

Matteo and facilitated communication

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Matteo working at home with Antonella, and with his classroom assistant, Nunzia

Matteo has just finished his geometry homework. Antonella, who comes to the house every afternoon to work with him, is delighted. For each problem he first indicated the sequence of operations he had to do and then worked them all out correctly. He sits basking in her praise and claps his hands when she tells him how clever he is. And all

this still seems like a miracle to me, for just eighteen months ago I didn't think he recognised the numbers from one to ten, let alone imagine that he would be able to understand Pythagoras.

Eighteen months ago Matteo moved from primary to middle school in Rome, where we live, although we had misgivings about it being the right thing for him. Matteo's speech is minimal, restricted to his very basic needs and repetition of what has just been said to him. He could read individual letters, but could not read two letters together without prompting. I had been using flash cards for years, but he was still not choosing accurately with a choice of only two options. And yet we knew he could write. His support teacher and I had learnt that, if we supported his hand, he could select the keys of the computer and write simple sentences without spelling errors. However what he wrote was at our prompting – a kind of dictation, "Let's tell grandma about going to have a pizza. Let's tell her about your swimming lesson." He wrote sentences he did not say, but the content of which was not beyond what we saw as his capabilities. This form of facilitated communication got round the problems of his poor co-ordination with the pencil, but still left us with the problem of his being able to write but not, apparently, to read what he had written. Some of those to whom I commented on this anomaly told me it was possible, because different learning processes were involved. Others found it strange, but were unable to give me any satisfactory explanation.

We would happily have left him at primary school for another year. Primary school was safe, and he had had loving and dedicated teachers. Middle school was an unknown quantity. How would he cope with

the confusion of so many subjects and teachers after the security of one morning and one afternoon teacher for the five years of Italian primary school? But his teachers and the school psychologist were convinced that Matteo needed to move on with his peers. They felt that holding him back for a year would achieve little from a scholastic point of view, and was more likely to distress rather than help him. Apprehensively we accepted their recommendations.

What I first noticed about the change of school was that Matteo was happy. He has never been a good sleeper, still awake as the last light is turned out, and waking him in the morning has always been a struggle. Now, when I would shake him awake, there was no longer the reluctance to get up, and I watched him go into and come out of school with a smile on his face. We had obviously been happier with his primary school than he had.

Matteo's specific difficulties, apart from the basic diagnosis of Down syndrome, had seemed to emerge, or to consolidate, after an operation for a dislocated kneecap when he was five. Before the operation he had been a sunny-natured child, reflective and with an inner concentration, although he did not yet take any initiative in play. His speech was slow, but this did not surprise me. We are a bi-lingual family and his elder brother had also spoken late. I had, however, always used Italian with Matteo on advice from the Italian DSA. The operation in itself was nothing exceptional, but Matteo's leg was in plaster for the whole of a hot Italian summer, after which he started to wear a calliper and do physiotherapy. Over the next few months, however, we saw our son regress and close in on himself. He stopped smiling and avoided eye contact. His hair fell out in patches,

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bladder-control disappeared completely, and he spent more and more time dangling any flexible object, totally concentrated on the movement to and fro, and angry at being interrupted. A psychologist defined the changes in our son as 'autistic traits', which threw me into panic and denial. I had been able to cope with the diagnosis of Down syndrome, helped by the stereotype of the chatty, happy child (although Matteo had not conformed to this stereotype), but autism was altogether more frightening.

Over the next few years Matteo had slowly emerged from the bleakness of his regression, but had never regained the degree of concentration he had had prior to the operation. This stood like a watershed in our lives, marking off what seemed to us like a golden age in comparison with the present. However we had a lot of support from the health authorities, the DSA and the school. Matteo had the maximum number of hours with a support teacher all through primary school, and started middle school with fourteen hours a week and with a classroom assistant for all the other hours. We were relieved at this level of support as our fear has always been that our quiet, passive son could easily be overlooked in a lively mainstream classroom.

One classroom assistant in particular was enthusiastic about Matteo's integration in the new school. She had worked for three years with a girl with severe disabilities and a diagnosis of autism as a result of a metabolic deficiency. In spite of her crippling disease the girl, Francesca, had made remarkable progress at school using facilitated communication.* It was our great good luck that Matteo was following on a path that had already been beaten by Francesca and by another boy who also had a diagnosis of autism. Both children had convinced the teachers that the problems were of expression, rather than of comprehension.

