

Don't Shine in My Reproducer!

by

Alena Konečná

Whoever receives one such child in my name receives me.
Jesus

Foreword

The story you are about to start, dear reader, is a love story. It is not an essay that would first define what love is, search for its roots and only then perhaps apply used definitions to practical life. The way which we will take as we read it is the way following the voice of the heart that by intuition senses which direction in life to take. Each single part of the way, followed by a new horizon of lived-through knowledge, has to be painfully discovered on one's own. When we watch the development of maternal and parental attitudes towards a child with a serious health disease we soon learn that love is not just a matter of a fading feeling but first of all courageous and repeated act of will. Act by which I tell the other person: I want your good. One Italian love song sings: *Ti voglio bene*. Literally it means "I want your good." but translated into a sentence it means "I love you."

The line of the story of the relationship between a mum and her sick child, between parents and children, well illustrates our experience of the projection of our imaginations and wishes onto the person we want to love: what he or she should be like, how he or she should behave and give our love back to us in return. The testimony about growth in love that you are about to read shows unique process of maturing parental love into the form which is able to perceive and accept the child as he or she is, not for his or her appearance or nice behavior but because this child is a unique Creator-designed being called to life who needs condition-less love telling him or her: I love you as you are. Such presupposed approach then creates prepared environment, as Mary Montessori would put it, for full development of child's all positive potentials. It is not crucial how great those potentials in reality are or how large is the vessel of child's capacities, but it is crucial to actualize, realize, fulfill and bring to life all the potentials. There exists a concept of normality which builds upon a criterion of power: who more, who further, who better. But when we look around and see around us our neighbors who were given great gifts which then remain unused we may be justified in concluding that there is also another important criterion of normality, which is the measure in which even the smallest positive developmental potentials are being realised, regardless of their absolute size. And it the very "YES" said to the child with regard to his or her potential, no matter how big it is, that creates the room for freedom in which these chances change into reality, being watered with love like well cared-for plants. Our story shows us vividly and concretely how our relationship to foster child changes from the relation to our own wishes into the relation to the being real and true: We know about the child everything or almost everything, and in spite of that, or perhaps right because of that we love the child.

Many people today talk about heroes. By that term they mean those who are able to perform extraordinary, unique things which others cannot do. And still there is one other kind of heroism which professor Matějček mentioned above pointed to. It the heroism of the ordinary day, based on faithful and day-to-day acceptance of a difficult fate, in this case raising a disabled child. And such situation which sometimes can become the source of crises and definitely means a great difficulty is at the same time a wonderful chance

that one can, while fulfilling such task, develop the qualities which otherwise might not even occur in his or her personality. That way he or she can contribute to the culture of life and love which makes out of this Earth welcoming and friendly place for every God's creature, for every one, even the weakest or the most handicapped child. Thanks to the author and the protagonist of the story in one person for the opportunity that in her, in her husband and in Deni's siblings we could meet the "week day heroes," the people who are the "salt of the earth" and who make it human and it bread tasty.

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Introduction

Once my friend asked me whether there was any value in love which one has to struggle for, dig it out of the heart because it does not spring out of one's depths by itself.

Yes, I thought of the power of spontaneous unselfish motherly love, capable of self-sacrifice. Truly deep emotion which perhaps every healthy mother has to experience when she carefully places to the cradle the sleeping little bundle just brought from the birth clinic.

And still, even such mother has already experienced the first pregnancy sicknesses, heartburn, hip joint and growing pelvis pain, painful birth-giving, psychic liability of the puerperium, rough nipples, callous breast; and still, there is yet to come a lot of self-denying, countless sleepless nights and lost nerves before she with relief releases her teenager into life. Such spontaneous love also grows up from the mycelium of suffering.

As we were leaving the area of the Infant Orphanage in Brno in year 2002, the eleventh of July, at eleven o'clock and eleven minutes, with the two-years old child on the rear seat, we felt nothing toward her but compassion over her fate. But compassion is not love. We were determined to change it. How far and deep in our hearts we would have to reach we had no idea.

The myth about the perfect foster parents filled with spontaneous love out of pure heart towards the poor orphans will collapse for every reader of this book. We are not like that. Nothing worthy of something is free. And what is free is worthy of nothing. This truth doubles for love.

In the beginning there was a *decision* motivated by compassion. The decision to love a child that nobody cares for. As a tangle of roots that keeps the tree firmly in the ground, we were kept in this decision by the faith in God and Biblical principles, and a univocal support of the wider family which never doubted the rightness of the decision, although we ourselves, tossed about by the winds of doubts, were bending the crown to the ground.

Our thanks then belong to the God living and present, and to the grandmas and grandpas, kind and patient, for not allowing our tree to be pulled out of its roots.

