



Rafał Motriuk

Autistic Son, Desperate Dad

How one family went from low- to high-functioning

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HOW ONE FAMILY WENT
FROM LOW- TO HIGH-FUNCTIONING

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FOREWORD—BARTEK MOTRIUK

I let my Dad publish this book because if you're autistic, you can thrive even better than people with no autism.

I think that my autism will help me become a computer programmer and IT tech engineer. There are many autistic programmers and IT hardware and software engineers. Programming is everywhere and helps train autistic people in logical thinking. These days programming is unavoidable. Programming is not easy and you need to think logically when you're writing a script. Autistic programmers can be very productive in programming.

I am sure this book will help parents of autistic children to worry less and encourage their kids to become IT techs and programmers.

—Bartek Motriuk, son of Rafal and Ola

PREFACE

It was my brother Grzegorz that got me started down this road. He's the one that encouraged me to keep a blog—which eventually came to form the major part of this diary. Not only that, but he even set the blog up and came up with its title. (Thanks, Grzegorz!)

I kept the blog between 2007–2011, and did so for three reasons.

Firstly, for my autistic son Bartek. Back then, I had no idea what his therapeutic path would be like. I only knew that it would be a long and hard path (and possibly an interesting one, too, when seen from a distance), and that the record of events might become an invaluable source of knowledge for Bartek later in his life; possibly for Bartek's sister, Nela, too.

Secondly, I hoped that sharing knowledge about autism would comprise a form of help for Bartek. When you hide something away you imply it's something to be feared, maybe even something taboo or shameful. But when you're open about something you normalize it, and demonstrate that it's nothing to be scared of—just something to be understood. This is why, once he was diagnosed, we told everyone: family, neighbors, and all the various people we were in contact with in the neighborhood including at the grocer's, the post office, the flower shop, and so on. It's also why I decided to write my blog under my own name, rather than anonymously.

Thirdly, the blog was effectively a form of self-therapy, something I was very much in need of during that difficult period. Emails from readers and comments from others blogging about autism played a similar role.

On top of all this, I know for a fact that there were people who found the blog beneficial: it either helped them understand the condition of someone close to them, else helped them through a difficult time. This was an added

value that I couldn't have anticipated.

I stopped writing the blog because Bartek asked me to. When I started, he was a boy with what looked like quite profound autism, and a very mediocre outlook for the future. He lacked the self-awareness or agency to make a call about publishing a blog or similar, and it wasn't clear he'd ever be in a position to. So I had to make that judgement call on his behalf.

But after many years of therapy his self-awareness grew to the point where he was able to decide for himself what he wanted. And his choice was clear—he wanted me to stop writing about him. I consider this to be a real champagne moment in his personal growth. I did as he asked, of course, and also took down the existing blog posts.

Yet more time has passed and, perhaps now more comfortable with the idea, he has given me his permission to publish the whole story.

This book comprises the content of the blog—which ran for four years and enjoyed 450,000 views—plus additional material to help flesh it out into a full story.

I want this book to be the account of a story which has a whole lifetime to run, but whose most important period has perhaps now reached its conclusion.

A few other points of note:

As well as being translated from Polish to English, the blog sections have been edited as to sharpen up awkward turns of phrase and improve clumsily expressed ideas. At the same time, I've done my best to keep it close to the original, as I think it's useful for the reader to know how I saw things at the time, rather than how I wish I might have seen them in hindsight.

On mature reflection, for instance, I'm not sure that inconsiderate dog owners should have their pets thrown into the nearest lake. Just the owners would suffice.

By keeping such thoughts intact, I can hopefully

communicate the frustration that comes with the territory of bringing up an autistic child in a world poorly equipped to deal with them (and by parents who are learning as they go).

Which brings us onto the next topic—language. By its very nature, this is something that’s always changing. Not only do words come into and fall out of vogue, but so do analogies, tropes and indeed whole concepts. Terminology becomes unacceptable and falls into disuse (is autism an illness, a disorder or a condition?), and even the way of looking at it can change (is autism a ‘tragedy?’)

With that in mind, I’ve tried to get the balance right between updating the content to reflect the current thinking and terminology (at the point of publication) and preserving my own authentic thinking at the time of writing. As part of this, I’ve tried to footnote examples of where my thoughts were inaccurate rather than correcting them after the fact. In this way I hope both to show my own growth during the period, and to help those new to the subject to navigate their own way through this difficult terrain.

