

Introduction. How this book came to be.

The idea of a publication concerning ASD (Autistic Spectrum Disorders) was an immediate result of my diagnosis and the motivations are numerous.

First of all, the need to formalise my knowledge in a particular field, something I have always done and which has led me, over the years, to publish many books and articles on a variety of topics, to the extent that it has become an integral part of my professional activity.

Then there is my awareness of the vastness of the autistic spectrum umbrella and the importance, therefore, that those with highly functioning ASD describe their lives, their experience and, especially, their survival strategies.

Personally, I consider it a duty, particularly towards people with ASD who have great problems expressing themselves and therefore have problems describing the difficulties, misunderstandings, frustrations and needs that they encounter on a daily basis.

We must, nonetheless, be careful how we express ourselves, considering the prejudice and lack of awareness that are still rife, even among people who work in this field (so we can imagine those who do not), concerning the real significance of a diagnosis of ASD and the enormous range of disorders that come under this umbrella, that puts together in a single classification people who are so very different from each other, but who have in common this very different perception of reality.

The word autism is almost always associated with an image of a solitary child, or the character from the movie *Rain Man* and people cannot conceive the idea that a trained professional, a company manager, a state employee, a university professor or a scientist can be among those who have been diagnosed with ASD.

Another aim and ambition of this book is to eliminate this typical misconception.

Neurotypical people must become aware of the fact that not only are there different races of people, but that there are also people who function differently in their way of thinking and interacting with others. People for whom communication (in itself rather lacking) is based more on the content of the message than on the intonation or the (unwitting) body language. People for whom the eyes are not the mirror of the soul, as they may not even be looking at the person they are talking to. People who are not judging you or refusing you simply because they stare at you with their arms crossed. These are all factors which often lead to serious misunderstandings.

These diversities are a source of wealth and as such should be cherished and enhanced.

Autistic people by way of birth “see things differently” and for this reason they are often misunderstood; nonetheless, if they are suitably guided, supported and motivated they can use their peculiarities very much to their advantage.

I have turned them into a plus in my numerous professional activities.

Steve Jobs, in his “Think Different” campaign applauded people who see things differently, because they are the ones who can change the world. Hans Asperger, too, as Tony Attwood reports in his book “The Complete Guide to Asperger’s Syndrome”, considered that: “It seems that for success in science or art a dash of autism is essential.

For success the necessary ingredient may be an ability to turn away from the everyday world, from the simply practical, an ability to re-think a subject with originality so as to create in new untrodden ways, with all abilities canalised into the one specialty.”

I am not saying that living with autism is easy: there is no lack of difficulties. In particular, the inability to interact “properly” with other people, the misunderstandings, the sense of exclusion, the feeling of being thrown into a world that you don’t belong to, not knowing what is the right thing to do (therefore not doing anything). Sometimes I watch the scene of a movie, observe the behaviour and I think, “Oh, so that’s how other people behave.”

It would be very convenient to be able to enhance characteristics that result in a positive outcome and to temper those that could have negative consequences, but this is actually true for all people. The difference is probably that we are not really aware of those that could have negative consequences unless they are explicitly pointed out to us (in words).

Publishing something is always a challenge for me and this is the first time I have written a book not about what I think, but about how I think. But then, all my life has been a challenge, constantly pushing beyond the limits whose existence I’m constantly conscious.

I have always been aware of the fact that I am unable to do the same things as other people (play ball, pass university exams, create relationships...); this is why I have always tried to do better than other people, usually going a different way about it, as traditional methods are out of the question.

Autistic people are often slow to understand and respond, as they are overwhelmed by an excess of information from the surrounding environment (unlike neurotypicals, this information is processed consciously). In fact, the very distinct intellectual abilities of these people are most evident when, even in a crowd, they manage to isolate themselves into their own world.

I would instinctively compare us to snails or tortoises; it is curious that both these “slow” animals have another aspect in common with autistic people: a shell they can withdraw into.

These differences, which I have always perceived, through diagnosis now have a name.

A name, not a solution, which, for that matter, I have never wanted or looked for, as I have always spoken out for emphasising differences rather than toning them down, trying to enhance as much as possible the peculiarities that nature has given me (a strategy that is decidedly different from those who try to adapt to the neurotypical way of doing things in order to attempt to fit in, to survive).

My diagnosis has enabled me to discover a whole new world, different ways of being (that up to then I had only sensed), totally different from mine and that, in all honesty, attract me less than ever. There are too many characteristics of the so-called neurotypicals that leave me bewildered, lost. First and foremost, the ease with which they lie, white lies, they say, so as not to wound, to strike a happy medium... Something that I consider ethically and morally unacceptable. Not to mention the tidal wave of information that comes across in non-verbal language, or the emotions and feelings that, they say, empower the rest of humanity with empathy.