The author

I stand by the sick, sleeping child, touching her gently with my hands, feeling her radiating. The tiredness is overcoming me, I'm looking somewhere through her, and still I cannot avoid noticing pulsing on her neck, sweat-wet hair, and deep, fast breathing. Is this all worthy the effort? The thoughts begin to swirl like flying snowflakes, I feel as if I were watching them behind the window. They swirl in the dark and it is not clear whether they descend or ascend. There is something comforting in the whirl but not meaningful. And the tiredness is like the deepening dark with which the snowflakes contrast. How can one possibly stand it? Where to find strength? Perspective? I am warming my hands over the child's body, heated with fever, the cold is penetrating me. I am looking at the white face, the saliva streaming from open mouth onto the pillow. What do I feel? Fear, compassion, despair, aversion, hatred, love? How harshly the Pandora's boxes open in me—old wounds, learned prejudices. Raw confrontation with myself, something that one would rather not to know about him or herself. Such is this snowstorm.

It all began by watching TV. I was watching a document about the children from an orphanage. Just by an accident. And somehow I was moved. I never thought about it before and now I was crying like an old turtle and my heart was torn to pieces with the injustice perpetrated on those who have been created for Mom's good-night kiss and for Dad's formative smack but instead of that they receive fiscal pajamas and an inculcated hopelessness. Horror. And I never got rid of that feeling. Never.

At the supper I described the document to my husband and we both together cried over the fates of those poor kids, and we agreed what a pity it was that there were not more people willing to take such children into their homes. Univocally we also recognized that we ourselves, regrettably, were not cut for a sacrifice like this. We definitely could not handle it. Well, there are other parents good for such task. Patience and kindness personified, a halo above their heads almost visible. No, certainly not us. Our own kids get on our nerves, let alone someone else's. It is as plain as a pikestaff that God would not want this from us. We have to pray that there would be more parents suitable for abandoned children. The woken-up consciousness was rocked to sleep and could go to bed in peace.

Exactly a week later it happened.

My husband saw a flier of the Association of Foster Families titled
THE KIDS LOOKING FOR PARENTS

He came home and said:

"Hey Mom, what if they're looking for us?"

The child kept sleeping with a deep sleep, twisted a little in an unnatural position. I patted her on her forehead and interrupted the dance of memories with a thought whether it was not the time for next doze of pills...

... yes, pills. We'd been given half plastic bag of pills, several pages of instructions how to use them plus 1× naked child. Thus equipped we were bringing home a little girl from the Infant Orphanage. We had already completed a marathon of psychological tests, a preparing course for the applicants for a substitute family care, piles of read books about raising the children, and personal talks with other fostering parents. We felt prepared enough, determined, and dying to have her, perhaps like the parents bringing home their first new born child. We did not have to wait too long before "allocating" the child, perhaps because we did not have any demands concerning the child's health, on the contrary, we wanted to help some disadvantageous one. And so when they offered to us two years old little Denisa with a heart disease and an immunity disorder, we did not hesitate.

On our way back home she did not communicate at all. She was apathetically staring into space and finally she felt asleep in her car seat. She seemed to me so mysterious, little—the package of surprises.

At home she kept staring somewhere through us and did not respond even to the joyful welcoming of the new siblings. We at least wanted to feed her and oops! We found out that she did not know how to swallow.

Th package began to unfold.

We went through the medicine documentation and learned that because of an extreme lac of interest in food she had to be sonded, in consequence of which she lost both biting and swallowing reflexes. Thanks God, we did not notice the lack of interest in food with her, on the contrary, she ate very, very long, and huge portions, although our first attempts to get food into her resembled rather loafing a goose. Later we discovered some massage exercises to activate the lost reflexes during eating but even so every now and then we had to press in some of the blocked morsels, like with the goose. Sometimes, however, she totally blocked and started choking, then all the children quickly jumped away from the table and protected their plates against the volley of vomit. Average feeding time was one and half to two hours, and the doze of two soup plates full up to the brim five times a day. It became a life style. We could not believe our eyes but it was so. Even more unbelievable was the fact that the first ten days in our home she did not do "big jobs" at all. I examined her tiny body from all over but I could not find out where she was putting it. So I used a purgative but in vain. After a week I became afraid for her health and I visited a doctor. The doctor palpated her belly and assured me that it was soft and the intestines empty!!! A mystery.

Further unfolding of our package brought one shock after another. The first night she was in our place, after the trouble with feeding and the first doze of medicine, we wanted to give her a shower because she was grubby had over heels. We put off all her clothes,

we managed that perfectly, and we turned the shower on...

As soon as she heard the sound of running water she started roaring horribly. Not cry or yell but really roar like a scared-to-death animal. She all stiffened in one big spasm, turned violet, shook and threw up. The food, carefully measured medicine, and our several hours work flew to the drain. By following experiences we learned that she responded in similar way to any noise—a motorbike, a storm, a vacuum cleaner but it was the worst to the running water.

Sleeping, rituals, stereotypes... This all brought about unexpected and shocking discoveries. And so we kept unpacking and unwrapping and believing that it would be alright. We were looking forward to see the gift inside.