As regards specific word choice, I’ve chosen to refer to those with autism as ‘autists’. This may not be a common choice, but it is my personal preference. Those without the condition I’ve tended to refer to as ‘neurotypical’.

Regarding the title, I’ve been told that I come across as far from a ‘desperate’ dad, and that if anything I cope well and am resourceful. To me, however, it’s the perfect label. I felt a sense of desperation a great many times during the journey, a situation not helped by a battle of my own—one I chose not to mention in the blog—which is that at the time of writing various parts of it, I was suffering from clinical depression.

In terms of the behaviors depicted in the book, Bartek’s is obviously easy to forgive. But I hope you will also give his parents—Ola and I—some leeway too. As every parent knows, it’s easy to judge from the outside, but less easy to

cope capably with such situations oneself.

Finally, as you'll likely notice, the book contains numerous references to Monty Python. This is firstly because it's something of a Polish obsession, and one of our key points of reference for English-language humor. But also because in some ways it reflects the nature of autism, an experience which brings moments of both tragedy and comedy—often at the same time.

—Rafal Motriuk

BEGINNINGS

That summer in Great Britain was scorching. The air-conditioning in what was a fairly good London hospital wasn't working too well, and we were hot.

Bartek was in no hurry to be born, and after more than twelve hours in the maternity ward the doctors decided to go ahead with a C-section. I was there in the operating room, wearing an elegant blue frock, holding Ola's hand. Meanwhile, the doctors joked and reminisced about their work in Africa where they delivered forty babies a day in conveyor-belt manner.

It all went by so fast.

After we left the hospital there were several weeks of breastfeeding problems and having to complement Bartek's diet with formula. But things soon settled down into something approaching a routine: getting up at night, breastfeeding, bottles. I sang soothing, nostalgic songs in Polish, like *Two Hearts Four Eyes* (*Dwa Serduszka, Cztery Oczy*), and *Blue Pan* (*Niebieska Patelnia*). While breastfeeding, Ola held Bartek with one hand, and typed her MBA thesis with the other. There were walks, a nanny, and diapers.

Bartek took his first steps in Canada Water tube station. The first word he said was "oxygen". One of my friends says it's because I was holding Bartek too tight to my chest. There was a short period of crawling, then he was fast up and running. Bartek ran ever faster, but always collision-free; his spatial awareness was superb. There were night-time stories. There were several weeks, maybe months of nightmares. Our pediatrician reassured us it was normal, that two percent of children experienced that. It would pass, he said.

The running was intense. We used to spend six or even eight hours a day in Dulwich Park. Bartek was an exceptionally lively child. They say that children are like

boomerangs—even if they venture out quite far, they still possess a natural impulse to return. Something that’s especially evident when they’re out on a walk with their parents. But Bartek wasn’t like that. He would run ahead and never turn back. We had to follow him running.

That might have been our first red flag. Many more would follow. Bartek didn’t want to catch or kick the ball. He couldn’t learn to wave goodbye. He didn’t react to his name. He was very stubborn. He was very independent.

When we talked to the pediatrician about our concerns, the diagnosis was, “no inhibitions.” That might be a good thing, we thought, he could do well in life. But there is no such medical condition as ‘no inhibitions’.

When Bartek was about to turn three, we went back to Poland on holiday. While we were there, we decided to see a child psychologist in Gdańsk, “just in case.” We told her about the limited contact. About the difficulties in managing Bartek. About his delayed and slightly peculiar speech. About the stories he wanted to hear a thousand times over—sometimes a specific page of a tale over and over again, sometimes a single sentence. About his repeating of phrases. About his watching the television at a sharp angle. About the obsessive interest he took in trains. About his lack of interest in other people. About the way he would flutter his arms. About his screaming. About his disobedience.

The diagnosis: “Give him a break, he’ll outgrow it.”

But he wasn’t outgrowing it. If anything, Bartek’s behavior was getting worse. The difference between him and his peers was becoming more and more pronounced, and our fears were worsening as a result. Was there something wrong with him? We asked around and did some reading, with no success. The instant-result internet tests weren’t much help, either.

3 YEARS OLD

September – December

In September, Bartek started preschool.

He wasn't really supposed to be there: according to the rules, children who still used diapers could not attend preschool, but they made an exception for Bartek. His nanny went with him and stayed the whole time, so that she could change his diaper when needed. On top of this, he had to be isolated from the other kids, or they had to be protected from him, as otherwise he would run around the small room, bumping into others, and trampling on the hands of the sitting children. He didn't participate in the activities, didn't sing songs, didn't learn rhymes, didn't draw pictures. For hours, he would simply switch the light on and off, or pour water or sand. He was also very picky about food.