I owe what I have to my wife, essentially, my only point of contact with reality, and if not for her I would probably stay locked up in my world, coming out every so often to experiment, with an uncertain outcome, some sort of interaction with the rest of humanity.

“Autistic children, if allowed to do what they want, will stay in their own little world,” writes Temple Grandin in *Thinking in pictures*; not that I think there is anything wrong with that, quite the opposite. However, I agree with the fact that external stimuli are essential to bring us out of our shells.

For all that, I do not believe that meeting my wife, or other opportunities that have been offered me, are just a question of luck. It is our duty and responsibility to create those opportunities necessary to meet someone to share our lives with or to build a career, fully aware that nobody owes us anything simply because we are part of one of the many minorities that inhabit this planet.

Talking about how to realise this book, I find it particularly interesting that Raffaella and I developed our own parts of the book completely independently and without consulting each other. Raffaella sent me what she wrote and my experiences, my life and my strategies simply fitted in quite naturally.

Strategies that I have had to develop over the years and that I have not only applied, but also patiently recorded in detail, in thousands of pages.

I have read over the text many times, as I usually do when I write a book, from different standpoints. Doing one thing at a time, while doing many things, is one of the most significant and successful strategies I have had to use.

I consider having to continually develop strategies in order to make up for my limits, finding alternative ways to achieve what other people achieve with such ease, very stimulating and leads one to understand, for example, connections and interactions that are not immediately obvious.

Editing the text was extremely demanding and diversified; fun, too, in the chapter on rigidity (which I feel has the least negative impact on the perceived quality of my life); heart-felt (and painful) from an emotional point of view in the chapters on communication and, in particular, interpersonal relations. They brought me to describe (and therefore re-live) the silences, the misunderstandings, being considered not particularly credible, to the point of being thought false (a paradox, when you consider that lack of sincerity is what I most disapprove of in neurotypicals...).

Fortunately nature has given us some strong defences, not letting us perceive the negative aspects of other people's reactions, although the repetition of their behaviour leads us to understand (through logical deduction, so rationally, not emotionally) that something is wrong: unexpected behaviour, unexpected and unexplainable reactions, to the point of showing resentment and contempt.

I must say that I have been particularly lucky and I have only experienced such extreme situations a couple of times. I am still paying the consequences. However, even in such cases I have found a silver lining. Among other things, I have understood the importance of people who do not understand me, do not appreciate me, who disparage me.

In particular, I have understood the importance of paying more attention to possible reactions, of considering with greater attention other people's remarks (when

the situation is still manageable), the importance of managing conflict, of showing appreciation for criticism and in fact requesting it, as a preventive measure plainly showing my way of being (in itself very difficult to modify) and showing that the way I appear to be might not correspond to the way I actually am.

I have supported what I have written with images and diagrams:

- writing helps me to understand what I know;
- creating a diagram helps me to understand and describe logical connections;
- transforming an idea into an image makes it more easily perceivable (even though in my case the opposite happens; the text describes in words what I perceive as an image).

These diagrams therefore allow me to describe my thoughts better (after all, they say that a picture is worth a thousand words...).

In order to guarantee some sort of continuity in the reading, we decided to insert my writings in with Raffaella's, differentiating them graphically.

My part is usually contextual, while my added notes and diagrams are at the end of each chapter.

By choice, my part of the book was not edited, so it is absolutely the original text.

Enjoy!

Lorenzo J.S.

This book was born exactly twenty-five years after I began working with adolescents who had psychiatric problems and twenty years after I began to be involved in autism. I started out as a professional educator and then moved on to psychology when, after meeting Enrico Micheli I developed a keen interest not only for the work itself, but also the challenges that this disorder continues to offer us. First of all, the challenge of the diagnosis: in recent years we have moved from diagnosing mostly schoolchildren and adolescents with intellectual disability and severe language delay, to dealing with people from both ends of the Autism Spectrum: so from seeing younger and younger children (even before they are eighteen months old) to diagnosing extremely intelligent adults who have asked themselves the question of whether they could have some sort of autism. Secondly, I have always been keen to understand why so many people, so different from one another, can come under the same diagnosis. And lastly, because of who I am, personally and professionally, it is impossible not to ask myself the repercussions all this must have on the therapy that we consider useful for them. In the light of many considerations, a great deal of study and a lot of work, what can we do to help and support people with autism and their families?

In recent years so many things have changed.

