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The Children of Hans Asperger

ExtaZ
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Today I begin a story which I probably regard — quite justifiably — as the hardest and most painful in my life so far: the story of the birth and upbringing of our two children, Paul and Lea Enev. I spoke with all members of the family before beginning (that is, with those of them with whom this is possible — Paul and his mother, Doreen Westphal), and all encouraged me with great understanding and — I would say — with great love. Doreen and I have been divorced for about fifteen years, and since then she has lived with another partner, Klaus Eichner, with whom I now also share a deep and strong sense of friendship, understanding, and mutual support. I suppose that in some sense I can now call myself a "lucky man."

The story, whether I want it or not, will revolve primarily around Lea, but I myself understand it as the story of the whole family. For all those who have had the fate (and the ordeal, and the privilege!) to become parents of neurodivergent children, it is surely something that hardly needs explanation. Wherever such a child is born, everything else inevitably takes a back seat.

And so, this is the story of a family into which a neurodivergent child was born. The term "neurodivergence" and "neurodiversity" comes, like most such things, from the United States, where it denotes the growing societal understanding of the fundamental equality and equal acceptance of people with mental differences (primarily those with autism and its significantly higher-functioning "cousin" — Asperger's syndrome). Neurodiversity is both a battle cry of the community — a cry for equality, a demand for self-acceptance and respect — and a call for help, for more understanding, acceptance, and — oh yes! — love from all "neurotypical" ("normal") people, whether close or not. Neurodiversity is, put simply, the normality of the future. Whether we want it or not, it is something we must reckon with, must accept, must learn. Not for abstractly correct reasons, but simply because it is the next step in the development of our own humanity. Neurodiversity is a new form, a new manifestation of something very old and well-known — humanism.

There is a very concrete reason why I am beginning this story exactly now, at this very moment, and it is as irritating as it is binding, at least in my own understanding. It concerns the sharp realisation of the mass ignorance, incomprehension and — as a consequence — the widespread public aggression in today's Bulgaria towards neurodivergent people. The unbearable feeling of the astonishing ugliness and coarseness that people in my native country are capable of when it comes to the "different," especially when the conversation includes distant and meaningless-sounding words like "Asperger's syndrome" or "autism." The primitive, ignorance-laden, almost barbaric indifference to the holes that all this leaves behind, as if it were not done by mature human beings, but by mean, ignorant children having fun torturing some little "animal"... Oh yes! Oh no!

Spread your wings wide and fly, incomparable soul, Bulgarian...

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Lea Enev was born around noon on the 3rd of November, 1996. It was a peaceful and calm birth, insofar as something like that can be described as "peaceful" or "calm." In any case, she came into the world without giving us the slightest reason for concern — unlike her older brother, who in an abso-



lutely typical manner insisted on having his own opinion about everything, including the beginning of his life, and nearly drove us all to despair for many hours — deciding to come out face down, not face up, as is proper for any obedient baby. Paul Enev, the eternal stubborn-head...

But with Lea everything seemed somehow beautifully sculpted, complete, and tastefully formed. Naturally, there is nothing more beautiful in the world than one's own baby, but this little girl had always looked somehow very well-formed, very proportional, lovely like a picture. She was a rosy-cheeked and slightly frowning baby, but otherwise quite calm and somehow easier compared to her brother. She began feeding immediately, hungrily and tirelessly; she slept, as far as I can remember, unusually peacefully for such a small baby. Not a child, but a dream. Those are the earliest memories in which I have preserved her.

And so it continued for about two months. Until suddenly, like a bolt from the blue, came the first warning that something about her was "atypical."

The child began to scream.

Of course, all children scream, especially at that age, but her screaming had nothing in common with what neurotypical children do. She simply refused to stop — and always during the night — for many hours, generally until morning, regardless of how much and what kind of effort we made to soothe her. It is hard to describe the reality of that experience, that first encounter — and, if you will, first confrontation — with autism, when one has not the faintest idea what one is dealing with or what awaits in the future (or rather, for the rest of one's life). The child screams and screams, and inside you a storm of emotions and sensations battle one another — most of them, at least in my case, bound to strong aggression, stemming from the lack of understanding and fear in the face of such an incomprehensible, inexplicable behaviour. The little being shakes with obvious spasms of uncontrollable terror — and someone knowledgeable and prepared would surely have been able to respond in the only way suitable for life with an autistic child: understanding, understanding, understanding; acceptance, acceptance, acceptance.