Over the next two months I listened to Nunzia's appreciation of Matteo's capacities with a mixture of pleasure and scepticism. We had always known that he understood far more than he expressed, and at times saw flashes of intelligence, but they were just that – flashes. When Nunzia told me that Matteo understood the concepts 'geographi-

Written at home with me as part of a series of exercises after a ghost story about a mischievous ghost. October 2003.

**SE IO FOSSI UN FANTASMA
IO MI DIVERTEREI A
PRENDERE IN GIRO LA
GENTE. ANDREI NELLE
CAMERE DA LETTO A
SPAVENTARLE. NON MI
COMPORTEREI BENE.**

**If I was a ghost I'd enjoy myself
playing jokes on people. I'd
go into their bedrooms and
frighten them. I wouldn't
behave well.**

cally' and 'chronologically' and had given her definitions of the words I was pleased at her enthusiasm, but not convinced – the words she said he used seemed a long way from the language of the e-mails to his grandmother. But Nunzia was more and more insistent about the need for Matteo to do homework on a regular basis in order to be more involved in what was going on in class. I had always worked with him in an effort to stop him from switching off. He enjoyed playing games and listening to stories about our family. Nonetheless, I had never had much success in holding his attention as far as schoolwork was concerned. After a few minutes he would start to misbehave and be silly. I asked Nunzia to come and show me how to work with him and watched as she first read him a passage from a book of Greek myths, and then asked him comprehension questions. Nunzia held him as I had been taught to do, sitting on his right, her left arm round his shoulder and her right hand blocking his right hand, exerting a pressure against which he had to push in order to touch the keys with his index finger. Between each letter she would pull his arm back to an upright position against his chest so he had to focus on the next letter he wanted to type and push against her pressure. In this way the facilitator feels clearly the direction in which the child wants to go and the child has to express that desire consciously. Too little pressure and the child is lost, too great a pressure and the child cannot hit the key.



GIUSEPPE UNGARETTI (*Written in class January 2005*) *I don't know to what extent they had already discussed the poem in these terms in class.*

**UNGARETTI ERA UN POETA CHE
RAPPRESENTAVA LA CORRENTE LETTERARIA
L'ERMETISMO. E UN MODO DI ESPRESSIONE
SIMBOLICA COME LA LUCE DEL SOLE E
IL BUIO DELLA NOTTE E L'IMMENSITA
DELL'INFINITO MONDO
IL POETA CON LA POESIA 'MATTINA'ESPRIME
IN DUE SOLE PAROLE TUTTOE ASPETTI E
GESTA DI SEDICENTI DI PICCOLI UOMINI CHE
ILLUMINATI DA UN RAGGIO DI SOLE VOLANO
NELL'IMMENSO MONDO DOVE NON CI SONO
CONFINI.**

Giuseppe Ungaretti

Ungaretti was a poet who represented the literary current *L'ermetismo*. It is a symbolic means of expression like the light of the sun and the darkness of the night and the immensity of the infinite world. With the poem 'Morning' the poet expresses in just two words all the aspects and would-be gestures of little men who illuminated by a ray of sunlight fly through the immense world where there are no boundaries.

* Francesca's story can be found on the website of the National Association for Autism and Rare Metabolic Diseases at <http://spazioinwind.libero.it/anpamm/>

I've tried to keep the same style as Matteo, making the same kind of mistakes that he has made – some of which are just typing errors while others are typical of his way of expressing himself. For this reason the following two pieces have the English and Italian on alternate lines so you can see where there are spelling or typing mistakes.

COMPITO IN CLASSE D'ITALIANO

Composition in class for class assessment, April 2003 (Matteo was nearly 13). This is the piece I like best. He has written a couple of poems with Antonella at home which are also very good.

Io da bambino volevo fare l'ingegnere
aereonautico perché mi piaceva immaginare che
When I was a child I wanted to be an aeronautical
engineer because I liked to imagine that the
tutto il mondo comincia e finisce immancabilmente
in cielo. Adesso che sono cresciuto penso che
whole world started and finished without fail in the sky.
Now that I've grown up I think that life

la vita sia molto cambiata perché io non credo più
che bisogna sognare ciò che non si può
has changed a lot because I no longer believe we should
dream for what we can't have perfectly.

avere perfettamente.

