was wondering was why at that very moment. My fear was mainly since this operation had been conducted under the (more or less) justified fear that sexual abuse would be perpetrated. Of course, I was reassured with regards to it, but as they say: "Thinking badly is a sin, but sometimes one hits the nail on the head". I did not have any further elements to support these disturbing thoughts, and then if I have to be honest, with hindsight, I also felt a bit cowardly for not having done anything at the time, when it would have been the right moment.

After having done the same work with other children, younger in age and with other problems, I had another new meeting that I could define as significant. Even on this occasion it only lasted a couple of months because my period of civil service had ended and I returned to my job, but I must say that it was quite a different experience from the one with Sonia. In September, I was entrusted with Ernesto, an eighteen-year-old boy with Down's syndrome (we were almost the same age), whom I had to look after during his introduction into the first year of an Agricultural Institute. Ernesto came from a wealthy family, who accepted him and defended his rights (especially his mother). I say this because I believe that it had not been easy to convince Italian educational institutions to try the "experiment" of placing a boy with Down's syndrome in a "normal" class. I can safely say that the experience with Ernesto was totally different from the one with Sonia. Ernesto was a very "polite", jovial boy and was a good companion. So, it was then that I began to suspect that at least the social context of origin had some influence on the possibilities of people with disabilities.

Turning to the experiences with people with disabilities within the university, I can say that they have been equally rich and significant. I have been involved with people with disabilities not only as a tutor, but also with some colleagues/users of my service who fall into the category of people with disabilities. As far as the relationship with colleagues is concerned, I believe I have never encountered great difficulties in relating to people with disabilities. Especially in the light of my experiences, as a tutor or not, I can say that motor difficulties, visual or learning disabilities, or any problem in the field of communication are easily overcome with a little common sense.

A reasonable level of mutual understanding is enough to recognize what can be done and what can be expected from each other in a polite relationship. I believe that all we need to do is take the time to get to know each other in order to put in place strategies that will make the relationship mutually beneficial. I do not want to be misunderstood – it is not all so simple, the difficulties of people classified as disabled exist, they are real. What I would like to say is that many difficulties could be overcome with a bit of patience: it takes time to get to know and understand each other and especially to understand when the difficulties are real or simple mental constructions and social restrictions.

Among my colleagues, a person with disabilities with whom I have a great relationship is Giacomo, a blind person who has been working at the university as an administrative employee for about thirty years. I've been meeting up with Giacomo for fifteen years now, practically every day to have a coffee and a chat together. Giacomo, who is more than fifty years old, is a person who has learned well how to move independently, but certainly there are some situations and contexts where he needs some help.

For example, in the management of the personal work computer, when roadworks begin in the area, when there are organizational changes that affect his habits. Anyway, never anything that can't be overcome with a bit of common sense. I remember, in particular, a couple of episodes that Giacomo might have experienced with a certain amount of stress. The first was when he was asked to be the tutor for a colleague with mental disorders. This would have created a situation unknown to him and, because of his condition, difficult to be controlled or managed. I think that this created a lot of embarrassment for Giacomo because he found himself having to make the Personnel Office understand that this cohabitation would have caused him a lot of problems. In my opinion, episodes like this one show a certain lack of tact, if not a lack of empathy on the part of an organization.

A second problematic episode that I remember concerning Giacomo was when he was asked to regularize his clocking in/out with a magnetic badge, when he had been working for the University for more than thirty years and didn't "clock in/out" – his times were manually inserted by another colleague on his instructions. The University of Bologna has every right to control the entrances and exits of its employees (with or without disabilities), but it should also put them in a position to be able to do so. I'll try to explain myself better: our organization is highly bureaucratic, working hours are standardized, it is necessary to do a certain number of hours, arrive within a certain time, leave within another and the timekeepers with which the University is equipped are not audible, so it is difficult for those who have visual impairments to check at what time the punching in/out took place. Now the problem was overcome by asking for the help of colleagues who work at Reception, next to the timekeeping clock, and who can tell Giacomo the exact time at which he clocks in/out. A little common sense was enough, and Giacomo was put in the position of needing the help of others. I wonder, however, whether it is so necessary to check the working hours of an employee who has never created problems and who has always done his job. I also wonder whether there would have been such an impact on the University's economy if it had been equipped with talking timecards. But most of all I wonder why no one thought of it. To this last question, Giacomo gave me an answer: "Because the problems are of those who have these problems". He said this while we were talking about the small inconveniences he encounters travelling from home to work and back. These are mostly difficulties in avoiding scooters, motorcycles, mopeds or bicycles parked under the porticoes. It is true, they are not insurmountable problems, but they certainly underline the general neglect, which now seems even more accentuated by the recent practice of refuse collection. Leaving bags full of paper and plastic outside the doors under the porticoes is a new obstacle for people like Giacomo (not to mention the occasions when these bags are emptied by unknown people leaving the trash on the street). In this case, we are faced with the fact that the Municipality of Bologna has involved itself in the implementation of separate refuse collection and solved the problem through a system of collection from door to door, but seems not to have taken into account what complications such political decisions entail for certain categories of people.

As I wrote at the beginning, I have also acted as a tutor for people with disabilities at the University of Bologna.

So far, I've tutored two people with different disabilities. Sandro was the first of them. Our collaboration began in 2011 and ended in 2016 when he was hired by the AUSL [the local health authority, editor's note]. Sandro, who was 24 years old at the beginning of our collaboration, has a disorder within in the autistic spectrum, Asperger's syndrome[17]. During those five years, we worked together in a very fruitful way, and it can be said that we established a fairly good friendship – in fact, even today we still meet frequently.

I don't think there were any problematic episodes arising directly from my relationship with Sandro, although it certainly took some time to get to know each other and understand what the mutual expectations were. The circumstances were, however, different regarding some episodes in which Sandro was with other colleagues. I remember a rather funny occasion when I was absent for a few minutes from the warehouse and in the meantime, a colleague who spoke with a marked Southern accent appeared to pick up some stationery. Not being able to understand him well, Sandro did the most logical thing: he called me (I was still in the office not far from the warehouse) and said, "There's a strange guy here who speaks in a strange way, and I don't understand what he wants." The colleague obviously got very angry – he didn't know about Asperger's syndrome and about the proverbial lack of "tact" associated with it. A similar situation happened with another colleague, who was trying to joke with Sandro, without knowing that the irony was not appreciated (this is also a common trait in people with Asperger's syndrome). Sandro understands irony, but since it seems that

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[17] Asperger's syndrome is considered a pervasive developmental disorder, related to autism, which however presents no impairment to intelligence, understanding or autonomy, unlike the other three diseases classified in this group; for this reason, it is commonly considered a disorder at the "high functioning" end of the autistic spectrum. People with this syndrome, whose aetiology is unknown, have persistent impairment of social interaction, repetitive and stereotypical patterns of behaviour, and in very few cases, limited activities and interests.

others do not understand when he uses irony, he prefers to abstain from it and likes other people to do the same. Perhaps it is worth pointing out that disability in general, and Sandro's in particular, not only brings out the negative aspects of our social organization but can also be a kind of added value to that organization. For example, while I was teaching Sandro about the use and functions of databases, he helped me to implement new functions in the database we use to manage the warehouse. I remember the fundamental contribution of Sandro also on another occasion: facing a change in the management of cleaning in the University, there was a need to compile a database with an infinite amount of data about all the rooms in the university buildings (offices, classrooms, bathrooms, etc.). It was impressive to see how on occasions like this, the peculiarity of Sandro, with his so-called visual memory, was really advantageous. I don't think I've ever seen anyone enter data in such a quick and accurate way.

The second experience with an intern started in mid-2016 and is still on-going, so I've been working with Mattia for about a year. Mattia is almost forty years old, he has a intellectual development disorder and a slight problem of gait due to a "crooked" leg. He worked for many years for a large construction cooperative, but it was declared bankrupt, so Mattia found himself without a job (for the record: my brother also worked for the same cooperative, so I had some "idea" of Mattia). Mattia was thus unemployed for a long time until (with the help of his mother) he was given a place in an internship program. Interacting with Mattia compared to how I interacted with Sandro is in some ways very different. His intellectual disorder makes it difficult for Mattia to think "too complexly", as the disorder is placed on the autistic spectrum, making it difficult for Sandro to establish "positive social relations".

However, Mattia is very willing, he is enthusiastic about the new job, he is also an extremely well-mannered person who is able to "make himself loved" by almost everyone. It didn't take us long to understand what he could and could not do. The slight problem with walking certainly creates some embarrassment in moving around a warehouse full of pitfalls such as shelves with sharp edges and pallets, but anyway, Mattia is aware of his condition and understands which dangerous situations are best to avoid. As I did with Sandro, I'm trying to teach Mattia to use the computer in general, and our databases to manage the warehouse. Also with Mattia, I feel I can say that we have managed to establish a more than positive relationship (for us and for the University organization for which we work). The occasion which has made me think the most since I've known Mattia happened recently. Mattia took part in a selection exam for people belonging to protected categories to be hired at the University of Bologna. He worked so hard that he was able to answer correctly the two questions in the test, questions that formally required a short answer, but he was not admitted to the shortlist. This caused him huge disappointment. Apparently, his exclusion was due to the brevity of his answers. So, I wonder, if the University allowed him to take the exam (knowing of his disabilities), why then exclude him only for the "simplicity" of his answers? A macro-category has been created in which people with different difficulties are included, but then no account has been taken at all of the differences between these types of difficulties. Only those who know Mattia were able to realize the stress he suffered in preparing for the exam, and the enormous disappointment that he experienced in being excluded, although his answers were exact. I can try to understand the difficulties of those who have to judge with equity such different types of people, but I think they could have taken certain aspects more into account.

I could use my previous studies in Cultural Anthropology and Ethnology to affirm that disability has historically established itself as an "exception" for the human condition. This vision could be defined as therapeutically oriented, but it is necessary to observe that, for example, disability, as an "exception", remains excluded from the academic tradition, apart from in "biomedical" or "pedagogical" interests. In this sense, disability has not so far enjoyed the same attention as categories of analysis such as class, ethnicity, gender, etc. In other words, the lack of attention to people with disabilities is found not only in wider society, but also in the academic world and in the official discourse about the knowledge acquisition process. The absence of categories that characterize research in the academic fields is not the only reason why studies on disability have been suppressed. The second reason is that the same disability has been removed from public discourse while other "robust" categories are present, so, unless writers, artists or directors are known for their disabilities (such as Beethoven), they are not thought of at all as disabled people.

As a result, their work is not included in any of the cultural production fields. This would be like suppressing the gender, colour, ethnicity or nationality of a writer. How many people know that the category of people with disabilities includes: John Milton, Sir Joshua Reynolds, Alexander Pope, Harriet Martineau, John Keats, George Gordon Byron, Henri de Toulouse-Lautrec, James Joyce, Virginia Woolf, Raoul Walsh, André de Toth, Nicholas Ray, Tay Garnett, William Wyler, Chuck Close and many more?