Yes, someone knowledgeable and prepared. But the person I was at the time was anything but knowledgeable and prepared — and, moreover, in moments of anger and fear, largely deprived of the natural, deep empathy with which her mother had always been gifted. And thus came the first great transgression, the first great guilt toward this child, with which I am fated to live until the end.

I decided that the little one needed "discipline." And I imposed it.

Sancta simplicitas! After one or two weeks of enormous effort, completely sleepless nights, and ever-growing fatigue and frustration, I finally "decreed" that this could not go on. Her mother tried to argue, to insist that we should cuddle her and keep her close to us no matter what. (Up until that point, Lea generally spent the nights in our bed, with one of us trying to soothe her and the other trying to "sleep." Paul, just over two years old, was already sleeping in his own room, but his nights were not exactly peaceful either, as a result of the enormous stress he was, of course, registering,

whether he wanted to or not.) But I did not back down: "No, what's needed here is a firm hand, she needs to learn her place. We've spoiled Paul enough already." Those, or words like those, must have been what I said. I was quite a bit younger and quite a bit more ignorant. I hope that may serve as some sort of explanation. I cannot find an excuse, nor do I think there's any need to look for one. That's who I was.

We made her a sort of nest from mattresses, sheets, and blankets in the next room — and we left her there "to cry it out." The heartlessness and cruelty of this decision seem to me today so inhuman that I am forced to fight the impulsive shame and self-pity that rise every time I remember it, but that helps nothing. I must tell it — it matters. The child would spend each following night in unceasing crying — five, six, or more hours in a row — until she finally fell into total exhaustion and "slept." Of course, we didn't leave her alone the entire time — every few hours we fed her, carried her around, and tried to calm her down, but far less than we had at the beginning. Doreen suffered greatly, but being herself on the brink of total exhaustion, accepted the "solution" as inevitable. And so we lived — and "disciplined" Lea.

I don't remember exactly how much time passed like this. It must have been at least three months. At long last, we reached some kind of "more stable" state. I have not the slightest idea whether Lea "learned" anything from the cruel training we subjected her to, or whether she simply reached some internal state of being able to cope with the horror and the fear. In any case, she became outwardly calmer, and at some point we — or at least I — lived with the sense of a deserved "victory." Good God, a victory? A victory over whom? Over our own child? Sometimes I wonder how I ever managed to find my way out of that labyrinth of blindness, egomania, and mere macho pigheadedness — if indeed I have found it at all.

Here I will make the first inevitable digression, to explain — and place in a broader context — the immediate reality of life with autism. It is extremely important that one is given the chance to understand, at least a little, what this thing actually is, what its causes and roots are, and — most importantly — what its approximate reality is. There already exist many personal testimonies, spoken, written, and formulated by autistic people,

about what the world looks like through their eyes, as well as many stories told by parents. It is important to be familiar with them, at least to some degree. Without such understanding, it is impossible for any kind of growth to be achieved — on either side.

I will speak later, if I manage, about the scientific and historical aspects of the phenomenon. Too many things are vying for expression in my head — I hope you understand. But the first thing I want, the first thing I must say, is that the reality of autism consists of one single, endless, dulling, maddening terror. This has been told by many autistics at later and more mature phases of their human development, but the beginning is the same for all: terror, terror, and more terror. The reason for this is as inaccessible to the rest of us as it is simple to understand — if only one learns to make the effort to understand:

They are simply not able to "shut off."

What exactly does this mean? Well, it's relatively simple: look around yourself for a moment — right now, as you're reading this text — and try to count all the stimuli that are vying for your attention in your immediate surroundings. In front of you is your computer screen, or a sheet of paper if you've printed the text. Somewhere in the next room (or maybe even in the same one), the TV, radio, or some music might be playing. Your loved ones, if they are nearby, are producing all kinds of noises, movements, sending verbal and non-verbal signals, engaged in things that generate some sort of auditory or visual background in your immediate environment. There is traffic on the street, something can be seen through the window that is likely also moving, buzzing, rumbling, groaning, doing as it pleases. Isn't it a miracle that despite all this, you're able to remain calm?