Several times a week, Bartek would wake up at two or three in the morning wanting to play. After only five hours of sleep he was fully rested. I would go to his room and lie down on a mat beside the door, so that he wouldn't go out and wake the rest of the family. Here, I would try to catch some sleep while Bartek talked to himself, laughed, tried to play with the toy train in the dark, or stomped on my head and back. It was only rarely that I managed to go back to sleep. The breaks in his sleep lasted between one and three hours. Bartek might typically wake up at two in the morning and then get back to sleep at five, exactly when it was time for me to get up to go to work.

He ate less and less. He excluded more and more from his diet. He was getting thinner, but stronger.

His obsessions grew stronger, too: the same stories, the same songs, the same movies, over and over again. On top of that he couldn't properly articulate what he wanted. If it was a cookie, he would take one of us by the hand and pull

us in the direction of the cabinet where the cookies were. Often, he screamed, kicked, threw himself on the ground. No traditional educational methods brought any results.

We used to joke about Bartek's intransigence: at English preschool, he would become the leader and the kids would start speaking Polish. Some of the kids started to imitate his behavior, to the understandable displeasure of the teachers. And in fact, the children in his group learned at least one Polish expression from the teacher: "Bartek, *siada!*" (Bartek, sit down!)

The special educational needs coordinator was concerned by the case. We were called to a meeting and informed that a representative from the Department of Education would come to observe Bartek's behavior. She came and spent a day with Bartek, then wrote a report and set up a meeting for us with a child psychiatrist. Bartek was three-and-a-half years old at this point (his sister, Nela, just two months).

Medical Assessment Report re: Bartek Motriuk

[excerpts]

Bartek expresses his needs by dragging his father or others towards what he wants, sometimes uttering the name of the object he wants, and at times raising his hand towards it. He does not often establish eye contact at the same time. He does not establish any social chat with anyone. He sometimes takes his parents' hands and uses them mechanically to manipulate an object or toy. He does not use his finger pointing to ask or to show. He most often does not respond to his name. He does not use other gestures to compensate or to accompany his language. He often repeats words or phrases that he has learned from books, almost verbatim, often in an unusual intonation¹.

Bartek likes playing with toy trains and cars. He will often

¹ This is a fairly common trait among autists, and is known as 'echolalia'.

take them apart and play with the wheels. He also likes looking at picture books and turning the pages of books. He does not perform any sequential imaginative play. He does not often play with other children and mostly his play is very object-orientated [sic] and self-directed.

Bartek likes gathering little pebbles or small bits of dirt. He will often look at objects or television from an angle and sideways. He gets upset and covers his ears if he hears the sound of a shower running. He will flap his hands and jump up and down when he gets excited or upset.

At the age of three years and five months, Bartek is presenting with difficulties of social communication, social interaction and restricted interests, with repetitive patterns of behaviour [sic].

I explained to Mr. Motriuk that Bartek has autism.

January – February

The beginning of the year was a huge challenge.

There was panic and all sorts of questions about the future, questions for which we had no answers. The first thing we did was to tell our families. Then we set about combing through the literature and searching the internet.

The National Autistic Society works rather efficiently, so within a very short time frame we had all the essential information. Several weeks and several books later, the future seemed clearer. At the same time, it also seemed almost unthinkably difficult. There would be a lot of work, but no therapy could guarantee success. There would also be long hours of tedious exercises. But what can you do?

For us the answer was simple—we started on the exercises right away.

The exercises looked something like this: Bartek would sit in a small chair at a small table. There was only him and me in the room. He would try to get away and run about, or he would just switch off completely. As instructed, I would take his face in my hands and say, “Bartek, do as I do”, and I would put my finger to my nose. The idea was to teach

him to simply imitate. At first Bartek, a three-and-a-half-year-old, did not react at all. So we introduced a motivational system: for each completed task he would get a quarter of an M&M.

It worked. After several days (or maybe it was weeks), Bartek finally followed my lead and touched his nose with his finger. Ola and I were ecstatic, even though we were perfectly aware that, at this stage of their own development, Bartek's peers were able to tell their parents about their day at preschool. The difference was colossal.