To conclude, I don't want to go on or preach, but I would like to recall what a professor taught us in the first lessons of Anthropology, which is that the groups we perceive as different are "good to think about" (also to study our own preconceptions about so-called different people). I will not go on about the fact that perhaps the people with disabilities with whom I have had significant experiences have given more to me than I have given them, but I would like to remember that "our" so-called circumstance of ability is not forever.

I only had to get experience, instead I found a friend

Luca Gioacchino De Sandoli
Former intern, University of Bologna

Translated by Nicola Bardasi

The 1st of September, 2011: I go for the first time to the Stationery and Goods Warehouse of the University of Bologna, at number 8, via Acri. The manager is Enrico Franceschi, who shows me the place. A corridor from the entrance, shelves for paper, envelopes and office tools, a bathroom, the landing of the stairs to the basement. Then the room itself, with a workbench and shelves full of material no longer used on the upper shelves and various items of stationery on the lower ones. Two desks, another corridor and another stationery shelf. A room with a cart, boxes, dox (a type of binder) and the elevator to the basement. During that morning, Enrico helps refresh my knowledge of Excel, in light of a selection exam that I'll have in via Belmeloro.

We talk a little bit to get to know each other, and I feel we've got a lot in common, such as the genres of books we read. Even today we still meet once every two weeks to talk.

It was the start of 4 years' internship, and of a friendship that we have had for six years.

Having previously worked as a computer programmer, Enrico once had the idea of managing the entire warehouse with an Access database. Considering it was appropriate that I had to learn something during my internship as a warehouse worker, he showed me how it worked, how he made the tables and the *query*, the Access basics. With a series of links between the tables, which indicate all the characteristics of each article, it's possible to *query* the database and then obtain useful results for practical purposes, done by formulating the *queries*. Enrico also showed me how he created the Access masks, which are useful for entering data into the database, and how to create the reports, which are lists made by the database indicating, for example, which stationery item is the most numerous in the warehouse.

Right now, I can't recall much of this. In fact, I may never have really applied the Access programme to work, but Enrico was never disappointed by how little I learnt. He trusted me, he saw that I tried to learn, and if I did actually show him that I wanted to learn, it must be because I always keep a series of Excel tables up to date at home. They have columns of movie data in meticulous order: title, production year, director, year and place it was set, main actor, day of lending or rental, day of return.

A small obsession, which however shows considerable potential, which could very well be exploited to create an Access database. My problem, at least I think it was, was that I couldn't conceive or project databases that went beyond a simple level. As long as they were easy, without complex links and about topics I really liked, I could get by. When they went a step beyond that, I found it difficult. But Enrico didn't take it badly. It's true he did everything to teach me the programme, giving me a detailed dossier on how to design and use an Access database, but it's also true he knew that we were on two different levels: at school I'd been limited to using only Word and Excel, while he had been a computer programmer, and he applied this previous experience to the work in the warehouse. Then, monitoring and updating the database first with his help and then by myself, I had some ideas: since the warehouse had precise opening and closing times to the public and only in some cases made exceptions for visitors requesting or collecting material, I thought of inserting two data into the database, specifically the reception and withdrawal times.

When we made the changes to the Access database, creating the necessary tables and *queries*, we made masks and began to insert the times. Then we obviously took the opportunity to *query* the database and calculate the times and days when there are more requests and withdrawals of material, and finally we printed a report. It's still a fact that in the warehouse database, there's also something of mine.

I admit that nowadays I hardly use Access anymore – no one in the office (now I work in the Local Health Authority) asks me to create databases, but Enrico told me that if I managed to learn with him at least how to create tables and *queries*, I can learn it again.

And in addition to using Access, I learnt (or at least I experienced) the activities that are typically done in a warehouse. One of these is putting the material we stocked on the shelves and pallets and then preparing it for the university users every time a request or order arrived - physical work is one of this activity's main features.

Indeed, when I arrived at the warehouse, I confess that I didn't really expect to find someone, i.e. Enrico, who ran and monitored the activity with a database, I was convinced everything would be done old-style, without such extensive use of the computer, limited only to the request e-mails and orders that we sent to suppliers after an inventory or the exhaustion of an article. And in fact, Enrico told me that a colleague, now retired, who worked with him used to run the warehouse manually. I thought that I would have written sheets and sheets of dates, maybe with a folder below, when we did the inventory.

Making the inventory wasn't difficult, it was just a long, tiring job. The warehouse was small, but very well-stocked, as I described at the start. There were at least some articles that no one asked for or used anymore, such as the Olivetti calculators with their tapes, or a certain type of labeller, or a copybook. These articles which are no longer used are excluded from the inventory. For this reason too, we used to keep these items on the highest shelves, which we reached by climbing a ladder. I almost never climbed it for fear of losing my balance, even though I didn't feel dizzy. I just limited myself to keeping the ladder steady while Enrico went up.

To do the inventory, we first printed a list of everything we had in the shelves, adding a serial number to the item name indicating shelf and floor number, and then we counted the units of each item, putting a tick if the number registered by the database corresponded, or marking a different number if it didn't, thus detecting lack or excess.

Using Access, we also calculated the average quantity of units that went out from the warehouse, also considering the possibility of very large requests, if there were any.

Doing the inventory, placing and possibly moving the material wasn't a problem for me, I took advantage of it to do some physical movement, which never hurts.

One type of article that we particularly dealt with was stationery. In fact, the vast majority of objects used by students or teachers are those things that are bought before the start of the school year: rubbers, pencils, pens, sharpeners, etc. Every time an election was held, we even had a part of the warehouse where we kept rubbers, pencils and anything else just for such occasions, and we put them in huge envelopes numbered for each polling station.

In the same corridor where we kept the stationery, we also had a pallet on which I had learned to put packages of 50 student register filing folders, originally called faculty folders, which were recognizable by their size and blue colour. Putting these packs together by alternating a layer of folders horizontally with one vertically, we managed to create a substantial stack which would not collapse.

And obviously, when the material arrived, we had to check that what we had ordered was all, absolutely all, there. I remember that on my very first day of work at the warehouse, three or four weeks after my first meeting with Enrico, there were whole pallets to be unloaded. We took the carts, left the warehouse, and went backward and forward to the truck, carrying the boxes inside a few at a time. Due to the volume and the large number of these boxes, I found myself doing a lot of manual loading and unloading. It can be called my "baptism of fire". Fortunately, however, in the following months, such deliveries were less frequent and voluminous.

Then, "baptism of fire" apart, we had to open the boxes, extract the contents and arrange everything well so as to check and count it all. With a pencil to hand, I put ticks on the bills and receipts next to the data for the delivered material. If there was anything missing, we immediately reported it, hoping that it would be resolved as soon as possible. Unfortunately, they sometimes happened to bring us the wrong material, such as envelopes that were too small, or a type of notebook different from our order.

As regards everyday activities in the warehouse, it all went quite well. We contacted or welcomed users and delivery men so that the orders were ready for collection and, when they arrived, we asked them to sign the pre-printed bill and then recorded the collection on the database. We had the signatures first in block letters, then in italics, because they were often illegible and we wanted to be sure that the person who had been sent to make the collection was the same person who appeared at the warehouse. In fact, I remember that towards the end of my internship there, in a moment when I was alone, I had an excess of zeal with a man I kept there for quite some time and who got very irritated when I asked him to write his name in block letters. I began to feel nervous, because of the aggressive tone in which he was speaking. Not knowing what to do, I had to call Enrico to intervene and calm him down and make sure that he was indeed the person sent from his office and not another delegate.

Fortunately there were a lot of calm periods, during which we had nothing to do. Indeed, Enrico told me that, stimulated by the university atmosphere, he took advantage of those free moments to study and then take a degree in Cultural Anthropology.

When there was no loading, unloading, requests or orders to deal with, Enrico and I used to do something constructive. He gave me lessons about Access, or we took inventory, or prepared the requests, carefully and consistently monitoring the e-mails, so we always knew who wanted the material. Or we were on our own to exchange opinions on various topics, two of which were books and movies, two great passions that we shared.

It often happened that he recommended or talked to me about authors and texts he liked, and I did the same. For example, I talked to him about George Orwell and H.G. Wells, and he talked to me about *steam-punk* books. It was precisely this double interest that made our relationship perfect.

In short, I was really fine. We hardly ever disagreed about any subject. I expected to have to face a period of tension when in the third year of my internship, we had to work on the construction of a database for the cleaning section, into which I inserted, or suggested inserting, a lot of data that could have been useful for those who would have to use this database. The preparation of the database was the only occasion that saw me so tense as to interrupt Enrico more than once while he was explaining what we had to do, and almost to irritate him by making an ironic comment, without any malice. My cause of my tension (calling it stress would be too much) was merely the fact that the maps for the cleaning section of number 3 via Acri were constantly changing, and so every day we had to redo all the work we had just done the day before.

It wasn't anyone's fault, it's just that I have difficulty adapting to changes, especially if they are too frequent or unannounced. I think that you can't change your mind every 5 minutes because that way you can't understand anything anymore and you no longer know what to do. By contrast, Enrico managed to handle the situation, kept calm, and fortunately didn't even have to make too much effort to calm me, because I've always been composed and calm in his presence. I repeat: Enrico never got angry, he trusted me, we had common interests, we worked in a quiet environment, all the more stimulating considering its location. Being in a place where it was possible to have contact with graduates who had studied or were studying, in the heart of the historic centre, near the university, is an experience that can only bring about something useful, even if I've never reached the point of being part of a literary circle, as has happened to many other writers of the past.

However, Enrico appreciated the fact that I had published books[18], and in addition to exchanging titles and texts, he had read my publications and also liked them. He even gave me some good advice when I asked him. However, he told me to take them only as a reader's opinion ("with reservations" he said). I trusted him because he had read so much, and knew many more authors than me. For a writer, the opinion of a reader is excellent advice.

My relationship with the my other colleagues was a bit different, but no less friendly than that with Enrico. You could say that I didn't have such a close relationship with them, but I got on well with them.

One of these colleagues was D. He was blind, but always smiling, at least whenever I saw him. Regarding him, Enrico told me to worry about saying say "to see" or "to look" because D. never get upset. At first, I had some difficulty doing so, because they are terms I often use, and saying it in front of D. made me worry about seeming insensitive, but he understood and said nothing.

One day I was really intrigued by how he was able to do his office work. He had a keyboard with Braille characters that allowed him to recognize the letters, and so he could write without any problems. When he finished writing, he verbally re-listened through his machine to what he had written and understood which words were split by a space, or when he had started a new paragraph. In short, he was doing much better than I could even remotely imagine. And D. assured me that Braille was not so difficult to learn, but I remained a little sceptical. Anyway, whenever Enrico and I went to visit him, he always liked it and he recognized me instantly, because of my loud voice.

Another colleague I dealt with was V., who spoke in a slightly mangled way. The first time I met her, when I was new to the warehouse, I didn't think I would have any problems working with her but once she'd left the warehouse, Enrico told me to look him in the eye and said something in a rather severe tone. I got worried: had I been rude? Too impetuous? Not at all: Enrico only wanted to tell me that V. had some hearing problems, so I always had to talk to her face-to-face, so she could read my lips.