I began working with autism when, in Italy, if you said that you had chosen a cognitive behavioural approach you were accused of training children as if they were

dogs (and I can assure you that this is exactly what they said); at a time when it was widely believed that autistic behaviour was the result of a sick relationship between a healthy baby and a pathological mother; when in Italy “high-functioning autism” was not even taken into consideration as a diagnostic category and we did not think that “high-functioning” could refer to people who live a substantially “normal” and completely independent life; when we thought that autistic geniuses were more than anything a charming little story. In the 90s, they barely diagnosed autism in very stereotyped children with no language development and I was present at a number of discussions between clinical doctors that today, fortunately, would be totally out of the question. At that time, to think that an intelligent, verbally fluent person, who studied and worked like anyone else, could be autistic was simply not taken into consideration by the clinical mind. In the last twenty years I have worked in simple and complex, public and private situations, with very different people and families. I have known a boy (who is now nine years old) since he was born and I have followed, step by step, every phase of his development, which I have shared with his mother from the start, with extraordinarily intense emotions on both sides. I have learnt to recognise autism and its characteristics and also to recognise when behaviour, which could seem autistic, is actually the symptom of a different problem. I have developed, together with other colleagues who are interested in this topic, a diagnostic protocol for intellectually high-functioning adolescents and adults, that implements international tools, which I helped translate and promote throughout Italy. I also helped in the translation and diffusion of internationally recognised tests and I have done and continue to do special training.

Over the years I have specialised in autism. I now deal almost exclusively with this field.

Autism is a way of functioning of the human mind that can be truly fascinating and interesting. Many colleagues share my passion, which has brought us to study and examine in depth the different possibilities of interpretation and to try to go beyond the conceptual and ideological boundaries when we were not or are not satisfied with our conclusions.

Today we have a great deal of data and evidence, regarding both diagnostics and therapy, especially children, even tiny children. We have much less material regarding autism in less intelligent children and adults.

However, I have discovered that by listening to them we can understand many things and understand better what we need to make available to those who are growing.

With this book I do not want to add my voice to the chorus of scientific studies and research that colleagues much more qualified than myself have published. But I do realise that it is much easier to talk about people with autism than to recognize the disorder. The most widespread social stereotype does not allow us to open our eyes to a reality that is much more complex. We all have difficulty in putting to one side our ideas, letting go of what we know, of the boxes that we have created in our minds, to make room for a new box. I, too, am often assailed by doubts and questions.

In recent years, many adults with autism I have worked with have told me of a positive sensation that they have acquired thanks to having reached an awareness, a feeling of being recognised and, finally, more understood. This and new studies that keep us continually up-to-date, push me to insist on this path because nowadays we run

the risk of going from not recognising cases at all, to including too many people and so mistaking other psychological pathologies for autism.

In these twenty years I have gone from hearing people say that I trained children, to being defined an autism extremist, to being accused of seeing autism in everybody. I am sorry about this, but at the same time I was also one of the first people in Italy who tried to understand how to differentiate and recognize autism also in completely independent adults. I am aware that diagnosis is never easy or obvious and I think that research has many more surprises in store for us. Exaggerating, through including or excluding, is a risk that everybody who deals with this Spectrum runs, be they doctors or psychologists. This is why I have tried to work closely with colleagues who have more experience than myself in psychiatric pathologies and who, at the same time, are familiar with autism and have an open mind, so as to get a second opinion.

With this book I would like to offer my experience and my reflections, with the parallel voice of a person with Autistic Spectrum Disorder who can, in his own words and through his own personal experience, explain what he lives through and bring a direct testimony. We have read many very interesting books written by people with autism, mostly from other countries; Temple Grandin is famous also in Italy for being the first person to speak directly about herself. But in Italy we have begun only recently to discern the possibility of listening to people with Autism describe their experience and their way of being. Some of them have written books, others have spoken at conferences. These are rare but precious opportunities, because up to now we have always worked by interpreting, or else getting the parents to “translate” for their children. Now we can begin to meditate upon the first-hand experience of knowing and aware people who can express themselves. Lorenzo is one of these people.

I diagnosed Lorenzo J.S. using the procedure described in the first chapter of this book, a diagnosis that was confirmed by Professor Antonello Persico, Psychologist of the Mafalda Luce Centre at the Biomedical Campus University of Rome. Lorenzo hypothesised that he might have Asperger’s Syndrome thanks to a relative who had heard of it and who recognized him in the description of this syndrome. His I.Q., measured using the WAIS-III (Wechsler Adult Intelligence Scale), was well above average, so over 140 in all three domains, Full, Performance and Verbal. Lorenzo had good language development (single words used appropriately by the age of 2, simple but meaningful phrases by the age of 3), but from an early age he showed signs of impaired social interaction, typical of an Autistic Spectrum Disorder, the most relevant being in his social interaction with peers throughout his school life, the lack of spontaneous development of games that involved imitation or pretending, the narrow range of interests, repetitive behaviour and routines. The parents did not think that Lorenzo’s behaviour might be out of the ordinary because he was very quiet and obedient and especially because he was very good at school and learnt so many things. But the overall description of him by his mother was of a person who “has always been like that”: a closed and unsociable person.

