

**STORIES:
THE SOCIAL MONSTER**

STORIES: THE SOCIAL MONSTER

At school, they often let me know that I was different and that my presence there was slowing everybody else down and that I should be grateful for being there with them. I constantly felt like I owed them something, that I should be glad that they accepted me among themselves.

I wanted to go home, to my apartment. They told me I didn't have an apartment anymore. I spent time in a retirement home, at a psychiatric ward and in an institution for mentally disabled women. Altogether, it's been almost 25 years. But a person can't stay locked away forever. I had to take medication, but it made me feel awful. I wanted to cook for myself, but I wasn't allowed. When I ran away, the police brought me back in. All this time, I was telling myself that I needed to get out. Now I have a home here, in this apartment. Assistants come here every day, every morning and evening, for about two hours. They help me with cleaning and managing the apartment. They sometimes take me out to get groceries, but I don't like going outside that much anymore. I learned to iron clothes. I can turn the stove on and cook myself soup. I'm scared of the boiler though, so the assistants are the ones who turn it on. At the age of 79, I was finally able to move from the institution to my own apartment.

While visiting a school, I heard a painful cry for help. I didn't want to believe it. I stopped and listened. Someone was desperately yelling for help from a nearby classroom. I rushed inside and saw three boys beating up a girl who was huddled on the ground. I grabbed her by the hand and led her out. We sat in an empty room and didn't say anything for a while. Then we started talking, though, and we talked to each other for a long time. After talking to others who saw what happen, I realized what it was I saw in the classroom. And not only that, I realized that she was being bullied - something that the teachers couldn't even see yet.

I have 8 hands and 12 eyes. I can see around corners and see all sides at the same time. I can use my hands to simultaneously hold a bag, talk on the phone, brush my

hair, drink water or riffle through a book. While two of my eyes are always resting, I keep the other ten peeled.

When I took a tram or a bus, people would sometimes move farther away from me. They tried to be discreet about it, making it look like they were about to get off, although in reality they'd just walk to the other end of the bus and stay there for several more stops. Alternatively, they would stare at me, thinking I couldn't see them.

I've been living here for years. In this room where the window is so high up than I can't see outside. Sometimes they take me out on the porch. The nurses just came in to change my underwear. They're nice to me. I tried to tell them, but I only know how to say two words. I'm looking forward to people coming over because I'm alone most of the time. My hands are tied to the bed so I can't take out the thing they put in my stomach at the hospital. It was so annoying I tried to remove it. Now I can only reach my head. The TV in the room is always on. I can't turn it off. I wonder what it would be like to live somewhere else, but I can't picture it.

I was walking past a construction site. The guys who work there were on break and they called me things: They said I'm a monster, xenomorph's sister, and that I shouldn't go outside so I don't frighten people.

I wish Jana could come back home from the institution. But I'd need her to go to school. At least for three or four hours. She's 14, but she can't look after herself. Somebody would have to take her to school. Then I'd also need someone to help us wash her - she's too heavy for me now. I would need help for myself from time to time, somebody who would take over my responsibilities for a bit. And I'd also need a place where Jana could stay for a little while when I need to go on rehabilitation stays. Then I'd also need somebody I could call and who'd help me if there were any issues. Right now, for example, Jana needs a new wheelchair. The most valuable tips I got came from other moms with disabled kids. And I'd need to be sure that the assistance would last.

Sometimes I'm glad they don't know what's going on in my head and while I can understand them. That I hear

everything they say. That I answer them in my mind and make fun of them and all the ridiculous things they say about me and how they keep pretending that they want to help me and that they understand me.

I was standing in a line at the store. There was a bunch of boys behind me, maybe fifteen- or sixteen-year-olds. They were whispering something and giggling. They shoved one of them into me and the poor boy turned red like a lobster. Honza would take you...for the doghouse in front of their house, they laughed.