Bartek and I would do our 'lessons' two or three times a day, stretching the boundaries of the patience of both of us each and every time. Katarzyna and Jola, specialists from Poland that we found through a London newspaper, were a big help to us at this stage. But progress was still minuscule. Then finally, after maybe four weeks of repeating the pattern (exercise, M&M) we noticed something.

A huge cavity in Bartek's first molar.

March

The cavities in Bartek's teeth appeared suddenly and were likely the result of two factors. Firstly the reward system for the exercises. Secondly because we'd been forced to exclude more and more foods from his diet.

(Come later that year, he would be eating French fries and potato pancakes almost exclusively, and wouldn't touch anything else. We would try to smuggle ground pieces of meat or vegetables in the pancakes, but it would rarely work: Bartek's overly sensitive palate would detect the pancake's uneven surface. He would react by spitting and screaming.)

Bartek was getting thinner and frailer, whilst we were getting closer to despair. It was probably around then that we began to truly take on board the hypothesis—that some autistic people are not happy at all in their limited world, that they want to get out but don't know how. What keeps

them trapped within that world is often their oversensitivity, their lack of awareness of their own body, their inability to communicate, and their lack of understanding of how the world works.

At some point, we learned of an autistic ‘miracle diet’, if you will. In its simplest terms, the hypothesis is that the autistic person has difficulty digesting gluten (the substance found in bread) and casein (found in milk). This improper digestion results in the production of a substance similar to morphine, which affects the autistic person’s brain and is responsible for some of their symptoms. The situation is made worse by fungi in the digestive system, which unseal the intestines, resulting in unwanted substances being transferred to the bloodstream. On top of this, children with autism suffer from food allergies much more often than non-autistic children. I always imagine it as a particularly nagging itch from the inside, which would perhaps explain the extreme hyperactivity of autistic children.

However, this so-called ‘leaky gut syndrome’ is not a medical diagnosis and nor is it an established part of Western medicine. And while increased intestinal permeability is a real condition, to consider it one of the causes of autism is really just a proposal—a long shot.

Science has yet to confirm the effectiveness of the regimen and to date the evidence remains anecdotal, limited to reports by parents who say they’ve experienced success with it.

The diet Bartek was recommended depended on the exclusion of gluten (bread), casein (all lactose products), sugar, colorants, and preservatives. After consulting a medical doctor with knowledge of the diet (and there are very few such specialists), we decided to give it a try.

It was no small thing we were taking on. This drastic diet demanded not only the following of a strict regime, but also—as some practitioners suggested—medical

supplements such as minerals, enzymes, and so on. Just to determine the required quantities, one first had to go through many costly genetic tests, on top of which blood, urine and stool tests were also required. Again: there wasn't (and still isn't) any reliable scientific evidence to support this approach.

But if this was the case, then why do it at all? Why go for a treatment whose efficacy, after decades of research, was still far from being proven? Were we being taken for the proverbial ride? The truth, I think, is that we were desperate by that stage, and willing to try anything. It was the kind of moment where both the skeptical journalist in me and the rational businesswoman in Ola was trumped by the emotional parent in both of us. The treatment was expensive—almost prohibitively so—but the skeptical voices of those concerned around us were far outweighed by our own desperation and our mutual need for our child to be okay.

Given the financial and emotional investment we'd both made, our observations were bound to be biased, but after several weeks of implementing the diet we both thought that Bartek seemed to be showing the symptoms of narcotic detox. His condition grew worse, he screamed more often, he searched obsessively for milk in the fridge, he demanded bread rolls, and his extreme hypermobility intensified further. But after several weeks more, these symptoms subsided and his condition began to improve. He started to look us in the eye more and to eat better. With the industrial quantities of calcium which we were pouring into him, his caries halted. This meant we managed to avoid a visit to the dentist—something which would have amounted to general anesthesia, as without it, Bartek would not even have stayed in the chair, let alone accepted any kind of treatment.

But did this improvement really happen? Was there a real change, or did we just see what we wanted to see? Ola

and I are of different opinions on this matter, but we don't really know for sure, and probably never will.

The diet and supplements, the testing, the doctors' visits—all this meant a huge amount of work in terms of cooking, and maintaining the regime of supplementation. It also meant—in our case, at least—the expenditure of about a thousand pounds a month. Bartek was surely on one of the costliest diets in the world.

Torture

A tortured person is not a familiar sight in everyday society. Yet this is precisely the impression that I have of a terrified autistic person. Sometimes, but not always, we can predict an outburst. Autists can often react extremely, and these reactions can include physical aggression, self-harm and screaming. Awful, horrible screaming.