The consequences of an emotional deprivation, well, we've read something about those.

We'll make it.

I am watching the sleeping ill. In the light of a lamp she looks even more sallow than usually. A piece of a thick ugly scar, the reminder of the heart surgery, shows in the neck of her nightgown. Thin hands cast over the pillow. Poor little creature, I feel sorry for her.

Back then, I felt sorry for her, too. She just looked terribly. At the age of two she weighted fifteen pounds, her legs with atrophied muscles hanged lifelessly as if they did not belong to her, she all supple like a cloth doll.

She could not walk, even stand; scared grandmas prophecied: "This child will never walk!" The strong-smelling saliva streamed out of her slightly open mouth, she kept staring to nowhere, did not keep the eye contact, monotonously swung to and fro. Most of the times she was silent, the only acoustic mark was the many-hours lasting roaring which nothing and nobody could stop. She was dripping with despair, emptiness, reluctance to life.

If human being is an image of God then she was a picture broken to pieces and treaded deep into mud with a boot dirty of dung.

We so wanted to help her! We believed that we would be able to clean the picture and glue the pieces together, return it to its original beauty. I imagined that in a year she would catch up with her peers, we all would rejoice over the miracle an only insignificant marks would remain out of the original cracks.

I was ready for an action. Several times a day I exercised the Vojta method with her in order to connect up the lifeless muscles and to move the psychomotorical development forward. We pressed the reflexive points for the remedy of swallowing and biting reflexes, and we massaged her whole body to promote the circulation in her coarse, depersonalized skin. I purchased stimulative toys and a hammock for sleeping so that she would not suffer the phobia of bars. We spent sleepless night singing the lullabies when she only cried and could not sleep. We contacted the experts, we tried our best... and nothing.

No miracle.

The child started coughing painfully, writhe and grasp for breath. I am lifting her up carefully, fluffing up the pillow so that her head is higher. She keeps sleeping even as she coughs. We will be the only ones awake. Hmm, I know, I should have compassion for her but I feel so irritated. It is not only tiredness, it is also the feeling that it's all useless.

That feeling came together with the strong sense of frustration, vanity, and despair, by rotation with my fading conviction that it would be alright. It wasn't. It was horrible. People around us, our family and friends kept telling us that little Denisa was making a wonderful progress but I knew that it wasn't it. It was great to see that she started laughing, communicated with others, kept an eye contact, stopped swinging, slept at night, and even hummed *Halee Belee*. But I was too disappointed and tired to appreciate all this. She should run in the park with peers, speak in sentences, and not just learn the first steps and do biggies to diapers.

After more than a half a year of an intensive endeavour the first enthusiasm faded off and a deep depression came. It was as if you care for your garden with all your strength, fertilize, graft, clean of caterpillars, and plant the most expensive seeds, but instead of beautiful flower beds you have just nettles, and instead of sweet apples and pears you pick up only rotten wild fruits. Your work was useless. It is worse than the sense of working in vain or lost time, it is deep frustrating vanity.

Perhaps the worst of all was the fact that I was not able to link up the inner contact with her. That intimate connection which moms have with their kids. She had her own world and that was enough. To the stimuli from outside she responded somewhat like to the weather change. She could be bred like an animal but it was impossible to lead and form the heart as with the normal child. This observation was the most formidable blow which brought bitterness to each day, to each of our efforts, even to her each single progress.

That was the time when I started realizing that something was not in order. I consulted her doctor and she assured me that "She may be little behind but don't be afraid, she will catch up." Next expert we contacted—the psychologist from the Special Center for Children with Combined Defects—came to the conclusion that "The child is well-adapted into the family and you should draw from the good feeling that you've helped he kid from the institution, I can't understand what you're complaining about."

I see, I thought, the experts say that everything with Deni is OK and we should feel happy.

But we don't.

Something isn't right. And it is not her.

Hmm, it is us.

We are not making it.

We've failed.

But what next?

My heart trembled as I recalled the coldest period of my life, as if I for a moment occurred in the middle of a blizzard. Is it really over? Have we moved on? I am looking at the sleeping child. She knows nothing and never will know. On the pillow next to her there lies a big pink cuddly pig. She has three more soft pigs in her bed. One red, one white, and one pink which she got from the doctor at the Intensive Care Unit when she underwent the hip joint surgery last year. She loves the pigs a lot.

Once, a long time ago, our kid drew a picture of our family enchanted into animals. We all were wild beasts playing together whereas Deni, the pig, dug some food in the mud, away from the rest of us and turned her back toward us. I was surprised how precisely the children captured Deni's position in the family. But they were not frustrated by it, unlike me. I wanted to make her a beast.