Well — none of this is available to autistics. For them, isolation from the stimuli coming from the surrounding environment is impossible for neurophysiological reasons that remain shrouded in deep mystery. Put in the simplest possible terms — from the very first moments of their lives, these people live in a whirlpool, a vortex, a dizzying flood of maximally amplified,

maximally unbearable, maximally terrifying auditory, visual, and all other types of sensory stimuli that do not give them peace for even a single moment. What exactly causes autism is still completely unclear. The prevailing theory at present is that it is a form of genetic difference which arises for unknown reasons, but is extremely persistent and constant in all human communities — similar to homosexuality.

All of this is of exceptional importance. In the paragraph above, there are several statements that constitute the cornerstones in building the capacity to develop understanding, later — unconditional acceptance, and finally — well-earned parental pride in the life and achievements that accompany this slow, painful, and very difficult growth: life with autism and with the autistic person. If my own experience does not mislead me, this even applies to our capacity to love these children. Believe me — none of this is easy.

And so:

First: it does not matter what exactly causes the (at first glance) inhuman reactions with which this child will confront you again and again over the course of many years. What matters is that you understand it has no other choice — at least not in the beginning, before it has learned to live with the terror. You have a choice — it doesn't. I repeat, this is an understanding of exceptional importance.

Second: it does not matter what exactly causes autism itself. It does not matter — on the contrary, it is extremely harmful — to nurture hopes that one day a miracle will happen and your child will be "cured." This is impossible, since autism is not an illness, but a mental condition with its own dynamics which — oh yes! — are subject to very slow, very gradual changes, but are in principle irreducible. Only when you accept that you are not fighting "against the illness," but for your child, will you gain any chance of growth, of achieving calm, balance, normalcy, humanity. Before that, you have only been a "victim" — a victim of your own and society's prejudices, linked to the mass ignorance that envelops this phenomenon.

On the contrary, it is of utmost importance to focus all your efforts — from the very first moment the diagnosis becomes relatively clear — on full devotion, love, and every kind of support for the child. All children need

love in order to grow up normally; autistic children need ten times more. This may seem like an unnecessary emphasis, but my own experience says otherwise: loving an autistic child is not at all easy; this strange and incomprehensible little being constantly, constantly, constantly pushes you to the limits of your own endurance and capacity for understanding, until you inevitably reach those moments — filled with a heavy, unbearable sense of guilt — when you are overwhelmed by the feeling that to love them is simply impossible. To fight against these dark, crushing feelings and states — the indifference, the fear, the aggressiveness toward one's own child — is extraordinarily difficult, and I have seen more than one or two parental couples collapse under their weight, abandon their children, or send them to institutions long before they had learned even the basic skills for communication and survival in a completely confusing, terrifying world — thereby robbing them of any chance of achieving a happy or even normal existence. They have taken it away both from the children and from themselves. No human being can forgive themselves for such a thing, whether they consciously realise it or not — and the result of parental failure in such cases is usually linked to a more or less total destruction of the personality. I don't need to say more about this — just keep it in mind: however hard life with the "little monster" may seem, there is no alternative to devotion, love, and unconditional support. Everything else is a slow suicide — conscious or not.

And yet — such is human nature — none of us can live with something like this without answers, however incomplete or contradictory they may be. The question "why, why, why... why exactly me?" accompanied by the unbearable feeling that you have been "punished" by life, by the world, by God, never leaves you, not even for a moment, especially during the first years. And the lack of an answer is so crushing that the efforts required to overcome the sense of fateful doom, and then to achieve calm, even happiness, seem inhuman, unattainable, unimaginable. That is why all of us, willingly or not, begin to develop our own explanations for the causes that led to the appearance of this human being in our own family.

In our case, there are several versions, and I will share them here with you, to complete the picture. In the first few years, we connected Lea's im-

pairment with a hypothesis as insane as it was plausible: that the development of her brain had been damaged during the embryonic phase under the influence of increased mercury levels in Doreen's body. The thing is, Lea was not planned — she came unexpectedly and surprisingly — and just a year before that, both my wife and I had undergone extensive and complex procedures to fully replace our old "socialist" fillings with new, "capitalist," harmless ones. The expensive and lengthy procedure frees you from the fear that you are slowly but surely poisoning your body from the inside, but at the same time — a proven fact — temporarily increases the concentration of mercury in the body, since the removal of the fillings is associated with some "leakage" of their toxic content into the metabolic system. Getting pregnant after such a procedure is, of course, anything but advisable. Well, it happened to us.