It was now spring, and Bartek and I went on a trip to Poland to have some tests done. Few doctors specialize in the biomedical method of treating autism (i.e. with diet and supplementation), but we'd heard of one that did so in our home town of Wrocław. With no direct flights available we flew to Poznań, and from there drove to Wrocław. Altogether, the journey took about eight hours door-to-door.

Even at the airport, Bartek seemed anxious. As a further unneeded problem, and despite the flight attendants' calls, our fellow Polish co-passengers flocked around the gate, presumably just in case any passengers with special needs or with small children needed to get through. With Bartek on my shoulders, I waded through the crowd, despite their determination not to let us pass.

Once we had taken our seats and the doors had closed, we discovered there was an hour's delay. But because we had already gone through passport control and the gate, we were not allowed back in the airport. I begged a flight attendant to open the door and let Bartek run free in the jet

bridge. Thankfully, she obliged. Bartek ran back and forth. Ten times, twenty, fifty. I ran after him. I was hoping he would get tired and hence be calmer on board.

When we finally boarded and the doors closed behind us, Bartek became frightened. Of what, I don't know, but he now demanded we get off the plane, and no amount of explaining would help. Bartek had a meltdown—he flung himself about, jerked and yanked, and gave out those horrible tortured screams which were becoming all too familiar. Building on what I said earlier, I am convinced that many autists sometimes perceive the presence of an undesired stimulus such as light, sound, a person, or a situation as nothing less than torture.

With necessary force, I pulled him to my chest and buckled up. Following a row with a flight attendant, we'd been provided with a belt for babies, which enables you to attach the child's belt to your own, with the child sitting on your lap. Prior to this the flight attendant had been requesting—between Bartek's blood-curdling screams—that I fasten Bartek in his own seat, next to mine, as required by regulations. She gave in only when I asked her to show me how to do it.

“If you can fasten Bartek's seatbelt and make him sit in his seat, then sure, go ahead,” I said to her. “If not, I'll hold Bartek on my lap.”

Bartek showed me that a stressed-out autistic is also much stronger than one might expect. I am not a frail man, but I couldn't handle such a four-year-old.

For the whole duration of the flight, Bartek's meltdown did not ease up. My poor co-passengers! They suffered in silence. And poor Bartek.

One sensitive person tried to help—it turned out she was a special education teacher and had experience with autists. Alas, her help, combined with my own efforts, had absolutely no effect. Bartek was screaming and throwing himself about right up until the moment we got off the

plane—a journey of over two hours.

For the flight back I bought a whole load of chocolate cupcakes. Wasn't that against the rules of the diet? Absolutely. But it helped, and sometimes that's just the call you have to make.

April

Ola says it was her first thought after the diagnosis. But in my own mind the idea of moving back to Poland grew much more slowly, germinating probably after four months, in April.

There were several reasons why such a move made sense. Firstly, to treat Bartek successfully, we needed the support of many people. In our home town of Wroclaw we had a dietician, family members (Bartek's grandparents plus uncles, aunts, and cousins), friends, and, although we didn't know it at the time, a large pool of willing (and, it would turn out, completely invaluable) volunteers. And it was only with the help of such a large support network that we felt we'd be able to cope.

Secondly, Bartek had serious problems with speaking, and we reasoned that a bilingual environment (Polish at home, English at preschool) would likely further hinder the development of his communication skills.

Thirdly, with our tiny Nela also needing looking after, and with Bartek needing both his therapy and also to have the food to be prepared for his special diet, one of us would have to give up work. But our London mortgage would not allow for that.

Finally, the public health care available in London had turned out to be wildly insufficient for us: a speech therapist was to come around once a week for six weeks, followed by a six-week break, and then again once a week. It was a mere drop in the vast ocean of our needs.

All that time ago, we had left Wroclaw for London with two bags, big smiles on our faces and gigantic hopes for the

future. Now, seven years on, we were coming back frightened, with two children and a truck full of belongings. And despite all the reasoning, we were still to some extent unsure that it was even the right thing to do.

A digression

Recently (while I was compiling this book, in fact) somebody insisted to me that autism in children was the actually fault of the mother for not devoting enough attention and time to the child, for going back to work too soon after maternity leave, and so on.

This isn't true.

