

Bulgaria: Monologue of a Mother

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Thirty years ago, I had a happy marriage and I gave birth to a son, and later I had a second child. I had a normal birth and devoted myself to looking after the baby. One day, while sleeping, my baby cried and I could see that he couldn't breathe and turned blue suffocating. I called the Emergency -- the doctor on duty was not a pediatrician. He looked at my baby and said: "The baby has a handicap. It is a rare syndrome and there is no treatment for it."

I was asking myself -- why nobody told me anything, was the doctor so ignorant or he just didn't care? I remember regularly visiting the baby centre the first seven months for examinations and vaccinations (later on I understood he shouldn't have been given the vaccinations). The pediatricians kept silent and nothing was written in the medical file of my baby.

After three months of consultations with specialists, I understood nobody could treat Down's syndrome. He got ill very often. He grew bigger very slowly and when I took him in my arms, he felt like a cloth ball without any strength in him.

And then, I received a letter from the hospital. I had to go there for a check. I met there 15 mothers with their 15 small children just like my son. A commission of several doctors examined the children and then they explained that, with time, we would have more difficulties caring for the children. The children would not be allowed to kindergartens -- they would need special training, staff and care -- and the state had provided these for such children with mental and physical disabilities.

There had been special hospitals for children where such were taken care of and medical services were provided, special education was offered to the children, like anywhere in the world (we were told). We had time to think it over.

My maternity leave was coming to an end. I had to go back to work. I had to take care of my other child and there was no one to offer help. We decided that we should give our child away -- it could be for the better.

The institution, where the children were taken to -- three enormous hospital buildings surrounded by high walls with a big entrance door with a guard -- was situated in an ancient forest. We were told we were not allowed to visit and we would be informed about the "changes" in a written form. After 3 months, we received a letter, saying that the children would live not more than 2 or 3 years, and several medical papers with different diagnoses.

A year passed and three of the mothers were asked to go to the hospital. We were told that our children had died and that the state had "taken care" of everything.

[...] My daughter, whom God sent as a gift, is an IT specialist. One day, she had to try a new database programme based on the equivalent of the Social Security Number of people. She had entered our family name and on the screen had appeared the full names and numbers of our family members, including the name and the PIN of her "dead" brother.

She started an investigation and she found him in an institution for elderly people, 30km from the town we live in. There had been no documents for him in the files of the institution. She had gone there to visit him and to assure herself that it had been him. One day she told me, "Mom, your son is alive!"

When I entered the institution, I saw the awful living conditions. Patients in rags walked around in the open without any shoes on, alongside people with walking sticks and in wheelchairs.

I asked the social worker for my son's documents. I was told that the young man had no birth certificate or other papers. He had come from an orphanage, had no parents and could not hear or speak. They brought him -- a young man dressed in torn clothes, dirty and smelly. He hugged me and uttered with a smile, "Mom!"

I took their food and clothes. I insisted that the staff gives him a bath and dress him properly regularly. And he looked like a new person. He was not deaf. He couldn't speak, but

understood everything. His medical file was in such a bad condition that it seemed to me someone tried to erase information and cover a mistake. He needed medical examinations and treatment. His health was in a very bad condition. I found specialists and took him to the hospital for a treatment. I looked for information. I had to find a way to take him away from the awful life he had in the institution, but I was on my own.

Then I met representatives of The Regional Society for Support of People with Mental Handicaps, a branch of the Bulgarian Association for People with Intellectual Disabilities. The organization works for the improvement of the situation of people with intellectual disabilities. It had built the first community group home for such people in the country. Four young men lived there, supported by teachers who help them learn skills for independent living.

My son, who is 31, was lucky to go to live in the group home. The living conditions there are excellent. The care is continuous. The residents also have labour activities -- they embroider tapestries, knit tablecloths, make cards. They also grow flowers and vegetables.

Now my son is a new person, full of strength and energy. He knows the alphabet and uses 15-20 words. He can write dashes, circles and commas. He knows how to write 10 letters and he can count up to 10. He learned how to put his signature to a document -- and before he was considered illiterate. He learned new skills, he puts everything in its place and he is very disciplined.

X. Y. (Bulgaria, 2004)