That pig in her bed she has not just for comfort of the soul. It is the Coward Pig and Deni hugs him so that he is not afraid in the night, and also that her hands and attention have something to be concerned with. Other cuddly toys also function to prevent masturbation. Yes, it is a shock. Such a small child and this... A wave of emotions raise inside you when you hear about it. And I can testify that even greater when you see it. The opinions vary, dominant position is not to draw attention to it, not to stop it, let them have it at their pleasure. I couldn't help but I did not allow her to have such pleasure. For one reason, she was able to start doing it whenever, wherever, and on whatever, and then, we noticed that after doing it she is by no means more satisfied, on the contrary, she more falls into her own world and loses the taste for contacts again.

When I first saw her winding around a bar in her bed and panting, and when I realized what she was actually doing there, I was flooded with a great revulsion. I had never experienced such a strong emotion before. I tried to convince myself that it was not her fault, that it was an expression of emotional suffering in the institution, that I should rather feel sorry for her... But it did not work. In the moment when I held her sitting on my hip and she started satisfying herself with me, a grenade of hatred and aversion exploded in me. I am trying my best here and she can do that! I had to go away from her presence, into other room, I knew it was more than I could handle.

I was at the end of my rope. There was so much to swallow, to fight for. My each spontaneous reaction was wrong, I could not feel nothing toward her but aversion. I hated myself for that but I could not help it. Thanks God my husband worked at home and he could help me with the care for a hated child. There are moments when I was trembling with anger and was afraid that I might physically hurt her. I wished that perhaps she would die...

Remorse about such thoughts, sense of a failure, disappointment with myself. I never thought that such ugliness hides in me, such evil, ability to hate a little child.

Faugh!

I was ashamed and I prayed for my own reform.

I realized that this was not the battle for her change for the better but for ours.

Frosty memories were interrupted by another cough fit. This time I was really sorry for her and at least inwardly I apologized to her for everything she had to undergo with me. I pat her and I wish I could pat her soul, too.

... well, these were the times. Perhaps as if the snow melts down and all the dog's poops show up. Not that I thought myself to be good, I knew my weaknesses, at least I thought I knew them. But this child discovered in me layers I had no idea about. This truth was unbearable. I knew that I could not stand when the children get out of their bed after eight p.m., then I yell at them and I have no patience for their trips to bathroom and for drinking.

But this was deeper. This truth reached down to subconsciously learned patterns, prejudices, and implicit expectations. It burnt and hurt and could not be ignored. Horrible. Perhaps as if you get to a dentist with some severely painful tooth. There's no way back.

In the worst times my friend, a believer, told me: "The Lord wants you to just love her." That was a shock for me. I was hit right between the eyes, my mind went blank. I was staring at her and thought, what can she know about it? We don't know one another so well, some time ago we attended the same church, now she was in our place only overnight, I told her nothing about my experiences, she's an ordinary scrub-woman... But in my head Jesus' words came up: *I desire mercy, and not sacrifice.*

But it was so hard. I sacrificed for Deni my free time, comfort, sleep... And everything was easier than just to love her. As she was. God created her like this, He gave her to us like this, she is and will be like this, as He wills, not I.

Suddenly I saw how I, totally subconsciously, applied the same conditional and intolerant up-raising on my children, too. But they were healthy, emotionally fulfilled, they managed to meet the expected demands.

Hmm, I guess I really have to change.

I am peeking at the watches. It is time for another doze of medicine. I am waking up Deni carefully.

"Is it moahnin?" she asks.

"No, not yet, you'll just swallow this pill and go to sleep again, OK?"

"And will there be a suppel?"

"Yes, there will be supper, breakfast, and lunch but you have to sleep first. Now quickly eat this pill."

She willingly swallows the pill and drinks a cup of tea.

"And here are no spooks and storm was in Blno, here were planes."

"Yes," I reply with a calm voice, "there are no spooks here, the storm was in Brno, and that's far away. The noise in the sky was caused by planes, not storm. You don't have to be afraid."

To change, easily said. But how? Until now I also tried but it was good for nothing. I controlled myself when I was going mad, I took her on my lap and patted her even when I didn't feel like it, and still there were situations which proved that these all was just an effort but not a permanent change.

As I examined my motives I realized that what frustrated me was my own attempt to get the child somewhere, move her forward. But I hesitated to leave it. Even own children one leads. Took the responsibility, knows what is good for them and what is there to be avoided, has presentiment of the next step and leads the child toward it. Yes, a parent wants to raise his or her children.

But here as if it was not possible. She was sifting through my fingers. I tried to watch Deni more. The way she played, what was important for her, what she laughed at.

I prayed that I would be able to understand her and not condemn her. It sounds harsh but it was so. Not condemn. For example, the joke number one for her is her own fart. It always makes her laugh. And as she laughs, loudly and relinquishly, she farts again. And the more she laughs the more she farts. Or I was angry at her because she destroys toys. Everything is broken, cuddly toys have their eyes and noses pulled out. I could not get it.

Then I noticed that she did not conceive a toy as whole and that she did not know what it was designed for. She does not know that a little car is a model of a big car and that it should drive around. Even when you explain it to her she would not understand it. She sees wheels but she does not know what to do with them so she examines them, turns them here and there, back and forth until she breaks them off.