The theory of 'refrigerator mothers,' popular in the United States in the 50s, was discredited several decades ago. A mother's behavior towards her child has no effect on their development of autism (it's worth noting that few ever blame the father, so there isn't even a theory to discredit on that side).

A cold, unloving mother can harm her child in many ways, but she cannot cause autism.

4 YEARS OLD

Summer

After coming back from London, we had to start all over again. Indeed, we had to face a new reality. In my case, this meant a new job (with Polskie Radio, Poland's public broadcaster), a new role as fixer-upper (for our new apartment), and other new responsibilities.

Hanging over us was a single question: would Bartek be able to lead an independent life as an adult? It was a question that would have to remain without an answer, at least for as far into the future as we could see.

One thing that was for sure—and this certainty was a plus—we had to give Bartek everything, and right away.

We got him a place at an excellent inclusive preschool, starting that August. We already had a doctor and a dietician in Wrocław. And we also had access to a team of three specialists in the city with a background in creating great educational programs. We're talking here about programs to be carried out at home by anyone with enough patience to endure endless letdowns and failures.

Despite all this, it was not a good period, filled as it was with a continual rushing to and from therapy, builders in the apartment, work, cooking, and getting up at night to feed baby Nela or change her diaper.

On top of all that: a heat wave.

Things finally started to get easier come September. Our fantastic volunteers began to take care of Bartek, while Nela got a full-time nanny, Ania, who was also priceless.

The heat wave was gone.

And, out of the blue, Bartek learned to use the toilet.

Fall / Winter

The rest of the year passed at the pace of the run-of-the-mill activities that made up every day. Wake up, breakfast,

preschool, work, back from preschool, therapy, exercises, walks, evenings, baths, sleep.

In between all of these, there was a lot of screaming, household damage, irritation, sighing—and dreams of a calmer future.

But during this time, Bartek compensated us for everything, as his progress astonished everybody, including his therapists.

The Diary

My brother suggested that I begin keeping a journal, something that I started doing shortly after the turn of the year. Most of what follows in this book is taken from that journal, which was effectively a diary.

As mentioned in the preface, the content has undergone significant editing as part of its conversion from Polish-language blog to English-language book. But the thoughts and feelings I experienced at the time are accurately observed. Also note that this is a contemporaneous account, meaning that I now understand things that escaped me at the time of writing. I've done my best to preserve my original thinking, correcting it where appropriate in the footnotes.

Anyway, that's quite enough writing about writing. On to the diary...

Friday, January 26th

The King of Gondoland

Woke up at 6:26. The kids were running rampant till late last night, so I was hoping they would get up a bit later, especially since Grandma Zosia, who helps us several mornings a week, didn't show up. Bartek often falls asleep, stays asleep, and wakes up in a position of which one might think capable only of yogis and teenage gymnasts: with one leg propped up on the wall and the other straight on the

bed, his body twisted like a double DNA helix. For us, this is nothing strange: right after Bartek was born, a doctor told us that he was very flexible and was “double-jointed.”

Bartek wakes up and immediately gets down to the floor to play with his toy train. The train is of course Thomas the Tank Engine, from the British children’s cartoon of the same name.

A lot of young autists are fascinated by Thomas and his friends. This is commonly explained as being because Thomas and friends sport very simple facial expressions, and hence can be understood by those who are otherwise unable to read and analyze a person’s face. Additionally, every tank engine has a number, a name and an uncomplicated function or character. Put all that together and it makes up a simple system, and autists adore clear, precise systems. Hence the UK Autism Research Centre’s idea for a cartoon of their own featuring trains with human faces. Called *The Transporters*, it is intended to help in the education of autistic children.

After a couple of minutes of playing, Bartek commands, “Pee?” with a rising intonation, and runs to the toilet. Only a year ago, we were sure Bartek would never outgrow diapers, and toilet training seemed a hopeless task. Today, he does everything on his own bar using the toilet paper. That said, no amount of persuasion can make him wash his hands afterwards.

When using the toilet, Bartek takes off his pajama pants, so it’s a good moment to dress him. In the blink of an eye he undresses completely. Nela, who is a bit over a year old, and who is playing beside him, demands he wear his trousers. He puts on his underpants and trousers on his own, and I help him with his sweatshirt. I always watch with pride as Bartek puts on his socks on his own. I told myself some time ago that if I could teach him to put on a pair of socks, I could teach him anything. Twenty-four months of struggle have paid off.