Io giovane con qualche problema non ho molte
possibilità non ho mai obbedito ai miei impulsi

*I a young boy with problems do not have many
possibilities I have never obeyed my impulses*

bujon ik ma mi lascio trasportare DALLA
QUOTIDIANITA' DELLA VITA

*but I let myself be carried along by the everyday events
of life*

IO COMUNQUE DA GRANDE VORREI FARE IL
RICERCATORE SCIENTIFICO

*However when I grow up I would like to do scientific
research because I feel I could help other*

PERCHÉ MI SENTO DI POTER AIUTARE GLI
ALTRI BAMBINI CHE ANNO GLI

children who have the same problems as me.

STESSI MIEI PROBLEMI.

This was the technique I had been using with Matteo for over a year, but what was completely different was the content. No concessions had been made for any learning difficulties. He completed the exercise with no difficulty, although he had seemed indifferent to the reading and his eyes had not seemed to focus on the page. Even as he wrote the answers his gaze appeared to wander

and there seemed little concentration on the task he was completing. I was struck instantly by the gap between what I had been asking him to do and what he had just completed. I understood that his past silliness and lack of desire to work with me was because the activities I had given him were far below his level of comprehension. They had seemed childish and a waste of time to him. He had been communicating just this but I had failed to understand the obvious.

That evening I typed the words "Down syndrome and facilitated communication" into a Google search. A wealth of articles appeared which explained to some extent the specific motor problems that caused Matteo's speech difficulties, and how facilitated communication, which was used successfully in cases of autism where language was restricted, could help get around these difficulties.

The next few months were a period of euphoria. Each day after school I would work with Matteo and see that, sponge-like, he had absorbed all that had been taught at school, but which, until that moment, had been untapped. Each night I would read more and more on the internet, writing off to the authors of the various articles to ask for more information, or to know more about the future developments of the children described in the articles. Dialogue with Matteo was suddenly possible and addictive. His desire to communicate was equal to my desire to understand. He wrote that he could not find the words in speech but that this was not a problem when it came to writing. He could multiply and divide and liked the operations with fractions. Various responses stand out and disturb me: "I know the numbers up to 100,000, but I don't want to show that I know them because no-one would believe me". When I asked why no one would believe him he wrote, "because I have Down syndrome".

We were thrilled at this new possibility for dialogue with Matteo, although it took some time for it to enter into the right perspective and for me to realise that the only thing that had changed was my perception of things. Matteo was the same child he had always been. On various occasions it was he himself who reminded me of this. During the

Christmas holidays we went to stay with friends who were delighted to see this new side to Matteo. On our return from a day trip I asked him what he had liked best about the day but he refused to type an answer in the presence of our friends, pressing keys at random until I gave up. When I asked him later why he had done this he wrote, "I'm not a puppet".

Communication is very much on Matteo's terms. He will do homework with me without complaining, but often, if I ask how he felt about an experience, or even what he wants to do, he will stop after the first few words and write nonsense words. His most creative work is written either at school or with Antonella, and I can only suppose that in this period of adolescence he is cutting the umbilical cord himself.

Life in these eighteen months has been revolutionised and much of the stress has been removed. I was spending just as much energy on trying to deal with the autistic traits and to keep Matteo in the present, but today that energy is not dissipated and I can relax more, knowing that he is, in fact, following what is going on. He will still dangle any piece of material, from a napkin to the sleeve of a jacket, but it is enough just to call his name and he will look up and laugh – and then continue dangling it, glancing sideways at us to see if he is successfully annoying us. (When I once asked him why he did it he wrote that it helps him to relax, but my gut reaction is to distract him by involving him in other things).

School is going well and he continues to be happy there. We are lucky that here in Italy virtually all children with special needs are integrated into mainstream schools, with the great benefit that for thirty years Italian children have accepted disabilities as a normal part of life. Matteo follows the normal lessons of his class, but is not expected to produce as much as the other pupils. Not all the teachers are convinced by facilitated communication. A few still insist that Matteo should be speaking, as though his lack of speech were a choice, and I sometimes feel frustration that we have not yet convinced them. In the meantime I have done a short course in order to use the technique better myself. From support at the wrist we moved to the elbow and I now hold him at the

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shoulder. He can type three or four letters without pulling the arm back between each letter, but then the concentration goes and it is necessary to pull the arm back close to the chest. His gaze wanders less when he is writing, although when I am reading I will sometimes move his head to make him look at the page, or remind him to follow my finger down the page. I have sometimes stopped in mid-sentence when reading if I thought he wasn't concentrating and asked him what comes next. Invariably he will type the rest of the sentence correctly. The psychologist who gave the course on facilitated communication explained that often these children have the ability to take in the content of a page in a matter of seconds. When I asked Matteo if he needed me to read the page aloud to him he wrote that for him it was easier if I did, and my impression is that this too is related to the lapses in concentration. However my questioning and experimenting to see what he knew and how he knew it go back mainly to that initial period of discovery. Everyday life is already demanding and it is as much as we can do to more or less keep up with class work and make sure that he gets enough practice writing. Each day there are also the normal after-school activities that he has always done.

