

Bulgaria: Give the children of Dzhurkovo a chance to realize their dreams

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Dzhurkovo is a small village in the Rodopi Mountains -- a magnificent range in Southern Bulgaria. From Plovdiv, the country's second largest city, one travels south for about 35km on the main road towards Smolyan. At the turn-off to Laki, a smaller road winds for about 15km through Yugovska river gorge. The scenery is stunningly beautiful.

The steep mountain sides are covered with pine forests with jagged rocks occasionally protruding as if reaching out to the clear blue skies. There are no signs that human activity has in any way affected this region, until just outside Laki, where an abandoned strip-mining site rudely reminds us of another era when industrial plants were a mark of progress even in the most virginal settings.

From Laki, it is 9km up the mountain to Dzhurkovo, which stands at close to 1,400m altitude. In our car, this part of the journey takes about half an hour in good weather conditions. In winter, it is difficult to imagine that this road will always be passable for the local bus that brings most of the medical staff to the institution found here or the vehicles that bring food and other supplies.

One enters Dzhurkovo social care home for children with mental disabilities through a paved yard with a high metal fence. The fence is probably hardly ever locked and the courtyard is paved because it would otherwise be difficult to use wheel-chairs outside the building. Anyone in a wheel chair would not be able to venture far beyond the paved yard.

Dzhurkovo children are safely isolated. Few will know of their existence or be painfully reminded of how little is provided for the most vulnerable members of society. For Dzhurkovo children, because of the serious nature of their developmental impairments, have been abandoned by their families and the society at large.

It is June 2004 and, since my first visit in October 2001, the number of children in this institution has been slightly reduced. There have been further improvements in the furnishings and state of decoration of the dormitories. There have also been some improvements in the general care, particularly for 43 children who are considered "bedridden". There is now a doctor on site. But these are very small steps and far from adequately meeting the children's needs.

The Dzhurkovo staff-members appear caring and deeply committed to providing the best for their charges despite their limited means. Their numbers remain grossly inadequate and most lack appropriate training. None of the children appear to have ever had their needs adequately assessed. Their individual programme plans seem superficially drafted. Even an effective implementation of these programmes would hardly begin to address the children's needs for rehabilitation and education.

Only their elemental needs for food and warmth and a clean environment seem to be fulfilled. The equipment in the room for physical rehabilitation, donated by a foreign charity, looks as new and unused as on my first visit.

Dzhurkovo succeeds in keeping the children alive and well out of our sight. On my first visit, the fate of Vera D. was deeply impressed in my memory. Her contorted body was so emaciated that her skin appeared very tightly stretched over her bones. The nurse on duty told us that she had a terminal liver disease and was wasting away, even though she was reportedly given large quantities of food.

Vera held the visitors' hands and appeared to be very calm and pleased with the attention she was receiving, albeit very briefly. Her underclothes were wet, which the orderly on duty had not promptly detected and changed. From her medical records, it was established that Vera D. was suffering from cerebral palsy. There apparently was no diagnosis of learning difficulties and she may in fact have fully understood the circumstances in which she lived, but was unable to verbalize any feelings or thoughts. Trapped in a body, she was never allowed to learn how to manipulate or communicate with the world around her.

Vera D. is still in the same dormitory on the second floor -- the second cot on the right hand side as one enters the room. It is a wooden cot, which is just long enough for her. She looks healthier and smiles at the visitors, a rare treat. I learn that Vera D. is 20 and that the staff had not requested for her to be transferred to an adult institution as they were afraid that she would not receive the same care there. She has probably spent most of her life since the age of three in this room.

I recognized another face in the same room -- an eight-year-old girl with Down's syndrome. On my first visit, she had been in the larger dormitory together with 11 five- and six-year-old children with Down's syndrome. Their physical development resembled that of one-year-olds. None of them could stand independently without holding on to the sides of the cot. There were two orderlies in attendance at the time of the visit, but there did not seem to be any organized activity for the children.

One of the girls had chewed the top of the cot frame. When this was pointed out to the orderly, she replied that the cot had been recently repainted with lead-free paint, appearing confident that this was done with concern for the girl's well-being. There was no understanding that the girl had been driven to chew the wood because she lacked attention and means to occupy herself in any other way. Three years later, I find the girl still standing in the cot, holding on to the side and chewing it.

Sadly very little has changed in the life of most Dzhurkovo children since my first visit or since the publication, in October 2002, of Amnesty International's report *Bulgaria: Far from the eyes of society, Systematic discrimination of people with mental disabilities* (AI Index EUR: 15/005/02). This report included detailed observations regarding the situation of Dzhurkovo children. It also contained recommendations, which, if effectively implemented, would have appropriately addressed the children's needs.

Little has changed and I am concerned for the children and I sympathize with the staff who work in this institution. What I cannot understand is the reasoning of officials in Sofia who bear the ultimate responsibility for the well-being of Dzhurkovo children. In early September, Amnesty International was informed by the State Agency for Child Protection that a commission, following its visit to Dzhurkovo, concluded: "[The institution] could be modified for children from 10 till 18 years old... For children under 10, [adjustment to]... the cool climate is very difficult because of their physical disabilities." How can anyone with any insight into the needs of children, regardless of their abilities or impairments, consider Dzhurkovo a suitable environment?

Winter in Rodopi Mountains comes early and the children in Dzhurkovo are still waiting for their chance to live like other children in Bulgaria. Children who live in families, attend schools, play with their school-mates; children who have dreams to realize -- children with a future.