At breakfast Bartek demands, “six sausages,” of which he only eats three or four, because it’s time for another tryst with Thomas the Tank Engine. Nela has managed to demolish the tracks, so Bartek, shaken by this fact, gets down to rebuilding them quickly. After breakfast he’s in a good mood and chatty. This is what he says in the next couple of minutes:

“Yellow train tracks? We’re going to have fun? Hey, oh dear!”

“Maya, come back right now! Maya, come back right now! Maya, come back right now! Maya, come back right now! Maya, come back right now! Maya, come back right now! Maya, come back right now!”

“A little fish is swimming in the taaank.”

“Daddy will put on his slippers.”

“Are we constructing train tracks?”

“Maya, come back right now!”

“He has a helmet and Sylvia has a helmet.”

“We put together blue train tracks.”

“Through the tunnel.”

“Will it be round?”

“I’m the king of Gondoland.”

“Percy is stuck in the water *and can move*.”

The train tracks are almost ready and Bartek starts playing in silence, so I’ll take a moment to explain the meaning behind those phrases.

The “Yellow train tracks” are the wooden tracks on which Thomas and his wooden friends ride. Bartek uses a questioning intonation when he wants something. He simply copies our intonation, which we use when we offer something to him, e.g. “Do you want a drink?” To which Bartek usually answers, “Drink?”. “We’re going to have fun” must be a quote from a cartoon, but I don’t know which one. “Hey, oh dear!” is also a quote, from a tale about robbers.

“Maya, come back right now!” is a quote from Maya the Bee, a popular cartoon in Poland. Bartek means something, but I can’t read his intentions.

His retort about the fish “swimming in the taaank” is a commentary on the situation. Bartek indeed has a tiny tank and one fish. In some situations Bartek uses singsong intonation characteristic of a teacher speaking to small kids, but I’m not sure if he picked it up at preschool; sometimes we catch ourselves speaking to him like that, which, by the way, shouldn’t happen because Bartek should be taught natural intonation.

The demand that I “put on [my] sliippers”, comes from Bartek, who thinks I should always have my slippers and my glasses on when at home—this is his vision of me. So he puts the slippers on my feet.

His question “Are we constructing train tracks?” is actually a request, i.e. “I want to construct train tracks.”

It takes me a while to understand what “Maya, come back right now!” means. It’s not until Bartek looks at me reproachingly that it clicks: he wants me to get off the couch and sit next to him, by the train tracks.

The comment about “he” and Sylvia having a helmet is a reference to his favorite cartoon, Muzzy, which is effectively an English-language course for kids. In one of the scenes, the protagonists Sylvia and Bob are riding a motorbike and are wearing helmets.

The other set of train tracks is blue, but Bartek decidedly prefers the yellow one, hence his comment about the “bluuue train traacks”. The tunnel he’s talking about, meanwhile, is a long, triangular CD stand which is positioned over the tracks, creating the perfect tunnel, while “Will it be round?” is a reference to the tracks being only a single element away from being finished and hence forming a circle. The line about him being “the king of Gondoland” is another quote from Muzzy.

The final one is perhaps the most convoluted. Bartek’s

reference to Percy being stuck in the water (but able to move) comes from Thomas the Tank Engine. Percy is the main engine in the train that Bartek has constructed on the tracks. In one episode of the cartoon, Percy was stuck in the water and couldn't move. Bartek doesn't like this idea at all and here he presents some wishful thinking: Percy can run no matter what.

In short, everything he says has a meaning. It just requires some specialist knowledge to be able to decode it.

Possibilities

We're going outdoors on a sled. After four years in a snowless England, snow is a huge attraction for Bartek. He sits on the sled like a good boy and lets himself be pulled. As recommended by the therapist, I need to tell him where we're going and what for, and thus here begins one of our typical conversations.

"Bartek, we're going to a greengrocer's..."

"Not to a greengrocer's?!?"

"...and to a newsagent's."

"Not to a newsagent's?!?"

"We're going to buy parsley..."

"Not parsley?!?"

"... and a paper."

"Not a paper?!?"

It's hard to know what expectations Bartek has of our expedition, but one thing's for sure—I'll be informed many times over of the things he doesn't want. He probably wants me to pull the sled, let him be, and let him eat snow in peace. With a lot of opposition, I carry out my plan and then we turn to go back home.

"Bartek, we're going back home."

"Not back home?!?"

"Okay then, we'll go straight ahead."

"Not straight ahead?!?"

"Well then, to the right, through a shortcut."