It wasn't a reproach, but only advice given to me to remedy my difficulty: I tend not to look people in the eye when I talk to them. Very often they've asked me why, as I have

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[18] Among the books published by the author, the novels *La Terra è femmina*! (Midgard, 2010; Aracne, 2017) and *Pausinite* (Midgard, 2012; Aracne Editrice, 2017).

asked myself. Initially I thought it was fear or shyness, then I thought that if I looked at people directly, I couldn't string words together, or I would say disconnected or meaningless phrases. In short, I ran the risk of looking as if I didn't know what I was saying.

In reality, this has deeper roots: I remember that during primary school, I was always alone. At break time, my classmates left me alone, or I chose to stay away from them. Always with my head in a comic book, or an illustrated book, or an atlas, I adopted this habit, which I've never abandoned and that I still always use with everyone. I always look shifty, like someone who has something to hide, but that's not how it is. And perhaps my problem doesn't come from the desire to focus on what I have to say. In fact, even when I talk to others, I often happen to talk in stops and starts, I still have to formulate the phrases to use and find the words to say, also ending up stopping and changing a sentence just started. Partly for this reason and partly due to the fear of being interrupted, the pressure builds in me and the situation doesn't improve if my interlocutor interrupts me – all of this makes it extremely difficult for me to hold a conversation while looking people in the eye. When I give the impression of knowing what I'm talking about, it is because I find myself using stock phrases, or full set sentences, just reorganized in an original and credible way. The tendency I had to school to memorize things to say in answer to questions has sunk in, like a kind of fear induced by the teachers. When I behaved badly and they scolded me, I looked them in the eye and I was so affected by their scolding that I gradually stopped looking at them, even though it was unavoidable for me when they ordered me to do so. In fact, they wanted me at all costs to look at them not because they wanted respect, but to be sure that my attention was all focused on them and nothing else. When I was 12 years old, I even began to look people that spoke or scolded me not in the eye, but at their foreheads. It might have seemed like a pathetic attempt to read their thoughts, but in reality it was an attempt to give the illusion of looking people in the eye when I was instead looking at their foreheads. So I avoided the eyes of the person talking to me, but without showing it.

The aggressive manner of people scolding me and some negative episodes that happened to me while I was at school, when I really did look directly at the person who was screaming at me, didn't help me at all, in fact it encouraged my tendency not to look people in the eye.

Enrico never had anything to say about this, on the contrary he understood me, gave me confidence, familiarity, and moreover never scolded me. He only asked me to not read aloud when he was reading or concentrating on something, or to not do personal things when there were users present. I was always quite good about this, because I stopped what I was doing and kept it hidden, knowing how to work when there was work to do. It was just a matter of understanding what to do, when it was time to do it, and then doing it, without hesitation.

I luckily didn't have more other difficulties with V., because she wasn't often at the warehouse, but I would have preferred to see her more, firstly because I could have worked on getting used to looking people in the eye, and secondly because she was a beautiful woman, so much so that soon after she was in a relationship. I had more difficulties with T., a delivery man who had more problems than V. in talking and hearing. Enrico was one of the few who knew how to treat him. He understood my state of restlessness, not only because I was frustrated at not making myself understood, but also because, as he told me, it is typical of people like T. to behave in a manner that is a little hard to accept because of their difficulty, their regret at not being able to make themselves understood. T. tried to be kind, but the situation was further complicated by the fact that he was not the only problem for me, there had also been a previous colleague during an internship at the AUSL [the local health authority, editor's note] in San Lazzaro who had the same problem as T., but much more accentuated, and with a character that forced all her colleagues to have to be very, very patient with her. It often happened that out of frustration they raised their voices with her. Fortunately, this didn't happening again in Via Acri.

A month after I started to work in the warehouse, I met another colleague called F. Right from the start I didn't have a good impression of her. She was not hateful or unbearable, but whenever she showed up, I wasn't very calm. I remember she said that Enrico had been on holiday for a while that he had been absent, and I told her that he had been on a training course. F. insisted, and me too: "No, he was on a training course. Ask Enrico if you don't believe it!".

F. once again stressed her opinion and left. I still thought that she had been unjust believing something that wasn't true, but Enrico told me to not think about it too much, because F. was like that and he knew she was joking. In short, she had a particular character. On another occasion, I saw a small bag with the top rolled over, like one of those in which bartenders or bakers put pastries or brioches. I asked F. what was inside, out of curiosity: first she brushed my hand away and told me that it was none of my business, finally, tired of my insistence (even if said with a polite tone), she said the bag contained a stamp that had to be returned.

Another example was when, at a buffet, one of the many that Enrico and I went to (usually to celebrate a colleague's retirement or transfer), she ordered me to go and get a plate, as I was taking and eating things directly from the trays, even if they were small things.

Luckily there were many other people I met around the warehouse, and whom I sometimes also saw away from via Acri. For example there was L., who sometimes came to visit and have lunch with us. She often smiled, but had some family problems, and I noticed this in her difficult moments, when she had a sad expression or when she didn't show up. She was a very sensitive person, even if she didn't allow the things that bothered her to affect her job. At most, I saw her a little frightened when there was a news item published about a user who had done something bad.

L. always spoke kindly, and once she gave me not exactly pearls of wisdom or lessons of humility, but she did tell me how important values such as family and love were. Once when she happened to read my report about a movie that I had proposed to a film club, another was when she heard me talking to my mother on the phone and I raised my voice a bit.

On this latter occasion, I had spoken to my mother in such a manner as to make them think that I lacked respect, so much so that when I apologized to L. and Enrico, who was also surprised by my unusual outburst, I explained to them that I had to go for an EEG[19] and so I had to wake up at 3 am and not fall asleep again in order to get properly tired and sleepy.

When my mother had told me, I hadn't taken it at all well, and in fact I had a flashback to when I used to have to get up at that hour for supposedly intelligent departures for the holidays. After I'd explained, L. made me promise to apologize to my mother, because

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[19] An electroencephalography (EEG) is a recording of the brain's electrical activity. The graphic representation of this recording is called an encephalogram.

she is the person who brought me into the world, who loves me more than anyone else and takes care of me, so she deserves only respect and kindness. This isn't old-fashioned or retrograde reasoning, but a value which is taught in the family as good manners, which unfortunately nowadays either people don't want to learn, or worse, can't be taught.

Another person I can mention is S. At first, I thought she was Enrico's girlfriend, because when she came to visit us in the warehouse shortly after 2 pm, rather than sitting on one of our armchairs, she sat on Enrico himself. I asked why she'd done so, and he jokingly said that she was a slightly clingy woman. In reality she was full of feeling, not like L., but in another way. She was more lively, cheerful, full of vitality. So much so that once when I was on holiday, I went to visit her house, and after showing me the apartment and introducing her husband, she convinced me to make a phone call directly to the warehouse, to give Enrico an unexpected surprise.

But Enrico also played some surprises and jokes. For example, once we went to number 3, via Acri to deliver some folders, and he told me to go and call M.. I reluctantly did so, partly because she was busy, partly because I didn't want to seem rude and overbearing in insisting that she had to immediately come to the desk. When she finally left her co-workers at the vending machine, I accompanied her to the office, where she saw an elongated box and was surprised to see Enrico pop out of it. You mustn't think, however, that my reluctance was because I thought this joke might be taken badly – in fact I was just worried that Enrico might not be able to breathe well in the box if M. made him wait too long. I had a good relationship with M., but I was afraid I had ruined it when Enrico pointed out to me that I had literally forced her to buy one of my books instead of presenting it to her. I found it very difficult to explain to him that in that moment I had thought it was right for me to earn something from my publications, difficult because I was blocked by the fear of giving him the impression of being mercenary, unscrupulous, unable to compromise, when I have always been willing to come to an agreement with others.

Enrico and I also went to the Post Office, although this rarely happened. I would like to mention a colleague called C. – good-natured, witty, always ready to open the door for us if we were stuck outside or in need of someone to hold it open so we could leave. I can say that he might have been a sportsman, because he had some cups near the desk, a bicycle and an offensive poster against Juventus F.C.

Among the many colleagues and friends I met in the office, there were also some intellectuals, who shared our interests. There was for example A., with whom Enrico was always talking about Coraline, a character in a novel, who was particularly dear to him. Or I., who was studying history and was just a few steps from graduating, whom I laughed with and heard laugh with enthusiasm and joy. Once, when I asked her not to postpone coming to visit us any longer, she replied: "Wait for me", and the next day I showed her why I wanted her to come so much: I wanted to boast by reeling off a list of good movies, mostly art-house, then opening a huge poster that I had bought in via Boldrini and surprise her. Despite my theatrical performance, I didn't succeed, because Enrico and I. had understood my intention and had helped me to open and close the poster without damaging it.

I could also talk about D.C., an American friend of Enrico's who speaks Italian quite well (even if you can hear her accent) and works as a projectionist. Despite this, however, it wasn't her who recommended some good film for me to see. Enrico often did this. Or another colleague, whose name I can't remember right now, who talked to me about *La Belle Verte*, a nice science-fiction movie that criticizes the defects of modern society in a good-natured, almost teasing, manner.

Another person I met was M.C., who came to visit us maybe a little less often than D.C., but I think she's just as important because she lent me her degree thesis that she had published as a book, which was about people with mental disorders. I think that she was familiar with Enrico, because when he did his civil service, he too dealt with people and children with such problems, including a psychotic child.

In conclusion, in four years at the warehouse, I had good relations with almost everyone. Many of those friendships have vanished over time, because now I continue to see only Enrico, once every two weeks, to have a chat and lunch together. Partly because some offices have been moved, partly because some colleagues have been transferred or retired, I don't see them anymore. But I have good memories of almost all of them. I appreciate the cordiality and easy-going manner of almost all of them. As regards those few of whom I don't have great memories, I won't say much. They didn't make a good impression on me either for their behaviour or because I saw them less than the others. Maybe if I had seen F. more, I would now have better memories of her, but I can't be sure.

Many colleagues I liked a lot because I immediately got on well with them, others were average simply because I saw them and interacted with them less. But Enrico is the one with whom I have always got on best, by virtue of so much time spent together and our shared interests.

It's not often you find people with whom you develop such an affinity that you come to consider them special and put them on your list of genuine friends. But when it happens, it's a really great satisfaction.

Interview with Matteo Corvino

Intern at the University of Bologna

Nicola Bardasi
Cultural Anthropology and Ethnology graduate, University of Bologna

Translated by Nicola Bardasi

Matteo Corvino works as an intern at the Stationery and Goods Warehouse of the University of Bologna. He got involved in the project through his tutor Enrico Franceschi, and specifically in agreement with Enrico and Matteo himself, we decided not to ask him for a contribution but rather to interview him. The interview took place at Matteo's place of work, where he appeared calm, also because he was in an environment he knew. The participation of Enrico Franceschi, who in some cases briefly discussed his answers with Matteo, made the interview an interaction between several voices. Matteo gradually seemed more and more at ease, although at first he seemed rather frightened by the presence of the interviewer, who he did not yet know well. His answers, often brief, concerned very significant aspects, especially as regards the perception of disability and how much it depends on the work and relational contexts in which it is found. After recording and transcribing the interview, Matteo immediately wanted to read it and let the interviewer know that he liked it very much.