My world is full of fragments. I can sort through them and sometimes even come to understand them. I listen to and take note of the various sounds and noises. Many of them I find annoying and tiresome, but some of them are exhilarating or stimulating. When I examine that mosaic with care and patience, I can find fragments in it that can be assembled into a whole, an understanding of what is happening all around. As such, listening for me means mainly sorting and distinguishing, connecting related things, making assumptions and coming to an understanding. Only that refines my hearing. Besides my ears, I can also use my hands. I like to put them down all around me to learn more about the world. My sense of touch isn't any more sensitive than that of sighted people, so I don't get a sort of an odd benefit. Same as with hearing, my sense of touch only gets better through continuous and deliberate use.

I dreamed that I had a normative body. I'm walking down the street and nobody's staring at me. I'm just a part of the crowd. I went to the doctor and he told me: Incredible, everything is fine! You're straight like a ruler. They could make mannequins based on you!

We finished writing the exam and the teacher left. We had 10 minutes left before mid-morning break. That was a total of 30 minutes, unattended. Three of the boys - Karel, Jirka and Robert - immediately started playing one of their favorite games. They came over to Hana and kicked her chair from under her so hard she fell to the floor. A wave of laughter ensued. Two of them grabbed her and dragged her to a large window. The third opened the window. They shook her and threatened they'd throw her out. They laughed and shouted in unison: *"You're gonna be a plane."* Then they threw

her to the ground. They pinned her down and started hurting her. Hana said: "I screamed. I screamed for help. They covered up my mouth to the point I started choking. It took a long time, at least ten minutes." This was not an isolated incident. Similar "games" happen during every break, whenever there's an opportunity. Oftentimes, they even happen outside and, occasionally, in subtle ways during class. Martina: "What they did to Hana, they do during almost every break. They pick a victim. It doesn't matter if it's a boy or a girl. Out of the boys, they usually pick Jonáš. They're getting excess energy out of their systems. They revel in seeing us upset." "Three boys pick us up and start hurting us. It hurts. It drives me nuts. At home, I'm in a bad mood all day. We tried to resist maybe twice, but it made things worse. Afterwards, the trio targeted a girl and were even rougher than usual. Nobody helps their victims. Everyone is scared. It's weird." "They know no bounds! They have lighters and use them to burn off the hairs on people's clothes. Sometimes it burns a lot. Sometimes, they strike the lighters next to people's hair and burn it. It smells awful." Darina: "We sit all day and can't move. The three of them are awfully bored. Sometimes they just lose it. They surround a person and start hurting them. Not too long ago, they taped over Hana's mouth, tied her hands with a hoodie and dragged her by her hair. They have several girl victims. Out of the boys, they mainly pick on Jonáš. When they're bored with the lecture, they throw peels and trash at him. During breaks, they throw chalk at him, but they do it with full force." Iveta: "The torture Hana suffers sucks. But there's nothing I can do to help, because then they'd go after me. I need to keep my friendship with Karel. I have to keep it to myself. I'm scared of him, he's capable of all sorts of things. I asked him if he'd ever kill someone. He said he would."

After the doctor didn't let Renata sign the release waiver in the morning, I called the senior doctor. I explained the situation to her and told her that I believe that my girlfriend is being held at the hospital unlawfully. She confirmed that that was the case and secured her release. Before she actually got released, five people - three doctors and two nurses - stood next to my girlfriend and threatened that signing a release waiver would get her into trouble and promised her that she'd get to go on more walks. The whole time she was at "ward one" she felt she

was under immense pressure and that they were genuinely trying to destroy her. We couldn't understand why they were acting that way. The release report stated that Renata suffers from paranoid-persecution delusions towards the medical staff, which was supposedly supported by the fact that she asked to be transferred to a different facility.

For blind people, it is very important that each thing in their house has its place. Once they've given their things some order or system, their surroundings become easier to navigate. They have to learn to recognize the things in stores - based on their shape, size and surface. They also tell clothing apart based on certain features - differences in cloth, seams, t-shirt collars or the edges. The ones that don't have a unique distinguishing feature can be assigned a specific place or differentiated through some sort of marker, such as a label written in Braille. Thus, each blind person creates their own system of sorting things which suits their personality and the way they spend their time. We also shouldn't overlook useful everyday tools such as scales, thermometers and measuring tools that need to come equipped with speech software. This also includes a personal watch, although those can also come in touch form with a removable glass panel. People often think that blind people are surrounded by darkness, but not being able to see means not receiving any sort of visual stimuli. Blackness, darkness, grey fog - those are still visual stimuli. So those who truly cannot see anything see about as much as you would if you tried observing the world through your elbow or your back. It's a sort of absence of visual stimuli that is difficult to describe.