Once I gave the children an old mattress to play on. There's nothing to destroy on it, I thought. They would tumble. When I came in half an hour later, the mattress was on the floor split at the seams, the springs jumped out of it, small pieces of the plastic foam everywhere. And next to it there's sitting little Denisa with uncomprehending look in her face and with a thread, stewed on her finger, which she unpicked and thus liquidated the whole thing... She absolutely could not get why I was mad.

Trying to understand her and not condemn did help. I saw that I needed to be connected to her. I cannot be a step ahead of her. I do not know what the next step for her would be, when it would come, and in which direction. I will be with her and when it comes I would support her to take it.

So I realized one big truth. How misleading it is to have my own ideas about the children and force my own way upon them. We do not know where God would lead them. The Bible instructs the parents *Train the child in the way he should go.*

He, not we.

Deni slept again with a deep sleep. I had to turn her pillow, pretty much wet of her saliva. We say that Deni does not seal. It sounds funny but it is not so funny. She loads full mouth with chewed-up food which drops and streams down onto her chin and dress the whole day until somebody reminds her to swallow it. She snores loudly, I better close the door to the other children's room.

She has her own room. It is the necessity. She does not understand the rules and have difficulties applying them into her life. And when she learns a rule it must have no exceptions. It is harsh and it brings a lot of misunderstandings. I recall how painfully we discovered and enforced it. We had Deni about a year, she came to life a lot, started talking and playing with children. Sometimes children played with a ball throwing it down the stairs. Hop, hop, it bounced the stairs, down it bumped against the wall, a lot of fun. But Deni was not able to distinguish between a ball and other objects in the room. And so quick! There went a car, a stroller, a chair, or box of Lego flying downstairs. Nothing could be done, we had to prohibit her throwing downstairs anything.

There were also embarrassing situations when in the park she was not able to distinguish between our lunch-bag and someone else's. And so she grabbed out some cookies out of a basket under a stroller of some other mom, she ate the crumbs which some elderly man was preparing for birds on the bench, once she even pulled out a roll from the shopping bag of a lady in the supermarket. We had to set up a rule that she must not take the food for herself, she can only get it if she asks for it. We had to punish her for breaking it and avoid all exceptions. It was clear that like shit she could not exist among people and that some rules she just had to perceive.

It was really hard. Even as I tried to be sensitive to her and to respect her, such situations were very embarrassing. She demanded a full time supervision and strict rules. The people around us often criticised us. We heard voices like "Why have you taken her in the first place? Wouldn't it be better for her to stay in the institution? You are far more strict to her than to your own..." etc. The grandmas could not understand why we would not allow her to play with the content of their purse ("Oh, let her be, I don't mind, she'll have something to play with for a while!"). And they did not believe that she would play in the same manner with the content of a purse of a lady in the tram. Our friends who came to visit us could not get hold of why they could not hold her on their lap and put up with some subtle intimacies ("Why, we're your friends!"). But they did not see her crawling to the lap of a lady in the church and peeking behind her neckline; walking into the open door of someone's house, intending to talk a seat at the table there; getting in a car just because it had an open door and a freckled teenager waved at her. Yes, it was both scary and a shame with her.

Often, as we came in some fellowship, we asked that nobody would feed her, hold her, allow her to wheedle out of them watches, necklaces, etc. We could not afford an exception. We were encouraged by the stories of other foster parents who did the same and it brought about a good fruit. But it was hard to endure. People condemned and criticised us.

I knew I had to draw strength from God, not men, and I learned that for someone in need, an expressed trust is more important than a judgement.

Oh well, I sighed, somewhat involuntarily. Where did the need to fight for that child even against myself come from? I am watching her as she sleeps. This year it is going to be five years that she has been with us. It seems to me like a hundred. I am going around other children, too. They sleep quietly, muffled up in their blankets, they are so cute! I am flooded with a warming feelings, contrasting with frosty tiredness over Denisa.

Oh well. But it is just so. Smart and lovely children evoke positive emotions in people around them. We tend to reward such children, as if it were their merit. And we mothers often think that they are our pride, and we love to expose such kids as our banner. But what if it is not so?

There were moments when I despised her. She did not look much attractive, asymmetrical body with skinny limbs, atrophied muscles, bulging belly, her dress wet of saliva, permanent snot around the nose. Because of her bad motor activity she moved like a puppet on the stage, her head bowed. She had a habit of looking to the ground all the time, therefore she often fell and hit the things and people, and at the same time she thought that it was someone else's fault. So she hit the door and cried: "It was Domi, he pushed me!"

When I tried to teach her something, she would not understand, and, on the contrary, she learned such things that we could not get it. For example, she noticed that we flush the paper handkerchief to the toilet when we don't bother to carry them to the trash can. That knowledge she applied in practise by flushing the clothe ones, and some toys, too.