What do you do at the University of Bologna?
Matteo: I work in the Stationery and Goods Warehouse. I record the orders for stationery and when the people who requested them come to pick them up, I also record that they have picked them up, that kind of thing... But in addition to recording orders, I'm also learning how to do new things such as, for example, recording returns and using the computer. That's my job here at the University of Bologna.

Can you tell me about your day at work?
Matteo: I always wake up at 6 a.m. I have breakfast at my house, at 7.30 a.m. I take the bus and arrive at the university warehouse at around 8 a.m. Then, at 8.30 a.m. I go and have a coffee with Enrico and another colleague and after the coffee we go back to the office and start working. If it's a day when there are a lot of orders and returns to record, that's what I do. If, on the other hand, it's a quieter day, I'll practice on my computer. At 12:30, my workday is over, I get my bus and I go back home.

Are there any colleagues you work with?
Matteo: No, here I work only with Enrico.
Enrico: You only work with me here in the warehouse, but there are people who work here at the university with whom we have contact, relationships...
M.: Yes, for example, there is a guy from the Post Office whom I know well because he worked with my mother many years ago. Then sometimes we have contact with our head of office, because we have to take her documents, and I sometimes I go and say hello to her. Then we have relationships with colleagues in the Purchasing Department.

E.: There are a lot of colleagues with whom we interact both in person when they come here and through the emails they send us to forward requests or even just to ask for information. Moreover, many couriers come here...

M: Yes, that's true. Then sometimes Enrico and I also go to stationery shops to get the materials we asked for and, then, I also have relationships with the people who work there.

I understand. Have you ever seen colleagues outside working hours?
M [hesitating]: No, that's never happened to me...
E: You and I have sometimes had dinner together. Do you remember?
M: Yes, that's true. We have also been to the retirement party of a colleague from the Post Office. Once in December last year, we went to the theatre with Enrico and his partner. I really like the theatre, and in fact I'm getting ready because on Sunday in the Sala del Silenzio[20], together with some other people, I'm going to recite some poems about the world war and the ghetto of Terezin[21]...
E: Going back to what we were saying before, we have never met in a systematic way, but we have happened to see each other several times outside working hours.

What are the positive experiences you have had working at the University of Bologna?
M: The positive aspects are that I am learning to do many things that I didn't know how to do before and that I feel comfortable with Enrico and the other colleagues. But there are also some negative aspects. One, for example, is that last year I had to do an exam for protected categories and there were questions that needed to be answered with a short answer. I answered well but unfortunately, I did not pass the exam. They only took eleven out of the fifty-four people who showed up. It's a negative experience because I'd studied a lot. My mother was not happy and wrote a letter of complaint, mainly because I had studied for the exam...
E: Eleven out of fifty-four people passed the first test. It is understandable, and from a certain point of view perhaps also right that it was decided to reward those who gave more expanded answers. But these, in my opinion, were not the prerequisites for the exam, since they were asked to give short answers and, therefore, to focus their preparation on those kinds of answers. It is for this reason that, in my opinion, Matteo's mother rightly went to the chairman of the exam committee, who acknowledged her reasoning. In particular, Matteo's mother asked for more consideration to be given to the differences within the protected categories, since these categories include people with various forms of disability... In my opinion, it is right and necessary to take into account the differences between such people. We will see what happens in the future...
M: Anyway, I worked hard, I did questionnaires at home. For a month, I studied every day with my parents, and I knew the rules and the main figures of the University, the Rector, his duties, the Vice Rectors, the University Senate... I knew the most important

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[20] The Sala del Silenzio is a hall owned by the municipality in the historic centre of Bologna where various kinds of cultural activities often take place.

[21] The interviewee is referring to a ghetto created by the Nazi authorities in the city of Terezin (in the current Czech Republic) in 1941. According to the Nazi propaganda of the time, it was an exemplary Jewish settlement. In fact, it was a place for the collection and sorting of prisoners meant for the extermination camps of Auschwitz and Treblinka. Bor, J. 2014, *Requiem per Terezin*, Bagno a Ripoli, Passigli and Murlmestein, B. 2013 *Terezin. Il ghetto modello di Eichman*, Brescia, La Scuola.

authorities of the University and their duties... This is the only negative experience I've had here at the University of Bologna. In the other job I did [previously Matteo worked as a clerk in a cooperative in the area, which, however, has declared bankruptcy and had to close], however, I had only positive experiences and even there I was got on well with my colleagues, who were nice. My first negative experience was this competition, because I was penalized by the fact that others had written a lot... But in general, I get on well and I have learned to do a lot of things... I also like to cancel invoices and reload them. At first, I didn't know how to do it, then I took some notes and yesterday I managed to carry it out on my own and I only made one mistake...

E: Yes, Matteo also assists me when, perhaps to speed up our work and reduce time, I decide to do everything myself. He is often the one who notices my typing errors and, in my absence, has been able to solve some practical problems. The required materials can be identified, prepared, indicated to the person collecting them, recorded and completed. He knows where the objects are and moves independently in the warehouse, even if for him it is a limiting context from a spatial and logistical point of view because there are many items placed high up and Matteo can't climb the ladder. He has learned to do this job very well since the early days...

M: Yes, indeed. From the second week I was here, Enrico showed me how to run the laundry service and I learned to do it myself. I also remember that on the third day of my internship I did my first record alone.

We are writing a book with texts by and interviews with people with disabilities. This book will be read by students of the University of Bologna. So, if you want to say something about disability to these students, it's a good opportunity. Is there anything you want to say?

M [hesitating]: I think we should be close to people who have problems, we have to help them more...

E: Is there any advice you would like to give to the students on how to treat people who have problems?

M [hesitating]: I don't know... I'd say we have help people who have problems and not be afraid. I think people with disabilities have to be calm. People have to make their motives clear, as my mother did after the exam, but in general we have to do our job as best we can.

What is disability, in your experience?

M: My disabilities are very slight: I have problems with my right foot and back. When I was a kid, the doctors said they would operate on my right foot, then they decided not to... From sixteen to eighteen years old, I had to wear a bust for my back because I had scoliosis. I was born with a cleft palate[22] and when I was born, I spent three months in the hospital because I could not feed myself and reach the right weight. And then as a kid, I had a lot of fears. I was afraid of very trivial things. For example, rubber puppets that make sounds and stuffed toys that looked like dogs were very scary for me. When I was little, I saw one of those little dogs in my friend's house and it really traumatized me, I threw up and woke up at night thinking about the little dog. I was even afraid to go into my friend's room even though they told me that the dog wasn't there. Now

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[22] Matteo is referring to a congenital malformation consisting of the presence of a fissure in the anterior part of the hard palate, which may extend into the nasal cavity. As mentioned by the interviewee, this malformation is treated surgically.

when I go to the markets, sometimes I look for that dog because if I recognize it, I would like to see if it still frightens me, even now that I'm big. Maybe it would still scare me a little, maybe I would shout but I wouldn't start crying like I did when I was little. I'd like to get past this fear... [Matteo talks at length describing objects and situations that frightened him during his childhood].

You've told me a lot about what disability is in your experience. In which situations does disability create difficulties and problems for you?
M [hesitating]: I get very worried when I have to reach something that's up high, because I'm afraid of taking the stairs and falling, when I don't know the places...
E: But in the environments you know, you can move around well enough on your own...
M: Yes, but if, for example, I had to take something from here to via Santo Stefano, I wouldn't be able to do it because I don't know the streets well and then I'd get nervous and someone would have to help me. When I have to come here though, I can do it by myself.

I think I understand. In the situations where you recognize your disabilities, they don't create problems for you...
M: No, absolutely not. I have no problem getting here, using the computer... When I'm with people, for example at the theatre or when I went on holiday with the Municipality and with ANFFAS[23] as a kid, I had no problem. I like being with people and I'm sociable and open.

Is there anything else you want to say about the things we've talked about in this interview?
M: I don't know. I think I've said it all. I'm very happy that you came to do this interview with me and that you're publishing this book. Thank you for that.

It's me that should thank you. In the future, can I come back and ask you more questions or clarify the things we've talked about today?
M: Sure. I'd be glad if you came back.

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[23] ANFFAS (Associazione Nazionale Famiglie di Persone con Disabilità Intellettiva e/o Relazionale – National Association of Families of People with Intellectual and/or Relational Disabilities) is a non-profit, socially useful organisation formed by parents, family members and friends of people with disabilities with the aim of promoting the development of structures and services that meet the needs of those who live with a disability on a daily basis (www.anffas.net, latest access 20th December, 2017).

Interview with Francesco Musolesi

Employee at the University of Bologna

Nicola Bardasi
Cultural Anthropology and Ethnology graduate, University of Bologna

Translated by Gabriele Savioli

Francesco Musolesi works as a computer technician at the History and Culture Department, which includes a Master's degree course in Cultural Anthropology and Ethnology. He has been involved in this project from the beginning and has always been interested in its development.

Unlike other collaborators, however, he decided to offer his contributions not with a written text but through an interview. The interview took place in his office, situated into the above-mentioned department. Our conversation was helped by the fact that we already knew each other: in fact, Francesco never appeared intimidated by the recorder, he was rather quite open. During the interview, his answers became expansive and more articulated, especially with regards to subjects he had a particular interest in. When the interview was over, Francesco was really surprised by the fact he had spoken at such length.

Could you please briefly introduce yourself?

My name is Francesco Musolesi and I'm 35 years old. Since 2009, I've been working as a computer technician at the History and Culture Department at the University of Bologna, the city where I was born and where I live with my family. I love my job, primarily because it gives me the chance to establish good relationships with students and teachers. I have a physical disability, a diastrophic dysplasia[24] which sets several boundaries in my life but despite my difficulties, I consider myself a strong and sometimes happy person.

You decided to contribute to this project with an interview, instead of a written text. I'm interested in knowing the reasons for this choice.

I think interviews have a more direct approach. I think I'm better at expressing myself out loud and I feel freer. Also, some perspectives surface more easily speaking out loud rather than writing. It's not that I don't like writing, but I prefer talking to people. It

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[24] Diastrophic dysplasia is a genetic birth defect, caused by a chromosome alteration. It consists in a bone deformity which causes a lack of growth. It is quite a rare pathology (the respondent states, at the moment, there are only 3 cases in Italy while abroad the disease is more common). People who suffer from this defect are commonly very short (from 110 to 130 cm) and their bodies are characterized by some peculiarities such as ear cup deformity and a slight external rotation of the left leg. This information has been supplied by the respondent and taken from www.orpha.net (latest access 20th December 2017), a website giving information about rare diseases, especially genetic ones. At the moment there is not a specific bibliography.

allows me to feel more comfortable in relating to the person I'm talking to, to their requests and their interests. The interview is a way of feeling freer.