“Not to the right?!? Not through a shortcut?!?”

“Let’s turn back then.”

“Not turn back?!?”

Bartek has used up all the possibilities, so now I have to make a decision knowing it will contradict his plans regardless of what it is. I choose to go back via the same route and Bartek starts crying.

Lunch

Bartek shouts out, “One o’clock,” in English—and it is, indeed, one o’clock.

In the cartoon Muzzy, a character called Norman tells the time and declares that one o’clock is time for lunch. Bartek’s English is limited, but his accent and his intonation are exquisite. Like many autists, Bartek imitates sounds faithfully, and as per Muzzy and Co.’s standards, Bartek speaks aristocratic English, or in any case, modern received pronunciation.

One o’clock means it’s time for lunch—on that we are agreed. But the food itself proves more of a problem. As previously mentioned, Bartek is very picky when it comes to what he puts in his mouth, as are many autists. Today he simply doesn’t have any lunch—he won’t eat anything.

Train to nowhere

Every Saturday we visit a speech therapist. Lately, Bartek’s been practicing, albeit reluctantly, with me and the volunteers, and also with Renata, the therapist at the center where we have sessions as part of the Early Intervention program. We try not to worry: autistic children tend to develop in bursts, meaning there are phases of stagnation and regression. But after the recent rapid progress, Bartek’s reluctance is very frustrating. During the session he runs away, switches off mentally, or starts repeating, “Lu lulu lu.” He reacts neither to treats nor threats.

Renata suggests that we come up with a reward system. Stars, for instance—one for each completed task. So far,

we've only managed to convince Bartek to do an exercise which involves sticking pins onto a cork board and clapping his hands, "Loud—quiet."

Before the session, in the building of the therapeutic center, a common parental fear becomes our reality: our child disappears. It's something which is not all that rare among little autists, and a second of distraction is all it takes. As mentioned earlier, by use of a slightly different analogy, neurotypical children are linked with their parents by an invisible thread—when the child runs away too far, the thread becomes taut, stopping the child from going any further. Many autists do not seem to experience this; so their impulses drive them yet further. I know of cases of searches involving numerous police units and helicopters. Luckily, this time Bartek acts according to habit, and not on impulse, hence I find him where I expect to—in front of the elevator for the disabled, where he has a fondness for jumping up in delight and flapping his arms. He really loves elevators.

We go back home. A moment after we arrive, so does Kaja. Kaja is a volunteer who drops by two or three times a week. She is a psychology student and she wants to get some experience, so she's helping Bartek with his learning exercises. Among them is a sequence that I haven't managed to successfully complete with Bartek in two weeks. Then Kaja turns up and together they ace it almost at once.

The serenity of this small victory is short-lived, though. Practically the moment the door closes after she leaves, there's screaming and crying. Bartek wants to play but he doesn't know "where [his] express train is?!" We don't know what to do first—calm him down and look for the train, or the other way round. The problem is that both of his long, white and grey express trains are right there in plain sight, on the train tracks. We promise Bartek, who's practically inconsolable, that we're going to find the train.

We start looking, even though we don't really know what it is we're looking for. Each wrong wagon that we show to Bartek simply amplifies his cries. At long last, after minutes of helplessness, I have a brainwave: there is in fact a third express train, but in reality it's not one or more carriages but a locomotive. Bartek gets hold of it and in the blink of an eye he is back to a state of calm.

Usually, late afternoon is a non-productive time, educationally speaking. Before the diagnosis we used to make fun of the fact that Bartek went deaf at around seven. He stopped reacting to anything. Now we just put on a DVD, feed him his dinner and try to keep some kind of control over his intensifying dances, jumps and contortions.

Dinner usually means rice cakes with margarine, gluten-free pudding with rice milk or, alternatively, corn flakes. Today Bartek wants corn flakes, but only under the condition that they are served with raisins. He then picks out and eats the raisins, and the flakes themselves have to be practically shoved down his throat.

To that we add a portion of supplements. As the diet itself is quite limiting, Bartek gets cod liver oil, calcium and a whole lot of vitamins, minerals, enzymes, and so on—altogether fifteen doses of different supplements a day. We are lucky that Bartek swallows the various syrups (which are not always particularly nice-tasting) and so on without much of a problem—some parents have had to give up the diet because their children simply wouldn't comply. Here, as in pretty much every part of an autistic's life, negotiations are largely futile. Generally speaking, autistic aren't big on compromise.