When she learned to talk and started to open her inner world to us, I also had to fight with despising feelings. At age of four she called all female persons *grandma*, by which she embarrassed twenty years old students. To the teenager on the bench she told: "Daddy, I'm your grandma!" As far as I can remember, she did not get any reply. At age of six she began to create intriguing sentences: "I will wear a cap because so that I could sleep and swim in the pool."

Often I had on the tip of my tongue: *She's so stupid, this is impossible!* Condemning thoughts automatically jumped into my mind, as if I were programmed. I recalled long-forgotten words which I overheard as a child when the adults talked about some not so clever child: "...*their boy is a simpleton, poor parents!*" And they offered themselves as an interpretation of current situations.

I felt strongly influenced by society norms, by the ideal of beauty and intelligence which is being imposed upon us as the task of the day. I also thought about a million comparisons with the children of the same age but incomparably smarter, better.

Yes, better. I felt this word burning in my conscience. Because—what is the measure of what is better, and why? What better quality is there in a child with a different starting line and a different potential? As I searched my conscience before God and asked him for transforming my heart, I realized how proud and distorted was this world-view. How it supports in us the matrix illusion of the vanity market so that we forget to collect the

treasures in heaven, where moth and rust do not destroy, and where thieves do not break in and steal.

Once again I look at her as she sleeps. Tiny head, vaulting forehead, sticking out ears, hay-stack hair, the scars of catheter on her neck. I have to slow myself down in the detail examination. It reminds me of the time when I almost drowned in it.

I was preoccupied with her too much. With her and with myself. With her, because she was so horrible, and with myself, because I was even more horrible. It filled up all my life. Uncertain prognosis and inability of the experts to explain what was going on contributed to the worsening of the situation. Our relatives and friends must have been overloaded with our criticism of Denisa's behavior. Regardless of all my effort and a change of heart and attitudes I still subconsciously searched for assurance that were normal parents, capable of love, that our reactions, although wrong, were still understandable, that it was really hard with her. What humiliated me the most was when somebody, trying to encourage me, minimized my experiences and outdid my describing of troubles with Deni with stories about difficulties that they had with their children, and enthusiastically comforted me, insisting that everything would be alright and how Denis is wonderful and sweet. After such encouragement I felt as if I'd just had a portion of mud and chickweed for lunch. In contrast with that, a blessing for my soul was every listening, patient, and not judging ear. Until today I thank God for friends who, in moments like these, were able just shrug their shoulders, offer me a handkerchief, and take the whole glorious Denisa with her snot for a walk.

Once, when I was really in despair, I managed to contact professor Matějček on phone. He advised me to get some rest without her. On regular basis. First I was disappointed, I expected an advise effective and definite like a scalpel. But then I obeyed him. I had to overcome the guilt feelings that I was abandoning her, that I did not care for her the whole day, and that I was bad mother, but it worked. She started attending a stationary for children with combined handicaps where she was half a day, at it was a true relief for me.

In about that time our twins have been born. Lack of free time and a full time busyness brought about some relax to my relationship with Deni, too. The circumstances forced me to stop worrying about our relationship and its development. And I think it was good. Life does not end and fall with one difficulty.

Life goes on.

My thoughts turned to the twins. I'm coming to look at them into their room, the tiredness is leaving me, I have overcome the evening crisis. They both are snoozing contentedly, I am patting them over their hair. From Deni's room deadened cough is audible. No change of them.

Had I overcome the crisis also back then? And once forever? True enough, much got loosened, became pliable, but certainly did not disappear. Rather, we learned to live with it. Learned to carry, know how to rest. Know the important things and throw the unimportant ones behind our head because we would not have strength to carry them.

I realized that as we planned to have a child from the orphanage I subconsciously demarcated certain budget of strength and patience for her. And she overdrew it multiple times. When I thought about returning her back to an orphanage I knew how drastic it would be not just for her but also for our other kids. What would we tell them by doing such thing about themselves! If you don't "meet" the demands and expectations, you follow her!. Oof, horror! There's no way back.

But when the three and half years younger twins began to catch up with her, it became clear that this did not just appear to us, this was not just a fading psychical deprivation, neither being just little slower in the psychomotorical development.

Moreover, there were still some anomalies. For example the need of rituals, spasmodic insisting on maintaining them, the necessity of small rules prevailing rain or shine. When it is time for her to go to bed daddy must sing *In the Morning, the Whole Day and Three Piggies*, pray with her and play the CD *Of a Dog and a Cat*. All cuddlies have to take their place in bed and a lamp must be on. If something is not exactly this way she reacts with anxiety, long cry, and despair.

Another problem is illnesses. She does not understand why something hurts and she thinks that it is our fault. Because of a flu she is able to stop talking to us, cry desperately for hours, and fall back to lower developmental stages. Even worse are her reactions to big life changes like moving or changing a kindergarten. She is able to fall in several months long depression and regression including dirtying her underwear, dabbling in food, etc.

We suspected mental retardation.