I understand. You mentioned your disability and the way it sets some limits on your normal life. How could you explain, concretely and not in a theoretical or medical way, disability to other people who are not affected by it?
It's very difficult to explain because, in my opinion, disability must – or should – be lived in some way to be able to understand it. So, for this reason it is difficult for a person that doesn't live with a disability to imagine being in the shoes of someone who does. One thing the people affected can do is talk about their own daily experiences. I can talk about my daily experiences, the difficulties I encounter, the limits I have to cope with and the moments I need assistance from other people. This is the key: talking about it. Do it using words, because there is no other way. Even if words can describe only a part of the situation, one must describe, in the clearest possible way, the condition in which one lives every day. But it is very difficult to describe to a physically able person how a person with a physical disability lives.

You talked about the necessity in explaining your condition clearly of trying to describe disability concretely to those who are not affected by it, and you also said it is difficult to do so. If you had to begin this difficult description, where would you start?
I would start by describing the simpler things, or to put it better, the everyday problems I face in my daily life. I'll give you some examples: I'm not able to get in or out of a car by myself, I need a hand with this. Another example could be cooking, I cannot cook by myself. I need a person who can make a plate of pasta, vegetables, washes dishes for me. There are other more specific situations in which I need help: washing, going to the toilet, personal hygiene. All these aspects can be talked about, written and explained to describe these problems to a person who does not live with a disability. There are many ways to transfer this information, but starting by recounting your own experiences, what you live with every day, is already very important. You can start with that.

You mentioned the limitations you meet in everyday life. Have there been times when you've had the feeling you could overcome these limits?
This question touches on two distinct points – the practical and the emotional. From a practical point of view, it has to be said that modern life is very difficult for people with a disability, since everything is made for physically-able people. Think about all the architectural barriers which are an unsurmountable problem for people in wheelchairs or very simply, short-statured people. If a world were created in which things were made in a way that was accessible for everyone, it would bring happiness, joy and make life easier for those with a disability. With regards to the emotional aspect, I have to say that the moments when I feel happy and where my situation seems more feasible are when they originate not from a social, but from a personal situation. For example, they come from people around me: having friends with whom I share experiences, having friends close by who make you feel good and who share common interests. It's very important for everybody, but especially for people with any disability. In my opinion, for a person with a disability to have people close by them willing to share time, experiences and interests is fundamental. I say this because in particular people with disabilities are compelled to give up many things from the start, from the first years of their life. Having people that make you happy, that make you feel good, surrounding yourself

with people who can give you moments of satisfaction, sharing and conviviality is key. Especially for a person with a disability. When I have these moments, as I've already mentioned, I'm a happy person.

In which situations, instead, do you feel your condition is insurmountable?
When I move, when I go out in the afternoon or the evening, when I go to bars... In these circumstances you realise that a lot of places you go to, unfortunately, are not accessible, they're not made for you. These are the practical moments when I realise my condition is a barrier because, as I said, the world is made for "normal" people. From an emotional point of view, instead, the barrier is when I get strange looks from other people, they treat me badly, or the way they don't respect me: on an emotional level refusals and exclusions are barriers.

From your experience, what are the most problematic aspects that characterise your relationship with non-disabled people?
There is very little knowledge. I call it "lack of social education". I mean that society is not interested in educating people about diversity. Diversity and disability are therefore seen as a burden and as a problem to be solved, not as a resource. Instead, every one of us has potential. gifts, talents, abilities, perspectives and activities which one person is better at than another. From my experience, however, today's society does not comprehend this on any level, doesn't even speculate either. It's by the behaviour of today's society that the problems we spoke about earlier are created: exclusion, discrimination. In my experience these problems are due to a lack of sensitivity and social education and the way in which it is organised. While there are moments of happiness, as I mentioned earlier, from the relationships we have, it's our job to cultivate these relationships and make our lives better because, at least in my experience, today's society and those who organise it do nothing to integrate different people – therefore also those with a disability - with others, in communities, in society. There is a separation: abled people on one side and disabled people on the other.

Do you think this is an exclusive trait of our society?
There are places where these problems are surely lesser, they are less present. Here – by which I mean the western world, Europe and not just Italy – right now, in 2017, there is a propensity towards wellness, materialism and consumerism, and these are considered the centre of the universe. Being well, making money and having fun are central aspects. These are the most important things in the lives of people and they also provoke the problems that I spoke about earlier and which we all know. Too much importance is given to futile things, the consequence of which is that people concentrate on wellbeing, consumerism, materialism, leading them to lose sight of other aspects: the human aspect, the educational aspect, personal growth, empathy for others. These aspects don't exist anymore, or at least they're very difficult to find: very few people are able to understand what a person has inside. Very few people are able to go beyond physical appearance: today, physical appearance is the criteria with which people are measured. Everything is upside down. When you meet someone for the first time and as you get to know them, everything is based on physical appearance. Think about it.. if someone has a disability, they are practically condemned. However, this is an error: it's the central aspect on which our society is badly created. Today we give too much importance to physical appearance, putting emotional characteristics, character, the

interior, the spirit and what we have inside in second place. People think: “If I am physically attracted to a person, everything’s is fine. I can make do with their character, I can accept it”. This is a mistake. You should first see, instead, the emotional side, you should give more importance to emotions, how the person makes you feel, their character. The invisible aspects should be the important ones and if someone if attractive, you can adapt to a person’s physical appearance, even if you don’t like it. Our society is completely reversed: what you see is what counts. Even if one has a bad personality, it doesn’t mean anything; the important thing is that they are nice to look at. Racism, exclusion and lack of manners are all provoked, in my opinion, by this fundamental error on which society is based. Non-disabled people are not prepared by the media to see a disabled person because they are used to the media showing them a tall, handsome, blonde, sporty, muscular man. So, they see a disabled guy, in a wheelchair, tetraplegic or maybe a metre tall, and they react badly: they are afraid, they run away. This is the world in which we live today. At least, from my experience. Of course, there are some differences between countries, I’ve seen it for myself while travelling.

In which countries did you find less of the reversal that you’ve talked about?
For sure, northern European countries: Belgium, Holland, Norway, Sweden. In these countries I met an openness, a willingness and knowledge a lot greater than in Italy. In those countries, no problems are created if someone has a disability, they don’t discriminate if they appear very different to the standard. These differences between what happens here and what happens in northern Europe is due to the fact that the governments there are organised differently in those countries, and there is different knowledge. Here’s an example. Up until 15 years ago, middle and high school students were studying “civic education”. You went to school and you learned the constitution and the civil code. It was a way to learn to respect public matters. It was just as important as any other subject, even though there were only a few hours of lessons a week. It was extremely important, because through this subject, students were taught to respect civil rules and other people. Today, unfortunately, it has been abolished. I believe that was a disaster. You can see the results: public places are dirty and degraded because it is believed, being public property, that it doesn’t belong to anyone. But this is wrong: what is public belongs to everyone and you can’t ruin it, destroy it. I think the abolition of Civic Education as a subject was an act of social self-destruction. The example I just gave is related to what I said before concerning disability: if you ask me, the relationship between who lives with a disability and who doesn’t is a reflection of society and changes according to that same society. If you learn to respect public property, you learn to have basic respect for the people who live in a different situation to the majority and live with more difficulty, compared to most people. We see that when there is a lack of respect for things belonging to everyone, the world goes in a dangerous direction. It’s very sad.

Just now you said the relationship between people who live with a disability and those who don’t is a reflection of society. Based on your experience as a computer technician at the University of Bologna, do you think this relationship develops differently within a university environment compared to outside of it?
Personally, I’ve never had negative experiences in the university environment, neither with teachers and colleagues nor with students with whom I’ve interacted with through

work. However, I’d like to say something else on this topic. I see a lot of students with disabilities that come here to study, I see them passing in the corridor or maybe I see them in the centre of Bologna. I don’t see more integration amongst universities, I don’t see more integration within the university compared to outside of it. A wheelchaired student who comes to the University is all alone. They might be accompanied by a parent, a friend or a tutor, but in the end they are alone. Let’s say they come to do an exam; they wait among 50 other students. The other students don’t treat them badly, don’t ignore them, don’t make fun of them and don’t exclude them. Yet I see indifference because everyone is going about their business without involving others. I see this indifference, I feel it, I sense it in the university environment as well.

Do you believe that the work the University of Bologna is doing to promote the right to study and the inclusion of disabled people is enough? What could be improved?
There are some very positive things. Most of the architectural barriers in the university locations in which I’ve been have been removed. They check and find a way to make classrooms, study rooms and libraries accessible to any type of disability. Nearly all disabled people, even if not all, can autonomously go to these places, study, go to professor’s visiting hours, attend workshops, just go about their university life autonomously. From this point of view, they are doing enough. However, I think the university should improve the integration of abled and disabled people and it should be done from relational and connective standpoints. There should be organised initiatives, occasions to meet, also outside of scheduled lessons, for example in the evening. Within the university there are great procedures on both legal and infrastructure levels, but more could be done through initiatives like the ones I’ve described.

Have you ever been discriminated against by someone who, conversely, wanted to help you?
Thinking about it, I don’t think so. Let me tell you, I always appreciate those who are willing to give me a hand, who wants to help me even doing little things. From memory, no, I’ve never had such an experience.

In general, what is the behaviour which, independently of the inclusive intentions of those who adopt them, can make a disabled person feel discriminated against?
I’ll tell you the truth. I cannot answer this question because it’s very subjective. It depends on subjective experience and each one of us reacts in a different way. It has never happened to me and I can’t say what circumstances or behaviour could make another person feel discriminated against. I don’t want to answer for others.

Starting from the experiences that we have talked about and the reflections that have emerged during this interview, what practical guidance, what “user guide” do you think you could give to people who do not have a disability so that relationships between those with and without disabilities improve, to the benefit of society as a whole?
The main issue is to not to be afraid, don’t run away from what surfaces from our ideas of normality. Most people without disabilities, and in particular young people, run away when they encounter someone or something which is outside their world. Luckily, not everybody is like this, but many have this reaction of fear. I think we should try to challenge ourselves, to not be afraid to experiment, to meet people with a disability and

not consider them a burden on society. Challenging yourself undoubtedly involves sacrifice, but it's the only "user guide" I feel I can give.