Certain characteristics are intriguing. In that early period I had given him anagrams with the Scrabble letters we had always played with, and he would get them immediately, even with words of three and four syllables. He translates from English to Italian and will identify synonyms in a text. Some of the work he has written for school is outstanding for any pupil of his age, but on other days his output is unremarkable and expressed in very simple terms. It is as if there are days when everything in his body is working properly and others when a fog descends. On the foggy days Matteo seems drugged, his gaze falling short of its object, and it is harder to keep him in the present. However, his comprehension of a text is consistently good when this is tested with gap-filling or multiple choice exercises. It is the level of his free expression that varies.

The search for solutions continues as before. We have found one key and unlocked one door, and it has

given us access to the child he has always been. We are the ones who have changed in all this, although of course Matteo is noticeably happier knowing that he is understood. (Acquaintances who have seen him again since he changed schools have noticed that he is much more alert and that his body language has changed.) Over the years I have tried eliminating gluten, done expensive tests in American labs and bought special vitamin and amino acid preparations. There will always be speculators looking to make money out of our search for solutions. None of the above seem to have made any difference whatsoever, although we did see an immediate improvement when we finally and definitively took milk and its derivatives out of his diet. What I see in general is that the more he uses his brain the greater his concentration is, and in the absence of other answers that is what I will continue to do. (Francesca's mother tells me it is like keeping an engine turning – the more we keep it on the less likely it is to go out on its own.)

The speech issue seems more complicated; when he was smaller he spoke more, mainly set phrases like "Can I have some water?" but very occasionally something spontaneous would come out: "What's happened?", when a lift broke down, "What are you doing?", when I rewound a film he wanted to watch. I remember each one of Matteo's phrases because there have been so very few of them over the years. What he says is always the result of a strong personal motivation, but again it seems related to the fog-free days. Today I am aware that he is hypersensitive about being different and about the fact that people do not always understand his pronunciation, and that it is easier for him not to try.

I no longer think that the problem is autism, but there are definitely characteristics in common. He reminds me of a toy whose battery has run down: a prod and he will start going again, but then the concentration lapses and he needs another prod to get him moving again. If I leave him to get undressed by himself he will sometimes succeed, but often after ten minutes he will have been distracted by the first sock.

History composition written in class as part of class assessment, Novembre 2004. Matteo had a choice of 3 titles and he in fact did a combination of 2 of them.

Devi sapere che in quel periodo si formarono dette civiltà benestanti che davano molto lustro alla politica del paese si formarono i primi partiti politici con diverse idee che cercavano di aiutare il

politics of the country the first political parties with different ideas developed which tried to help popolo era l'anno 1870

the people it was the year 1870

Si discuteva di non essere come delle marionette ma uomini pensanti di poter gestire la propria

They discussed the fact that they were not puppets but people who could think and organize their existence in fact the liberal movement affirmed this concept better than all the other political movements

La seconda rivoluzione industriale fu molto importante per le scoperte che vi furono come la luce

The second industrial revolution was very important because of the discoveries like electric light elettrica il telefono acciaio il motore a scoppio apparecchio cinematografico i primi pozzi di

the telephone steel the combustion engine cinematographic equipment the first oil wells

petrolio

In quel secolo si sviluppò come una macchia d'olio la catena di montaggio in tutte le industrie

In that century industrial production lines spread like wildfire in all the industries and so a mass

quindi si sviluppò anche una società di massa che vuol dire più merce prodotta più consumi facili

society developed which means more goods produced more consumption for the population and so

quindi si sviluppò anche una società di massa che vuol dire più merce prodotta più consumi facili

democracy was born with universal suffrage the most important political movements were defined at

per il popolo quindi nacque la democrazia con il suffragio universale si definirono i momenti politici

that time and in the following years these were perfected more and more

più importanti di quel momento che con gli anni che seguono sono stati sempre più perfezionati