Our suspecting was confirmed by an examination in special pedagogical center which was supposed to help us decide about Denisa's further education. The psychologist talked to me very sensitively and carefully, with long breaks. She informed me, beating around the bush, that Denisa had IQ fifty-four in overestimated test and with help, therefore the real values do not even reach fifty.

She paused and expected my breakdown. But I was rejoicing. I wanted to shout with joy. It was as if she just told me: The whole time your feelings were correct. YOU ARE NORMAL!

When she saw that I was not breaking down but rather was interested in concrete next steps he explained to me that for ambitious parents the truth about their children is unacceptable; they often force the children to a performance over their strength. Hallelujah,

I thanked God that this was already behind us and that this truth had not brought me a chock but rather understanding the past and envisioning the future.

Perhaps it sounds absurd but for me this message was really liberating. I learned that I was not a bad mother when my child does not grow according to the tablets. It does not mean that I am doing something wrong or with not enough effort. Now I could search for the literature, and contact the parents of the children handicapped in the similar way. I could learn that to have ambivalent feelings in raising mentally retarded children is normal. It is impossible without them. The only question is, how to handle them. I learned about the need for rituals, rigid rules, stereotyped thinking, and I saw in it our own problems with which we were at our wit's end. It helped me to know her better, understand her, know her maximum and tolerate her minimum.

And so we made plan to let her attend the special school with a helping program. It is more important that she is happy than educated.

The cough is getting stronger. I am coming back to Deni's room. She is coughing terribly and crying from the half-sleep, smearing the snot all over her face. I am trying to make her blow her nose but it doesn't work much, she is cooperating with difficulties, and crying is making everything worse. I am adjusting the pillow so that she has her head higher and I am trying to comfort her by singing Halee Belee. It works, she is calming down and falling to sleep.

It is interesting to see how simple melodies like that work on her. It was the first way of making connection with her after we brought her home from the orphanage. These melodies penetrated into her almost autistic world and brought her back to life. Before she could speak she imitated the speech intonation and hummed melodies. She likes singing a lot, and she sing surprisingly in tune. It is as if she had a tape-recorder in her head which records the melody that she hears, and then plays it back. It is not distorted by reason, asking whether it is beautiful and precise enough, perhaps as healthy children do, and so her singing has a special magic and serves as a windows to her soul.

Anyway, her soul is much different, special, and in order to get there one must bother to search for the key and perceive her rather oneself. We adults are oriented on verbal part of a message and if that doesn't work, oops! we do not know what to do with it. We think that we express our love to the children by asking how it went at school, whereas the most of them would rather prefer some rampaging, tickling, cuddling... And for such non-typical children this truth doubles.

I have to keep learning how to see and understand Deni's world through her expressions. It is similar to looking into a house from outside. You have to look through the window further in; if you look at the window itself you might get confused with old frames, flaked off paint, dusty glass, tousled curtain, dead flies on the ledge. The mentally retarded do not care about the windows design, the do not arrange the curtains and maces, nevertheless there can be something beautiful and precious inside.

Only to see it!

I am smiling in my heart and perhaps on my face, too. My hand on her violet blanket with dinosaurs. Deni is snoozing like an infant and I am recalling both the situations when I could peek inside and when I got caught too much by the worry about the tousled curtains.

Let's take first the curtains. The food is for Deni one of the fixed points in the universe. She thinks of it wherever she goes, and all the time she wants an assurance that there would be something to eat. In the morning she fears whether there would be a snack, lunch, and another snack in the kindergarten. (Once she ate the snack even from the teacher's table!) As soon as she gets home she reports being hungry and makes sure that I plan to make a supper. She likes eating very much and she eats very much but it is interesting that she does not have the feeling of hunger connected to the taste. She can eat four rolls with a chocolate cream but over a bread with cheese she declares that she likes honey and a chocolate cream and that she doesn't like this. If I force her to eat it anyway, against her protests, she eats slowly, swallows hardly, each bite turns three times in mouth before she finally swallows it with a look of an invincible aversion in her face.

On the other hand, if she likes something she shows no idea of proportion in eating it. She is able to overeat until she throws up. She is also fascinated when someone else eats. She sits next to a person and from the distance of six inches she watches the movements of the cutlery, lips, teeth, decrease of the food on the plate, and raises questions like: "You have eating, don't you? And you like it, don't you? I like it, too." We are trying to teach her not to do so but with a little success. It is better not to get excited too much and take it as it comes. Just curtains. But sometimes one gets tangled up in them. (And from the table you can hear: "Denisa, don't shine in my reproducer!" "Mom, she is staring into my mouth, tell her to stop!")

But other times I catch a glimpse of something very nice inside. It is not covered by gloss of hypocrisy, by trying to look better, by calculating expediency, or by cunning, she is not capable of anything like that. For example if she sees somebody crying she cries too. This is something that we do not know. We rather ask questions and give instructions: "And how exactly did it happen?" "You see, if you did not do what you ought not to it would not happen to you!" "It's your fault!" But Deni does not care who's fault it is, there is a pain so it is time to cry.