On a practical level, concretely, what does "challenging yourself" mean to you? How can we "challenge ourselves"?
This could be an example. If there was an initiative like the ones I spoke to you about earlier, people should go, they should participate, rather than choose to do something else or stay at home. Disability is a different reality for the majority of people, but this isn't a reason to see it as a problem. Challenging yourself is needed for this. It's the crux. In challenging yourself, everyone can understand that people with disabilities have bodies with certain characteristics, but it's not their body. Until now I haven't taken part in any such initiatives within the University because I wanted to see how they evolved first, but I intend to take part in the next ones to be organised. Challenging yourself and getting involved can be done in many ways. For example, a few friends and I are organising a football school for people with disabilities. These types of organisations are already active in Turin and in other places, and we are trying to set up a similar organisation here in Bologna. It's an ambitious project and it's difficult to achieve. We're making good progress and we hope to start by September. We have already contacted a group of people, who in my opinion are very knowledgeable and will follow a training course in Turin on the theme of disability in relation to sport. Then, after these courses, we'll start the real activities. I think this is a great idea. In fact, through football there will be a direct relationship between the person with the disability, the instructor, the coach and the psychologist. So what we create is a twofold opportunity of comparison and reciprocal awareness between those with disabilities and those without. This is the way, I think, you create friendships, connections. Through sport, a relationship between those with and without disabilities is created, and in my opinion, it's extraordinary. Challenging yourself is really seizing the opportunity of this personal relationship, breaking society-created taboos. Disability doesn't have to be a problem. A disabled person can do everything that other people can, even if, clearly, they do it in another way. They come at it from another angle. A disabled person can go to the pub, drive a car, work. I even had a day trip in a submarine. A disabled person can fall in love as well. But too often modern society thinks that disabled people can't do any of these things. It's up to us to break these taboos.

A lot of projects on disability have this goal, even if their extent and modalities are different. This project is no exception. I wanted to ask you, do you think this project is useful and in what way could it be improved?
I think it's very positive, very valid and I like it. It seems very useful to me because it's like a planted seed. A superficial reader will probably not understand all the aspects that emerge from the experiences of the various participants in this project, but it will allow more sensitive readers to understand disability better. When it comes to improvements to this project, I wouldn't know what to tell you. The important thing is doing it. A project that doesn't begin doesn't make mistakes, but does leave things the way they are. The most important thing, the basis, is to do something.

In general terms, also apart from this project, do you think it's possible to improve disabled people's situations both inside and outside of the university?

The initiatives that I spoke about before, which I think should be held outside of scheduled lessons, could be a start. Otherwise, I think the CUSB (Bologna University Sports Centre) could organize communal sporting events between abled and disabled people. My aim is integration. I believe integration is bringing together both abled and disabled people, and I think these kinds of projects help integration both inside and outside the University.

Is there anything else you wish to talk about regarding this interview?
The idea of gathering experiences of different disabled people in a book is a very good idea and could be very helpful in understanding better the problems that we have spoken about. Try to finish this project, to spread and to publish the testimonies that you collect. It’s important to make it known to as many people as possible.

Thank you very much for your time, your words and your support. In the future, could I contact you again for possible clarifications and analysis, or to ask you other questions on this subject?
Yes, of course. Thank you.

My story

Giulia Baraldi
Educator in Childhood Social Services student, University of Bologna

Translated by Nicola Bardasi

My name is Giulia and I'm 22 years old. My passion has always been dancing, and my dream was to become the prima ballerina at La Scala in Milan. Over time, however, I realized that my path was not this but another, namely, to become a kindergarten or primary school teacher. Now I'd like to tell you my story.

It all started when I was in ninth grade. I was attending high school at the Classical High School in Mirandola and at the same time I was dancing at a competitive level. I also had a dance audition to enter the Balletto di Toscana and I won a scholarship, which consisted of attending the dance academy for a year. It was a dream for me, but then I realized that dance wouldn't be my future. In that year, I failed my first year at High school and I blamed it on dancing, considering that I studied very little because I did too many hours of dance classes.

In 2010-2011, I repeated the year at the Classical High School, but then I realized that was not the school for me because I had difficulty studying, especially Greek and Latin. So I enrolled in the Humanities High School, in Finale Emilia. In 2012, there was an earthquake in my hometown and in the neighbouring ones and consequently the school year ended on the 20th of May

On the night of the 20th of May, I was shocked. I started to hear all the vases falling, the house shaking, that indescribable sound that came from underground. It was like the ground had split in half and we had fallen into a ravine. For a week my parents and I slept in the car, because I was terrified, but on Monday, my mum went back to work and then we all returned home to sleep, even though I was not yet convinced about coming back home. On the morning of the 29th of May, my mum went to work, my dad went out and I stayed in bed. At nine o'clock in the morning, there was another tremor: it began quietly and then became more and more intense. I couldn't stand up and I fell down the stairs. For two and a half months, I couldn't go back home. I was shocked. Unfortunately, because the school year had finished early, I failed the year for the second time. I was devastated because I really didn't expect it. The following year I repeated tenth grade in Finale Emilia.

At the end of the school year 2012/2013, my psychology teacher called me aside during the handing out of the report cards. She told me and my mum that in her and other teachers' opinion, there was something wrong with me, because I had failed, even though that year I had stopped dancing and I had studied a lot.

I didn't understand right away and I felt terrible about it. I thought I didn't have any problem and I had always given my all. At the end of June, my mum made an appointment with a psychologist who made me do a lot of tests. I didn't immediately understand why he made me do them, then I understood why. I was diagnosed as suffering from a learning disability at the age of 19. At first, I couldn't accept this diagnosis because I was wondering, "What the hell does that mean? Learning disability? Am I handicapped? Why hasn't anyone noticed this before?". That day I wanted to run away, I felt so bad that I started crying, without telling anyone about my "huge" problem.

I started the twelfth grade and I learned that there were two classmates of mine who had been previously diagnosed as having a learning disability. So I felt relieved, because I realized I wasn't alone, and in the meantime, I started to learn more about what a learning disability really meant.

When written tests and oral exams began, I asked two of my classmates if they wanted to take the oral exam on a particular day, as agreed with the teacher – they replied no. Quietly, without saying anything to anyone, I went to the teacher to ask her if would be okay for her to let me take the oral exam that day. It wasn't a problem for the teacher. I didn't tell the rest of the class about this agreement between me and her, because they didn't know I had been diagnosed as suffering from a learning disability yet. When I got home, I realized that, even though I don't know how and why, all my classmates had found out that I had been diagnosed with a learning disability. I received a lot of messages, especially in the class WhatsApp group, which were really more insults than messages. They started to tell me, "You take advantage of your situation", "You are a childish person", "You're older than us and you're acting like a child".

From that day on, I didn't want to go to school. When I entered the classroom, it was as if I couldn't breathe and time stopped for five hours. Those hours at school were hell for me. Every time I got into class, my classmates teased me, they threw my schoolbooks on the floor, they threatened me. For example, when I stayed home from school because I was sick, they texted me that I had to go to school to take an oral exam or a test. The problem was that I was alone against the whole class and so I suffered, I suffered, and I suffered. I was so helpless that I didn't even have the strength to react. I would cry when I got home, I refused to do my homework and, above all, I didn't want to go to school anymore. I told my parents everything and they went to talk to the psychology teacher and the headmaster. Initially, the psychology teacher was very disappointed, because in a class of Humanities students, they should have had a bit of sensitivity towards people who have difficulties, but in this case, it was not so. I also became the victim of cyberbullying, on the Internet and in particular on social networks.

I started going to Modena to the afterschool centre SOS DISLESSIA, where young people with learning disabilities are helped to do their homework. To go to Modena, I had to leave school early once a week. I really liked going to the afterschool centre because in the first half hour, we sat in a circle and started talking about our difficulties with our homework, with our classmates, with exams, with the teachers, and then we started doing our homework. Going to this centre, I realized that there were other people who had the same problem as me. We were in the same boat, and so we comforted each other. Not only my classmates but also some teachers criticized me heavily and humiliated me in front of the whole class. For example, I remember that one day I had done an English test and when the teacher handed it to me she said: "If you copy, you should copy the verbs well too" and she had put a nice 2 on it [an extremely low mark] and she had also written "cheated" on the page. On that occasion, my parents got very angry and went directly to the headmaster. Unfortunately, however, that didn't solve much.

The final year of high school finally arrived. Around December of that year, I began to feel weak and to pass out. At first, I thought it was because of the stress and tension with the class. One day my parents took me to the Emergency Room, and I stayed overnight under observation. I was analysed and the doctors said I was anaemic. I told the doctor that I didn't feel well, I felt itchy everywhere, I had difficulty breathing, I had a fever in the evening, but he said to me: "In my opinion, you don't have anything. A 20-year-old girl can't be so depressed." He made me go to a psychiatrist. To him I was just crazy, even though I knew that psychologically I was actually fine. In January, I had an emergency CT scan, and from the X-rays you could see a very large sphere in the mediastinum: at that point I realized I had a tumour. Immediately they sent me for a biopsy, an examination that should have lasted about an hour and a half but actually lasted six hours of surgery and two days of intensive care.

It got complicated. In the vena cava, the doctors found a 3-centimetre-long clot, the right lung was no longer ventilating, and I had a heart problem, which was fortunately resolved over time. To take a blood sample from me, doctors began to pierce my feet because they couldn't touch my arms and hands. At first, I didn't know I had a tumour. The doctors told me that I had to do the biopsy because it was necessary to understand what type of mass this was, but I did not trust them. I secretly went on the Internet and I understood the diagnosis. My parents knew it too, but they didn't tell me anything. I stayed in the hospital for about three weeks, unaware of the CT scan diagnosis. In those weeks, I made friends with all the doctors and nurses in the hospital ward. The doctors and nurses were awesome! They were angels. They treated me like I was their daughter. They washed my hair and brought me food, until one morning a girl about my age arrived in the hospital and, fortunately, they put her in my room.

That day I made friends with this wonderful girl named Carlotta. We connected immediately, we gave each other advice, we comforted each other, we played cards, we made fun of the elderly people who were in the room with us, we joked around. I mean, we knew right from the start that there was a strong connection. Fortunately we live near each other, so even today we hear and see each other regularly. Carlotta instantly became like a sister to me.

One morning I went to the bathroom with my Dad to wash, because I had trouble doing it alone. I had a drain in me, morphine and lots of other needles. At a certain point, a doctor from the Thoracic Surgery hospital ward came and began to knock on the bathroom door shouting and saying to me, "Where are you?! I have news." I saw my father turn white. I sat down on the bed, my father was next to me and the doctor very loudly said to us: "See?! After three weeks of waiting, we have an answer! Okay, it's Hodgkin's lymphoma[25]. Now you can go to the oncology centre for treatment!". I looked at the professor, as everyone in that hospital ward called him, as if to say, "What is he saying?!" I looked at my father and I said, "What is it that I have?" and he started to explain to me that I had a tumour. That's when I started crying. I felt like I was living a nightmare. It's as if my whole life had collapsed at that moment. He explained what

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[25] Hodgkin's lymphoma is a tumour of the lymphatic system, i.e. of the cells and tissues that have the task of defending the body from external agents and diseases and ensuring proper circulation of fluids in the organism. There are two types of Hodgkin's lymphoma: the "classic" one (to which I refer in this paper) and the one called "non-Hodgkin". Classic Hodgkin's lymphoma mainly affects young people between 15 and 35 years of age and the elderly from 70 years of age and is 99% curable. This means that, at least in most cases, once the treatment has been completed, the tumour will not be reactivated. However, in the case of lymphoma known as "non-Hodgkin", with the passage of time there is often a recurrence, even if at first the tumour had not shown signs of activity immediately after treatment. In general, the two types of Hodgkin's lymphoma can cause an enlargement of the lymph nodes, fever that recurs constantly for weeks or months, night sweats, weight loss and itching throughout the body. In addition, it is important not to neglect sensations such as fatigue and lack of appetite. If the disease particularly affects the lymph nodes in the chest, coughing, chest pain and difficulty breathing may also occur.

type of tumour it was, where it was, and we did some research on the Internet about it. My Dad tried to comfort me, telling me that this kind of tumour is 99% curable. From that moment on, I stopped crying and I said: “Okay! Now I have to bring out all the determination I have in me and I absolutely have to beat it! So the sooner we start, the sooner we finish!”. I was transferred to another hospital and I stayed there for a week. In the meantime, I met my haematologist, who started to explain to me how chemotherapy works. He told me all the side effects that the therapy could cause – nausea, vomiting, hair loss. When he said “hair loss”, I broke down and cried. I absolutely didn’t want to lose my hair because, inside, I told myself that I had to beat it, that I would be strong and therefore my hair would withstand it too.