I used the word "insane" above because all the while, right under our noses, there were far more objective and intellectually accessible explanations that we live with today. I mean our own family trees and the presence of entirely visible, entirely obvious "genetic forerunners" connected to the appearance of our child. Doreen has a first cousin who also carries some form of mental impairment. As for me — a development occurred that is well known from the stories of many other parents of autistics: over time and through life with Lea, I began to realise, slowly and gradually, to what extent my own psychological, and likely genetic, profile already carried within it the seeds of autism. Put more briefly, over the years I have come to understand and feel myself more and more as a carrier of Asperger's syndrome — that is, a person endowed with high intelligence, but at the same time so burdened by internal tensions, insecurities, and fears that he ultimately lacks some of the most basic mechanisms for experiencing co-belonging and togetherness with other people. An eternal loner, always searching for the path to togetherness, but unable to find it. A child of Hans Asperger.

Sometimes I think that if I were to be hung on a hook and sliced open from top to bottom, what would spill out would not be the usual things that fall from such a human sack — guts, blood, shit — but words.

I say this without any real sense of exaggeration, apart from the consciously sought starkness of the image: in my own experience, words have always been something independent, even contrary to my conscious will. Something that swells within me, often torments me, and generally does whatever it pleases. From early childhood, when they often got me into trouble — with parents, with teachers, with other children who, in a burst of some group instinct, would isolate me and prefer to keep their distance — right up to today, when again words, this time written down and placed everywhere, keep getting me into trouble over and over... Yes, throughout all this time they have consistently been — and remain — something completely independent, cosmically mysterious, slightly threatening, and most importantly — something that isolates me, not something that brings me together with people.

Ah yes, the isolation. The invisible, elastic and endlessly expandable, but in any case impenetrable wall that has always separated me from "people" even in the moments of greatest intimacy and closeness. The feeling of not belonging, of insurmountable difference and foreignness; the thing I only learned to accept as inevitable at a mature, almost fully "adult" age. Without ever overcoming that irrepressible itch, at times turning into pain, associated with this hard-to-bear condition. The inability to feel truly engaged, involved, part of something — anywhere or anytime. The perpetually downcast gaze, which always got me into the same kind of trouble with my mother — a strange woman who managed to combine in one and the same person both a very deep, boundless individual sense of beauty, and a sort of unconditional, almost paranoid reverence for the necessity of public propriety. "People keep complaining again that you don't greet them on the street! When will you finally learn to behave properly, when?"

Today, when my son has begun — most unexpectedly — to confront me with the revelation that for him it's exactly the same, that he, like his father, has enormous problems with *Zusammensein* (togetherness), with that which all others, it seems, can achieve just like that, with a snap of the fingers, I try in vain to reassure him that the heaviest forms of this kind of isolation are inevitably linked to youth. That with age, one learns to outsmart oneself or

at least no longer experiences the burning intensity of loneliness so painfully... That this is just the price people of this type — whatever type that may be — are forced to pay for their uniqueness. That there is also a reward for the isolation, for the failure in communication, for the solitude. For him, all of this is just words — words that might offer a fleeting, and heavily egomaniacal, relief. And how could it be otherwise?

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But let us return to the main story...

We lived, more or less, peacefully and happily — like in a fairy tale. (In fact, the seeds of what would eventually separate us about ten years later had already begun to sprout, but that is part of another story.) The baby had calmed down, little Pavel too became more settled, and we slowly began to forget the horror of Lea's nightly screams. Yes. *We* began to forget them. What was going on with her, no one knows, of course. But at least from the outside, nothing could be seen. For several more months.

Until the real, unbearable encounter with autism appeared on the horizon. The diagnosis.

As always, it was her mother who was the first to raise the alarm. God help me, another sin I must confess. When she first said, "Something isn't right with this child," I reacted so badly, flared up so harshly and argued so forcefully, nearly started a fight — it still makes me feel ashamed. "You're always looking for something to poison everyone's peace and happiness. How can you be so pessimistic? Just look how beautiful and calm this child is!" And she looked at me in that way — both angry and tearful — pursed her lips and pointed out: put her in a sitting position, and she flops over to one side like some poorly made doll; she's about to turn one, and still has absolutely no sense of balance, she can't even sit. God help us, God!

We went, we showed her, we shrank down, and we waited. And the conclusion didn't take long: delayed child development, with presumptions of mental impairment. Brace yourselves, people!

I don't know why human beings are made in such a way that everything which makes them happy, calm, and content somehow refuses to