Or she likes to help a lot. She loves to be helpful and it brings her joy to cooperate with somebody else. And so we rake the grass. She can keep doing it as long as necessary, even several hours. And she is happy how nice it is to work together. For other children, the healthy ones, it is just a bothering duty. They do what they must, have remarks, and rush away. It is not fun for them, they prefer more sophisticated tasks, they delight in delegated responsibility, they want to be creative, assertive. But not so Deni, she loves simplicity, monotonousness, predictability.

I say to myself, how great it is that we all are so different, equipped with various abilities, potentials. And how deceitful is the ideal of beauty and intelligence which rejects all who are not able to reach or even see it.

The blizzard of my thoughts is slowly turning into peaceful and joyful dance of big snowflakes. Gratitude is filling my heart and changing the tiredness and hopelessness into calm and deep joy of knowing that everything is happening as it is supposed to. That this road of mine, although often steep and bumpy, brought me to the knowledge of the things that are eternal, valid beyond time or space. Now I understand why the Native Americans cherish the mentally retarded and consider them to be the speakers of the divine. In their world they do not play at prestige, the hunt for the money tells them nothing, and the cellulite does not jeopardize them. There rule the laws of heart, the original ones, as the Lord God has created them.

The Methodist Bishop of Mississippi, Jack Meadors, tells a wonderful story of an incident that occurred during the Special Olympics many years ago. Nine children lined up for the 100 yard dash. The gun sounded and the race was off. But only a few yards into the race, one of the children fell and began to cry. For some reason these challenged children did not understand the world's concept of competition and getting ahead and taking advantage when a competitor was down. The other eight children stopped running and came back to their fallen comrade. A young girl with Down's Syndrome kissed him and brushed him off. The children lifted him up together, arm in arm, they ran over the finish line. The audience rose to their feet in applause. There was not one winner, there were nine winners.

I have heard about some adoption agency in the U.S.A. which focuses on arranging adoption of the children with Down's Syndrome. The agency's clients are the parents who wish to adopt a mentally retarded child because, after some experiences, they desire to have such "sun" in the family.

Deni came to our family as such sun, too. Without her knowing about it, her presence shed new, sharper, although not always desired light on everything. Black dumps were uncovered and the skeletons had to get out of their closets.

Deni's consummation of much of our attention, hand in hand with the necessity to constantly watch her needs, squeezed our family into a sort of pressure cooker. Ordinary life goes on under higher pressure and temperature. It is a great onrush for other children, too. They have to learn to accept her along with her handicap: love her even though she is different, tolerate, respect, forgive, and not patronize her, and at the same time not let her abuse them and be able to set the boundaries the way she can understand, and perhaps even "beat her up" a little, if necessary. Some times it is very rough but so what, I say to myself, at least we all shall be boiled sooner.

And so I am thankful that God gave her to us although we ourselves would never opt for her. She has brought us to a deeper thinking about both ourselves and the things that we subconsciously believe and then apply in raising the other kids, too. She has taught us to be thankful for each good day and rejoice over little things that we used to take for granted before. Every single progress is worthy of celebration even if it is just the ability to put on her stockings right (at age of six). After all, every child deserves ovations for a progress, no matter how far from the norm he or she is.

The example is her memory of the heart. What she lives through in emotions she remembers very long time and it does not fade with time. She experiences the summer storm and then the whole year she gets scared when she hears loud rumbling sound and looks for the sky coming over cloudy. She experiences Christmas and every day she repeats the list of what she had received. She knows about every little present, she remembers nice visitors, trips, and she is able to rejoice over old experiences again and again. I wish I too could use the power of beautiful memories when I am stressed with worries and I am losing hope! And also remember the bad things and not repeat the same mistakes again and again just because "perhaps this time it's not going to be so horrible."

I have read that the mentally retarded do not understand the world around them, that is why they need somebody who would be their protector, refuge, and the source of security. I see that it is so. Deni, through this need, has found the relationship with me and given it the unique place in her life. I know that other children grow in their both physical and psychical abilities, know the world, conquer and overcome it, and break away from us parents. But not so Deni. On the contrary, the older she gets the more she knows that she does not understand it, and the more she hangs on me.

This brings me to the sense of responsibility and humility. Humility before God. I too, the more I get to know the world around me the more I feel the need to trust Someone who understands it here more than I and who leads me on my way and knows where.

I am patting little Denisa on her hair, it seems that the medicine is working and the fever dropped down. I am passing my hand over her forehead, it is really colder, the cheeks also are not so red of warm. She certainly feels better.

So do I.

Suddenly she woke up. Perhaps the movement of my hands, or some dream, disturbed her. She is looking at me—or maybe through me—pupils widened, light blue eyes. They remind me of heaven. As I am looking in them, it is as if I saw emptiness, in which nevertheless the angels are flying.