On the 27th of January 2016, I started chemo. The night before, I couldn’t sleep for the fear; when that morning came, I wanted to run away. During the treatment, I ate – I was always hungry: to comfort myself I ate a brioche with a cappuccino, after an hour or so I ate some cookies, and two hours later it was lunchtime. To distract myself, I ate. When I finally got home, after a month in hospital, I immediately went to buy a wig, because for me losing my hair was a shock.

When I started chemotherapy, I started a countdown of the cycles because I wanted this nightmare to finish soon. The treatment consisted of six cycles. Each cycle consisted of two sessions and, therefore, in total there were twelve sessions. I started to vomit and feel sick at the end of the sessions: over time I began to feel the burden of the therapy on my body. On a positive note, my blood tests were always perfect before treatment. If they hadn’t been, I would have skipped the chemo session and I would have had injections to increase the number of white blood cells. During the sessions that I had, I met many people with whom I am still in contact today. I also met another girl who had Hodgkin’s lymphoma.

She was always negative. Every time she had treatment, she locked herself in her room and for weeks she didn’t go out and didn’t see anyone. I always gave her some advice – for example, I told her that she had to go out. I was completely the opposite. When I finished chemo, I went to have a drink with my friends, or I went to the disco and danced. I used to go out with a mask, and I didn’t care if people looked at me badly or criticized me. I went out and I said to myself: “If it bothers people to see me with a mask, it’s not my problem, because I’m not hurting anyone!”. Other people would say, “I envy you!” or “You’re an example to imitate!” or “My God, how can you have all this strength?”. I sometimes didn’t know how to answer these circumstantial questions, which were often asked in an attempt to find the right words to address me. It was a new and critical situation for everyone.

At the end of the chemo cycle, I had a CT and PET scan in preparation for the radiation therapy, but unfortunately the PET didn’t give a completely positive result. Even though I had a very good response mid-cycle with a CT scan because at that moment the mass had been reduced by more than half, the mass had not been reduced in the last CT. The doctors moved me to another hospital and there I started the second type of chemo. It was a very tough therapy. Once every three weeks, but for four days in a row. While I was undergoing this treatment, I had to go to the hospital at 7 am and I came back home at 8 pm on all four days. I had to have twenty IV’s of chemotherapy.

After the first cycle, I lost my hair. One Sunday I realized it was time to cut it off because I only had a few strands left. That Sunday, my dad shaved the rest off with a razor. At that moment, it was a very strange feeling. I went to my grandparents to eat and they said, “You look really nice!” From that day on, I went out without a wig or scarf. I took a makeup class and I went out without a wig, wearing makeup and using my mask. I really liked it! People looked at me, but I didn't care what they said or thought. At the end of the cycle, I retook my CT and PET, but the mass remained the same size. My haematologist gave me medication to take once every three weeks, but after half a cycle of that treatment, she had to suspend it because the mass was increasing. The last option was a transplant. However, before doing either bone marrow or autologous transplantation, the haematologist wanted me to go to the sterile room with the best possible chance, i.e. with a dead lymphoma or, at least, with a lymphoma reduced as much as possible. The only solution, therefore, would be to take another type of drug, other than those used in chemotherapy, to reduce the mass. Unfortunately, due to a protocol, that drug could only be used after the transplant had been carried out, but the haematologist wanted to use it on me before then. She called over almost all of Italy and abroad to ask if there were any new protocols, but unfortunately, they were all the same as those already in existence.

The haematologist asked me if I agreed to apply to the European Commission to have permission to use the drug. I said, "Absolutely! I'll do anything to get better". Sunday the 2nd of April 2017 was a special day because two important things happened to me. I met Cécile Kyenge and asked her if she could somehow get me that medicine because it was very important to me. She asked me, "What's your name, what's your doctor's name, and what hospital do you go to?" I told her and she said to me, "I can't promise you anything, but I'll do everything I can to get it for you!". When she left, a girl came up to me and interviewed me and the next day I saw the interview published in *Il Resto del Carlino* [a Bolognese daily newspaper, editor's note]. The same day, the Pope came to visit Mirandola and all the cities damaged by the 2012 earthquake. I went to Mirandola, and after the Pope's mass, I was blessed by him. When I saw him in front of me, I began to cry because the emotion was so strong that I could hardly believe what was happening to me. That day was intense because I interacted with two people who I admire very much.

The following Tuesday, I received a call from my doctor, who said, "I have news for you!" I immediately thought, "Oh, my God! The drug has been rejected". The haematologist, on the contrary, said to me: "Yesterday, that is Monday, the drug was approved. But when I got the answer, I was given a letter informing me of the approval of a new drug with the same active ingredient as the other but which has been developed specifically to be taken before a transplant. Yesterday in the afternoon I re-sent all the paperwork to get this new drug and today the approval has come through! You will be the first person in Italy to use this drug." I was immediately amazed because I didn't expect it. I think, in the end, nothing happens by chance: Cécile Kyenge, the Pope, the new drug. I thought to myself: "Kyenge managed to get the drug approved! Surely the Pope's blessing also helped! There's no such thing as coincidence!". I started taking the medication and I'm still taking it today. The therapy lasts 30 minutes and I do it every three weeks. It doesn't affect me at all, except that it makes me sleep a lot. I sleep, sleep and sleep. After four cycles of this drug, I had a CT scan and finally, after a year, I had some good news: the mass had reduced by more than half.

In the meantime, I went to talk to the director of the transplant centre, who explained to me what entering the data bank as a bone marrow receiver entailed and did some special tests. A week later, a letter arrived at my house informing me that the centre was looking for a compatible donor.

After three months, we still haven’t found a donor. A week ago, my parents were called by my doctor to find out if they were willing to donate bone marrow to me, compatibility permitting. Monday the 4th of September 2017, the analyses will be carried out...

I don’t know what’s going to happen in the future. The only thing I know for sure at the moment is that I’m going to have the bone marrow transplant. I’m afraid of the future because you never know what life throws your way.

However, I do have a motto that I always carry with me. It’s a phrase by Daniel Pennac which says: “It’s just when you think it’s all over that it all begins”. This phrase really mirrors me a lot, because when you are faced with serious difficulties in life, you have to face them, you have to fight. Maybe sometimes life puts these tests in front of us just to make us stronger. My life has changed in three years, both psychologically and physically. Life puts different obstacles in front of me every day: first dyslexia, now lymphoma. I believe that, as I have written, nothing happens by chance.

Physical (and then also psychological) disadvantages

Anonymous
School of Arts, Humanities, and Cultural Heritage professor, University of Bologna

Translated by Nicola Bardasi

The person writing these lines is a teacher at the Alma Mater Studiorum, the University of Bologna. The "disadvantage" that will be discussed here consists of a deficit in the neurological centres of balance which results in difficulty going down the stairs without strong support at least on one side (in some cases on both sides), in strong discomfort with relative hesitation in situations where there are contiguous empty spaces to cross/go through, and possible and more or less influential imbalances in the transition from sitting to standing position. A disorder, not a disability in the strict sense of the word, but a condition which anyway requires maximum assistance and support while travelling by train or plane.

This lack of equilibrium and stability leads, above all, to considerable discomfort in social relations, when the interlocutors are not willing to believe (accept?) that they are not faced with banal psychological "blues".

At a professional level, at present, it can cause temporary problems in the management of teaching activities during the two hours of class. However, students have never shown signs of impatience or misunderstanding, so now the problem, basically, does not arise.

However, in previous years it has arisen in a heavy and substantially unfair manner. I would like to focus my attention on this, even if I have only the knowledge of my personal experience and I have never had to face other similar motor or neurological problems.

Even this situation of "disadvantage" can meet with resistance, refusal, minimization and even contemptuous manners in work situations in which maximum efficiency and a strong competitive spirit would be required. I have omitted to point out that the problem we are talking about can make it more difficult to access high places or places accessed by rather steep stairways, in the absence of lifts. The effects on intellectual activity in the broadest sense are absolutely zero or non-existent, not even vaguely hypothetical.

So, again, the problem should not arise. Perhaps it is not necessary to recall the general conditions in which the (usually long) periods of precariousness in the world of university research and teaching take place: many physical realities (and many others of a different nature) can become reasons for penalization, stigmatization, underestimation and ultimately for marginalization.

It is a problem related to the residual arbitrary and personal factors which regulate the long period of waiting, even in these times of national qualifications and "arithmetic" competitions. Some people go so far as to suggest suspending or cancelling the benefit of scholarships and checks, while others even consider the probable mental alienation of the subject in question.

Let me be clear: reactions of this kind end up falling apart most of the time in the face of objective, impersonal evaluations about the curricula. So, after all, much ado (and gossip) about nothing. However, we should perhaps think that equal opportunities also consist of full integration and targeted facilitation of all the (documentable) “disadvantages” that could render the normal activity of research and teaching – which can involve sudden changes and the use of spaces that are not always suitably “equipped” – slower, more difficult and ultimately frightening, especially when it concerns an activity, often solitary, whose results are often measured in an inaccurate way and must be carried out in a determined lapse of time, sometimes agreed with by various institutions.

I repeat: at a “certain point” the problem no longer exists and is indeed universally understood. However, this is not the case if we do not find ourselves dealing with shrewd, objective, informed and, above all, fair managers, in particular during the period in which a visible “ healthy and robust physique” represents a criterion for inclusion and advancement tacitly pushed to the top of the evaluation grids. Very few people are aware that the writer of this piece asked for assistance in the case of travel by train or by plane: now it can be common knowledge – end of problem… but are we sure that we must be forced to hide it (and therefore to travel “outside of the group” or not travel in groups of colleagues) so as to avoid possible rejection, often hastened by the anxiety to reduce the ranks of aspiring academics? Are we sure that the “healthy and robust physique”, beyond the psychophysical ability to carry out the tasks requested by the position and the contract, is still a requirement to be understood in an integral, inflexible sense? For many, this rhetorical question will open a door, but maybe some temporary worker (of either sex) or in other precarious positions within the University structure will relate to these considerations about so many penalizing implications that can (but shouldn’t) appear on the horizon of a career carried out in a serious, productive and correct way. And we have to say it clearly when discussing the “real” academic life involving dozens and dozens of people who work in a precarious situation.