The clumsiness, the difficulty and lack of interest in team games, reported by Lorenzo himself, although they do not make for a diagnosis in themselves, are very often associated with Asperger’s Syndrome or with any other Autistic Spectrum Disorder. Furthermore, Lorenzo had always been a child, and then an adult, who was

unwilling to combine verbal communication (where he had very high skills) with non-verbal communication (gestures, looks, body language, facial expressions). Finally, it is relevant to point out how Lorenzo's internal way of being did not undergo any substantial change while he was growing up. Lorenzo has keen visual skills which translate into his need to write down everything he is calculating or learning. Through writing and through a very personal way of translating into diagrams, Lorenzo manages to understand the general sense of things much better. In his daily life, too, Lorenzo uses diagrams of the things he has to do and this strategy is used also by his wife, to help him to deal with the small problems of everyday life that he would otherwise be unable to deal with adequately.

He has used this strategy also in his work life and it has even been given substance through the publication of a number of papers about his work.

Lorenzo and I decided to develop different forms of collaboration, from reflections on his way of being that we develop together with his wife in order to further their understanding of each other, to writing this book and other projects that we are working on. A very complex job and in places difficult, at least for me, but which has provided endless food for thought for both of us. While our book was unfolding, an idea that has been milling around my head for the last ten years was confirmed regarding the importance of finding some form or forms of mediation or facilitation between the so-called neurotypical and what we define as autistic: in order to understand each other we all have to do our part, not only medical staff and family but also the person with autism can do their part. In order to be able to understand each other a joint path is necessary.

Therefore, this book would like to be a direct testimony of how it is possible to find ways of collaborating, mediating and comparing that allow both parties to express themselves and understand the other. It is the voices of two people speaking, at times parallelly, at times alternately. For the readers I hope that it will be a pleasure to hear and perceive our different styles and our different ways of reflecting together on the same topic.

To our voices I have tried to add accounts of my experience with many autistic people: their voices, their thoughts. I hope that our book may generate some interesting questions and that it may help people to understand a little-known world. After so many years I do appreciate the possibility that I have been given and that I have cultivated, to specialise and so to come to know many aspects of the workings of the human brain that oblige us to rethink many pathologies and the classifications that we know and share and I hope that our joint voices may pass on a part of this experience.

I still feel that as medics we do not yet know enough and that there is much more that we need to understand, that we need to ask and that we need to discover. For this reason, too, I consider the contribution of people like Lorenzo to be a piece of the puzzle that is this knowledge, along with our studies, the thoughts of parents, of relatives, the thoughts of the social world (school, work...), just as precious and important. In closing, I would like to share a concept that was developed by colleagues of Division TEACCH and by Laura Schreibman some decades ago, who, in order to explain the relationship between staff and parents, proposed a four-piece jigsaw puzzle: the parents as the greatest expert of their child, professional experts with their

experience of the many different ways of being autistic, the reciprocal alliance in the endeavour to educate and look after the person with autism and the reciprocal alliance to support them in their rights within society. In recent years more pieces have been added: school and the workplace, which are both becoming more and more aware and knowledgeable. Today I believe that we can consider a new candidate for a piece of the puzzle of “experts”, which is the autistic people themselves who are their own experts and who can give a singular contribution to the big picture. And we can share with them the pieces of reciprocal support and alliance toward society.

Expert Parents	Alliance within the Social World	Expert Schools	Expert Workplaces
Expert Professionals	Reciprocal Support	Autistic People who are Experts of Themselves	

I believe that nobody nowadays can claim to be The Expert, nobody can presume to be totally informed and nobody can speak on behalf of everybody, but we can all give a significant contribution to our common knowledge and to the development of suitable strategies to interact, communicate and live together in the best possible way in as receptive a world as possible. This is the aim of Lorenzo, Cecilia and myself in writing this book together.

May the reading of this book provoke many questions.

Raffaella Faggioli

Before starting work on this book, my knowledge of autism and, in particular, of high-functioning autism were mostly based on stereotypes.

The pages written by Raffaella, the first person account of Lorenzo, have opened up a world to me, a world of challenges, difficulties, misunderstandings (that are often very painful) and bewilderment, but also a world of great inner strength and the ability to transform diversity into an enriching experience.

Working with them on this project has taught me so much and I really hope that this publication may be a small but important part of building the reciprocal understanding and acceptance that are so often urged in these pages.

Cecilia Vallardi

The stories and the examples in this book are real, but they have been slightly altered in order to change those elements that could make the people recognisable. The names and some circumstances have been changed (except in the case of Gabriele Naretto who is already well-known for his musical ability). If one of my patients should recognise him- or herself in this book, he or she needs to know that the alterations were made in order to protect their privacy while maintaining the scientific value of this book.

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