That was when I developed a love for animals. They always knew when I was feeling at my worst. In seventh grade, I started practicing martial arts, hoping that I could learn to defend myself. But my self-confidence was already so low that it didn't end up helping. There was another sort of miracle, though. Two girls from my old class used to come there with me. And so, for the first time in my life, I had best friends. We didn't care about anybody else. But then came the grammar school entrance exams. When I read the final results posted on the board, I exclaimed with joy: "Yes, I did it!" And so, I got into a new class. What I wanted most of

all was for everybody to leave me alone. I wanted a fresh start. But I chose the wrong path. I tried to cope with my bad memories through food. I gained 13 kilos in the first semester. All of that was made worse by family issues, the amount of studying I needed to do, and I also came to realize that I was constantly feeling anxious and threatened. I lacked communication skills and couldn't move when there were too many people around me. On one hand, I was free, but on the other...? It was like this for the entire four years of school.

People kept offering me their help on the street, which I mostly appreciated. At the very least, it showed me that our society isn't entirely indifferent. The help people offered me was typically small things - crossing the road, finding the subway stairs, things like that. But there were some who went even further. They could restore sight - or at least they claimed they could. The last time I was offered this sort of "enlightenment," it was from two women at the main train station in Prague. I wanted to grab a cup of coffee before the trip when they pounced on me. They told me that we were going to pray together and my sight will come back. I heard things like that are common in the US.

I dreamed that I had a new wheelchair. It looked normal at first glance, although the design looked a bit like something from a sci-fi movie. It could turn into an armored car and fly. Thanks to it, I became completely independent. I bought an apartment on the top floor of a high-rise building. I had no trouble even with long distances. I could finally travel and see the other side of the ocean.

I was in a clothing store. Two young saleswomen started staring at me weird and then one said rather sharply that I should leave immediately because I'll chase away the customers.

It's a lot of work to train one's hearing and touch. Those of us who cannot see differ widely in how good we are at these things. There are many people who never develop their sense of touch to the point where they can read Braille. In fact, we differ in a lot of things. The one thing we have in common is that we live our

lives while either blind or with limited vision. Obviously, this fact carries with it several other commonalities, such as having difficulties with getting around alone, having to relearn how to do everyday things, having limited access to information and other things. How does each of us respond to these different - and, certainly, challenging - living conditions? How patient are we when it comes to learning all the new skills? How accustomed do we get to living while blind? Just as sighted people differ in how they approach their lives, so do we. Outside of our own preparedness to live fully - or the willingness and effort to find this preparedness - the other thing that strongly affects us is the response from our loved ones. Their trust that even without the ability to walk or see, we'll be able to find a place for ourselves in society; their support in our efforts to be self-reliant; their encouragement to follow our dreams, even if they may seem difficult to reconcile with our abilities; their willingness to make demands and be willing to provide helpful criticism - all of these are attitudes that can help us view ourselves as equals and become fully realized people who know what they are capable of, where their limits lie and who can accept or request help from others without having it affect our sense of self-worth.

I was upset by my stay at the hospital at Karlovo náměstí. I left after signing a release waiver. I asked them how often they bathe their patients and they told me that it's each Thursday, but that they won't bathe me. There was one nurse whose brother was disabled and he was going to the same institute for disabled people as I was. She had to do all the work herself.