A learning curve

Simona Fabiola Girneata
Anthropology, Religions and Oriental Civilizations student, University of Bologna

Translated by Eleonora Perugini

I would like to start this brief story with a foreword about an event from my childhood before talking about an experience I find particularly important for my growth: the non-profit association "Accaparlante".

My first "encounter" with "disability" was at the age of six. It was my first day of school. While I was climbing the huge stairs of that grey building, the walls covered with colourful posters and paper flowers, I felt my heart beating fast. I was excited and nervous, and I couldn't stop myself from running, still holding my mother's hand. She tried to calm me down, but I couldn't help it: I was fidgeting. Suddenly my enthusiasm faded to make room for curiosity about a girl whose name was Elisa. She was wearing a red headband like mine, but she was going up the huge stairs in a strange way: to one side, far from the other children, on a kind of "service elevator" because she was sitting in a wheelchair. She too was holding her mother's hand, but with less excitement and a numb expression on her face as her mother accompanied her slowly to the classroom.

The following day Elisa changed classrooms to the ground floor for reasons I could not wrap my head around at the time.

That is the reason why I never had the possibility to become friends with that girl who is still a vivid memory of my first day of school.

That wasn't my only experience with "disability" because during my high school period, there was a boy in my classroom who was considered "autistic". Our communication was limited, but I was sure he understood what I was telling him, especially when I used to offer him strawberry-flavoured sweets. He was often out of the classroom or absent from school, so our friendship was fleeting.

Consequently, I had never had a true experience of what "disability" means. Nobody had explained it to me, and I had always thought it was something utterly distant from me and my life. I had thought that the words "disability" or "disabled" should have been pronounced as a whisper in order not to offend anybody. That was what I had thought until last year. At my university, I had the chance to take part in an initiative about "disability". It was an experimental workshop organized by an association in Bologna called "Accaparlante", which aimed to attract interest and inform students about disability, diversity and disadvantages. I still had the same curiosity and desire to understand as fourteen years earlier on my first day of school. I wanted to finally be part of this initiative, so I rushed to sign up with my friends. Having a quick sandwich in via Petroni, opinions and expectations went back and forth between us, along with questions as to what types of activities we might do.

The evening of the workshop arrived quite soon, and I had previously made plans with my friends to see each other a few minutes before the workshop to go in together. Since "punctuality" is not one of my virtues, I arrived late and realized my friends had already entered the building. I entered hesitantly into the sixth classroom of 38 via Zamboni, in which the meeting was to take place. Since I knew the arrangement of the chairs, I decided to enter through the last door so as not to disturb the other students who had already arrived and were surely involved in the explanations of the activities, facing the teacher's desk. Unfortunately, despite my other gifts, I definitely don't have the ability to predict the future, which is why I found myself inside a huge circle of people: not the usual seating arrangement. As you've probably already understood, I'm not only a chronic latecomer but I'm also very clumsy, so, overcome with embarrassment and thinking that everyone was staring at me, I tried to look for my friends or at least for a free chair on which to hide myself quickly.

Later, I realized that my colleagues' eyes were actually looking at something else. I breathed a sigh of relief and pondered what could be so strange or interesting to watch that everyone was completely ignoring what else was happening in the classroom. Turning my gaze in the same direction, I saw three people sitting on wheelchairs. The first one was quiet, even if we should define what "quiet" really means because all three of them were very talkative, especially the oldest who was the typical "Don Giovanni" with "*savoir faire*" towards the girls in the room. The second one was a girl who had difficulties communicating with respect to the other two, but she wasn't intimidated by this. In fact, during the brainstorming activity, we wrote forty words on blackboards and fifteen of those were thought of by her. Seeing her made me remember my first day of school, which was why I was looking at her for the rest of the evening. By their side there were some people who worked for their association. I was curious and fascinated by their friendly, happy way of being. I was looking forward to starting the activities and to opening my mind to a new world. I finally had the possibility to speak, ask and see first-hand, without any filters, fears or righteousness.

The activity started with a few presentations: a joyful moment which let the preconceptions dissipate. From that moment, "we" or "they" became "a group of people working together".

We kept brainstorming: a moment of sharing to get to know each other, a moment in which, through talking and laughing, we were giving true meanings to all those big words such as "disability", "Down syndrome", "handicap" and "different".

While on the one hand I found the discussion a way to start my own important reflection on ideas such as how we take many things for granted in our daily lives, when the practical part started, my reflections turned into reality because someone else's difficulties and fears became mine, and I could feel the latter to the core.

What we had to do next was actually very simple, so for this reason I immediately volunteered. For the activity, I had to ask to one of my colleagues, who had been sent out of the room, to turn off the lights. The only difficulty was that I had to stay still on my chair, without talking.

I sat down and the exercise began. At the beginning I thought it was a simple game, but frozen still on that chair I began to feel as if the chair itself was becoming an integral part of me, like a hand or a foot. After ten seconds, I started to see my body shaking and I tried to find a way to stop myself from doing so – me, who usually uses all her body to communicate. Everybody kept telling me to stay still and not to talk. I was starting to feel awkward. Not being able to use my body felt odd: I felt as if it wasn't mine, as if it was there but was useless. I started to get angry with myself: I moved my finger, I shook my head, I wrinkled my nose to communicate to turn off the lights, I puffed out my cheeks because I was nervous, my lips were closed to avoid talking. Staying still is the easiest thing in the world but in that moment, I couldn't do it.

When my colleague came back into the room, I started to panic. "What if he doesn't understand?", I thought. My task here was simply to ask him, without using the words, to turn off the lights, but what if I had actually felt sick? How could I have explained it to him? I was terrified of not being understood. It wasn't a game anymore; it was something more real. Everything we had talked about, the preparatory exercises and the context, before that moment let me experience something unique and profound. It wasn't a simulation. I felt the fear: the real fear, to the pit of my stomach.

Suddenly I noticed that my colleague, much more relaxed and calmer than me, was trying to create a code to communicate. "Genius!" I thought, and immediately felt relieved. I understood that collaborating with him by creating the code would have helped me. In fact, he understood he had to turn off the lights, to my great satisfaction. I had managed to communicate, and was also able to manage my body better. Finally, I relaxed, and the initial fear went away.

I had never thought I could have experienced something so intense in such a context. I had thought it would have been a theoretical discussion and nothing more. From the moment I entered the room until I left, it had been a surprise. I left the room aware that my way of seeing the world still needed to change and develop itself. I understood the dependence I have on my body, and that in reality, more often it takes command of me rather than the other way around.

I had had a vivid encounter with disability, and although it may seem banal or exaggerated to say so, in those ten minutes, I had been living with a disability, feeling as the disabled feel every day.

That glass case had finally been shattered – everything was closer and more tangible.

I left emotional but happy. I hope this experience will become a regular occurrence so that all Alma Mater students can take part, because it's not just a theoretical or academic workshop, it's a learning curve.

APPENDIX

Project presentation letter

(forwarded by the Disability/SLD Student Service)

Translated by Zazie Alberta Piva

Dear students,

I'm writing to you as your disability advisor for the School of Arts, Humanities and Cultural Heritage with regards to a project developed with the support of the School's Vice Presidency.

The project consists of a collection of short essays written by university students, alumni, faculty and administrative staff who share a condition of disability.

These contributions should constitute somewhat of a "user's guide" written by people with disabilities and addressed to the university community as a whole. In fact, in many cases, when encountering someone with a disability, the behaviour of a person who has never experienced it is characterized by embarrassment, inability to act and the fear of hurting the feelings of those living with such a condition. The collected essays are intended to contribute usefully to overcoming this embarrassment, in the belief that also thanks to this an improvement in social relations will emerge, from which we can all benefit.

Participation in the project is open to anyone, regardless of their degree, who would like to share with readers their experiences from their university career or from their work life.

The idea for this anthology came from a discussion among students and professors of the Master's degree in Cultural Anthropology and Ethnology and has a close link with anthropologists' disciplinary inclination to "put themselves in other people's shoes", therefore conferring special significance to experience and its narration. It is precisely the element of experience along with its narrative dimension which should ideally create a common thread uniting the essays which, as the result of a creative and personal process by the participants, will no doubt be heterogeneous.

As regards content – given that all the participants have been totally free to choose the themes of their papers and the approach to them – the essays should focus particularly on the writers' experience of interpersonal interactions. There are two reasons for the emphasis placed on this issue. Firstly, it derives from the idea that disability is not a category that should be assumed as a fact, but rather as a condition largely influenced by the environment in which it takes place and by the fact that interpersonal relationships play a fundamental role in this context. Secondly, choosing to devote special attention to the relationship aspect is connected to the desire not to fall into descriptions centred too much on what is considered "normal" or "having to be a certain way", but rather to give relevance to aspects that might apparently be of little importance but are in fact rich in meaning for the individual actually living through them.

The contributions will make a collective volume, which could become highly recommended, though not required, reading within the bibliography of some of the courses taught at the University of Bologna.

Those who contribute to the project will be guaranteed anonymity, should they so wish[26]. Furthermore, any details which could enable identification and violate privacy rights will be modified.
To voice opinions and suggestions, participate in the project or ask for any kind of information or clarification, you can contact me at cristiana.natali@unibo.it.

Thank you for your consideration.
Kind regards,
Cristiana Natali

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[26] Upon publication, many authors preferred to use their name.

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by Nicola Bardasi

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The authors

Anonymous: Professor at the School of Arts, Humanities, and Cultural Heritage at the University of Bologna

Anonymous: student of the Single Cycle Degree in Veterinary Medicine at the University of Bologna

Cecilia Bacconi: student of the First Cycle Degree in Nursing at the University of Bologna

Giulia Baraldi: student of the First Cycle Degree in Educator in Childhood Social Services at the University of Bologna

Nicola Bardasi: graduate in the Second Cycle Degree in Cultural Anthropology and Ethnology at the University of Bologna

Maria Paola Chiaverini: graduate in Modern Literature at the University of Bologna

Matteo Corvino: intern at the University of Bologna

Luca Gioacchino De Sandoli: former intern at the University of Bologna

Enrico Franceschi: graduate in the Second Cycle Degree in Cultural Anthropology and Ethnology, and an employee at the University of Bologna

Fabiola Girneata: student of the First Cycle Degree in Anthropology, Religions, Oriental Civilizations at the University of Bologna

Luca Mozzachiodi: doctoral candidate in Literary and Philological Cultures at the University of Bologna

Francesco Musolesi: employee at the University of Bologna

Cristiana Natali: professor of Cultural Anthropology and Methodologies of Ethnographic Research at the University of Bologna

Francesco Nurra: student of the Second Cycle Degree in History and Oriental Studies at the University of Bologna

Jennifer Pallotta: student of the Second Cycle Degree in Biodiversity and Evolution at the University of Bologna

Rocco Pessolano: student of the Second Cycle Degree in Cultural Anthropology and Ethnology at the University of Bologna

Michela Ricci Malerbi: student of the Single Cycle Degree in Pharmacy at the University of Bologna