Hearing teachers at boarding schools for the Deaf forced their deaf students to learn how to lip-read and practice using their voices. Deaf students spent long and strenuous hours working with speech therapists and were forbidden from using the language they chose for themselves. This long-term form of oppression managed to nearly eradicate sign language. A whole generation of Deaf students kept this language alive only by secretly signing with their classmates at night in their rooms. If a student had even a bit of hearing, they were forced to wear hearing aids. However, at the time, the technology behind hearing aids was not as developed as today - they were immensely uncomfortable to wear and they weren't particularly

useful. Deaf students developed a tradition of celebrating their graduation from school by throwing those hearing aids away. The oppression they suffered at the hand of hearing teachers caused an entire generation of Deaf people to become distrustful towards hearing members of society. This mistrust persists to this day, largely due to incidents in which hospitals and courts failed to secure a qualified interpreter for communicating with a Deaf person, giving rise to stories of unlawful imprisonments, refusals to provide medical care etc. It is still a common insensitive practice among the police to put a Deaf person's hands in handcuffs, which prevents them from communicating with their interpreter - if they're even provided one in the first place.

I felt stigmatized even after I left the hospital. One woman was caring for my mother while simultaneously stealing her money. The police didn't believe me because of the psychiatric treatment I'd received. Besides, I think it's unfair that everybody has access to this information and berate me for it. All my hospital visits add up to about 15 months. I felt like nobody actually wanted to hear that I was feeling well, something I believe is the main point to living. If that's not the case, then you're preventing people from feeling good while they're free. When I said that I was in a good mood, they always went straight to suspecting that I was in a manic phase. I wasn't the only one who was dissatisfied with the doctors' approach. I heard other patients say that they weren't happy with the approach of the medical staff, but everybody was too scared to speak openly. Until you admit that you're ill, they'll claim that you don't have enough of a perspective on your own illness. You have to sign that you entered voluntarily, otherwise you have no hope of getting out.

As part of their audit, the Supreme Audit Office found, among other things, that between 2010 and 2015, the vast majority of subsidies intended for the employment of disabled people went to the sheltered labor market. Sheltered labor market entities (such as sheltered workshops), where disabled people make up 50% or more of the employees received upwards of 96% of the resources available during this time period. Only a fraction of the financial aid went to the open labor market. The SAO made the logical conclusion that, in this case, the employment policy of the labor market does not

support the inclusion of disabled people – despite the fact that their employment under regular employers is listed as preferable by the Employment Policy Strategy to be enacted by 2020 and the 2015 National Plan to Support Equal Opportunities for Disabled People.

At home, where I can create the right environment, I'm basically not disabled at all. I still have a disorder and it obviously limits me in some respect, but the impact of the disability is lower. In an environment that doesn't disadvantage me as much, I can talk about myself differently and be proud of it. In fact, I prefer calling myself a "*crip*". Calling myself a "*crip*" feels empowering, similarly to how many people in the gay and lesbian community have reclaimed the word "queer" as something empowering – although that's certainly not true for everybody. Even some of my favorite people from abroad proudly refer to themselves as *crips*. In the ten years I've been calling myself disabled, I've been told at least a hundred times that I need to talk about myself first-and-foremost as a person – as if that was something I hadn't considered. In fact, when I was a teenager, I learned "people-first terminology," and I was very into it. But a lot of things in my life have changed, including how I view myself. The idea that I should need to clarify that I'm a person feels massively degrading. No one else is being asked to label themselves a person. Gay men and lesbians are not "people with homosexuality," women are not "people who are female" and footballers are not "people who play football". Throughout my life, I've met a lot of disabled people, but I've never met anybody with disorders so serious that it'd question their personhood.

I think it should be more common for people try and adapt jobs to better suit disabled people. Everybody is under a lot of pressure when they get a new job – more so when they feel like they need to prove that they didn't get the job by mistake. I think it can be too much for a person to handle, which might make them not actually want to go to work. In a way, the initial demands on them are higher than they are for able-bodied people. I think that should change. It would also definitely help if it were easier for disabled people to find housing. My sister, who also has a physical disability, would like to get an apartment for herself and her husband, but the market provides very few options. Landlords

usually don't like having extra responsibilities and when they see that one of the potential renters is somebody on a wheelchair, they immediately assume they'd have additional issues to deal with. So, they opt for somebody else instead. Not to mention how hugely expensive it is to rent an apartment on your own. The state should also improve accessibility, because a lot of places are still very difficult to access. For example, you might want to get a new qualification certificate, but the courses are often taught in inaccessible buildings.

I support the social model of disability, which distinguishes between disability and disorder. A disorder is a physical or neurological condition such as paraplegia or blindness, while disability is something created by the obstacles we encounter in society - such as buildings without elevators or information in formats that are inaccessible to us. To say that someone "has a disability" suggests that these obstacles are their own problem. However, my disability is not caused by the fact that I use a wheelchair, the issue is the fact that my environment is not accessible to wheelchair users.

It's interesting to see how difficult it is for some people to talk to me directly when it comes to things actually related to me. If I'm accompanied by somebody, they'll often just talk to them instead. In practice, it looks something like this: Doctor: "Let him sit down." Or, even worse: "Sit him down over there." So, I'll ask him to show me where "over there" is and the "consultation" continues: Doctor: "So, what's been bothering him?" And I suddenly feel like I'm at a vet and my personal assistant is being asked about a pet they brought over. Me and a classmate of mine developed a way to respond to this - when they ask "what's bothering him," I turn to my assistant and say: "Please, tell the doctor that I have awful chest pains." That's usually enough to make the doctor realize how absurd the whole situation is and start talking directly to me.

I want to develop. I want to overcome challenges. And I often manage to do so. Hope is life. I even have hope that I'll be able to see one day. My blindness was caused by anti-diarrhea drugs given to me when I was less than two years old. My brother, who is three years older, was also administered the same drug and

also has limited eyesight. It damaged our eye nerves. A few weeks ago, there was an article in the news about a protein that might be able to fix damaged eye nerves. Reading it, I was completely beside myself. But I'm worried that it only works for people who are still growing, which would mean that the discovery came twenty years too late for me.

As a child, I was institutionalized. I was there during the week and sometimes over the weekend. At the time, I didn't think it was so bad, because I was a kid. Looking back at what I experienced there, though, I think it was horrible - but I guess there wasn't much more they could've done, given how few of them there were. The small staff wasn't able to provide the sort of care that people can get when they're being looked after individually. With my diagnosis, I probably wouldn't have lived as long. I can't imagine living any sort of an active life there with my diagnosis. It probably would've been enormously difficult and I'd only do it out of absolute necessity. I definitely wouldn't be willing to go back there, not if I could help it.

It was my own dad who brought me to the psychiatric hospital in Bohnice. He thought I wasn't behaving in a healthy way. I began to realize the weight of my parents' marriage that had been placed on me ever since my childhood. I was diagnosed with borderline personality disorder and anxiety. I don't accept this diagnosis. In fact, I think I'm completely stable and anxiety-free. I'd go as far as to say that I don't know what anxiety feels like. The emotions of anger and guilt I expressed were a normal response given the extreme situation. There is a logical explanation for my emotions. I would never hurt myself or the people around me. I remember when I was admitted during my first involuntary hospitalization. I was telling my dad that I've had enough. At the time, I couldn't trust my friends and others around me. I refused to take my Klonopin. I wanted to process the situation and talk about it. But nobody was willing to listen to me. The staff at Ward 27 forcefully stripped me of my clothes and tied me down. They treated me like an animal. I assume I was getting huge doses of drugs, because I slept constantly. I don't think it's right for somebody to be stripped and tied down, especially considering I'm a woman and the staff members were men.

I feel that people are afraid of me. That they get restless or nervous when they're close to me because I'm different and they don't know what to expect from me, where to look or how to speak to me. Nobody prepares them for dealing with difference. They've had it reinforced since their childhood that they should avoid and shun those who are different.

I'm a special investigative officer with the Central Investigation Service which sounds like a big deal, but I could be doing more. "That's all that's available," I thought right after I started working here. I knew I would never be an investigator, but to spend all day behind a computer with headphones on my head? "You should be glad you have a job," they tell me all the time. "And what's more, a job at the police. I know a blind guy who works in a soup factory." That's fair, only a small fraction of blind people have an income and maybe I should be as happy as a clam, but that doesn't change how I feel. I'm a workaholic. I don't have kids and, outside of sports and close friends, I'm always willing to put a nice job that I can lose myself in first. I want to work fifty hours a week, give it my 500%. When I got accepted to the police, I asked at the first interview what my career prospects were. "You've been hired to listen to wire taps, that's it," they told me. I knew what I wanted - to become a criminal analyst. That would mean being a part of the investigation team, thinking about the investigation, analyzing and connecting the available information. I'm still trying. I still have some hope that I can convince the right people that I can do it. I will admit, though, that I've almost given up - the number of issues that would need to be sorted out, especially technical ones, is huge. For example, I would not be able to attach a Braille display to my computer keyboard due to computer safety concerns. I use the Braille display to read what's on the computer screen. But technology isn't the only obstacle. My first boss straight-up said: "I'm not interested in a blind analyst."

Being disabled doesn't inherently mean not being able to work as much - it certainly doesn't suggest being less willing to work. Employment policies should not make assumptions about who is and

isn't employable in the open labor market, since those things are determined by how competent and motivated a given disabled person is, as well as the environment created for them by the employer. If these policies continue to consider certain people as difficult to employ and heavily subsidize the sheltered labor market, then we shouldn't be surprised when it becomes a self-fulfilling prophecy. The much-talked-about inclusion in the labor market is never going to manifest. That's quite sad, because the idea that disabled people belong into sheltered workshops is just as wrong as the idea that disabled kids need to go to special education schools.

During the first two years in primary school, there were some incidents that I didn't think were worth mentioning. For example, one of my notebooks would get thrown in the trash or my schoolbag would end up with my classmates' leftovers in it. I never told anybody because I thought those things were normal. But as time went by, I realized that that stuff wasn't okay. At that point, though, it was probably too late. I had no friends. I was a nobody. One day when I was walking from school, two classmates started running towards me. The first tripped me and pinned me to the ground while the other started kicking me with full force. Then then just ran away and left me there. I couldn't even get up. Although, surprisingly, there were no permanent physical consequences, it's hard to forget what followed after. They treated me like I was a plague. With the exception of a few of my classmates who refused to participate, pretty much everybody else shunned me. Even if I just came closer, they'd start calling me names and say that I'm a plague. They pretended to disinfect everything I touched. It went so far that I tried to commit suicide. I was afraid to go to school. Nobody wanted to sit with me and I had to borrow a pencil from the teacher. That was a huge mistake. It made me realize that if I stayed close to the teacher, I'd be somewhat safe. What I didn't realize was that I was removing myself further and further from the outside world and started losing some basic human skills.

I've been living in this body for a long time now. I rather fond of it. It does what I needed it to do and, much like you and all those disabled people in motivational photos, I learned how to use it to its fullest potential. The people in those photos aren't doing

anything special, just using their body to its full potential. Does that make it fair to objectify them? To share those photos? When people say "I admire you," they think it's a compliment. And I get why. It's because of that lie - we are fed the lie that being disabled makes people exceptional. I don't even know how many times strangers turned to me to tell me that I'm brave or amazing. They're basically congratulating me for being able to get up in the morning and remembering my name. That's objectification! You're turning a person into an object. Pictures like those turn disabled people into objects for able-bodied people. The main idea is that you look at them and realize that you're not doing so bad after all. They give you a different perspective of your own issues. But, in fact, living as a disabled person can be rather hard. There are some things we need to overcome - but not the ones you think. They have nothing to do with our bodies. I use the term "disabled person" deliberately because I support the so-called social model of disability, according to which we are more disabled by the society we live in than by our bodies or diagnoses.

Adults are often nervous when they see blind children running around. This poorly-concealed fear ends up telling blind kids that running around is something that's very dangerous for them. The kids are directly or indirectly discouraged from exploring the world around them and learning what they can do. They don't get enough support and help for experiencing and overcoming small collisions, which would help them gain valuable experience about moving around as well as teach them about their abilities and limitations. Instead, the kids are bit by bit taught to give up on moving and they learn not to express themselves through movement. Among other people, who freely move through space for various reasons, they end up seeking out passive roles.

Get used to my body because I like living in it. Ask what they taught you when you don't know how to accept difference. Stop staring and ask.