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Children of Dzhurkovo denied life of dignity and respect

Until recently, living conditions in many homes for children in Bulgaria were so poor that they amounted to cruel, inhuman or degrading treatment. In many institutions improvements took place as a result of government efforts and contributions by non-governmental organizations. The material situation for the children of Dzhurkovo has also considerably improved since the winter of 1997 when six children and one 18-year-old died from hypothermia and malnutrition. But clean sheets, warm dormitories and basic medical care are not sufficient for the 69 children of Dzhurkovo, a remote village in the Rodopi mountains. The lack of continuous assessment, treatment and rehabilitation by therapists, psychologists and physicians is profoundly damaging to the development of the Dzhurkovo children and deprives them of their fundamental right to life with dignity and respect in violation of international human rights standards.



View from Dzhurkovo, Rodopi mountains, June 2004 © Al

Two and a half years following Amnesty International's first visit to Dzhurkovo, a delegation visiting in June 2004 observed some improvements. However, most of the crucial problems for this institution arise from an insurmountable condition: its remote and wholly inappropriate location.

Amnesty International's findings

Dzhurkovo, which cares for 69 children, some of whom have very complex medical and other needs, now has a full-time physician² working in this institution. However, specialist medical care is only

¹ See also Far from the eyes of society - Systematic discrimination against people with mental disabilities, October 2004 (AI Index: EUR 15/002/2004), p.24 and 29.

² The post is currently held by a doctor without any relevant specialist qualification.

available in urban centres which are relatively far away and difficult to reach in an emergency. For example, a young child with hydrocephalus whose condition has evidently deteriorated since the first visit had not been provided with appropriate medical care to allow drainage of the excess fluid and relieve the pressure on the brain. According to the institution's doctor there are no hospitals in Bulgaria



Young child with hydrocephalus, Dzhurkovo, June 2004 © Al

that can carry out the required operation. Another example of inadequate medical care concerns 10 children who are being treated with anti-psychotic medication but the home is visited only once a year by a psychiatrist who travels from Plovdiv, around 60 kilometres away, on mostly mountainous roads.

Eighteen children have been diagnosed with Down's syndrome and 51 with cerebral palsy. Forty-three are considered 'bedridden' and apparently provided with very little contact or activity. There are three 'educators' for the entire institution but even they do not have appropriate training. At the time of the visit there was only one 'educator', with a degree in chemistry, on duty for all 'bedridden' children. The other 'educators' have degrees in agriculture and sociology, respectively. None of the three educators have any training or experience in teaching children with special needs.

The children's individual activity plans and rehabilitation reports (presumably for programmes of physical rehabilitation)³ appeared inadequate and were aimed at complying with state regulations rather than addressing the needs of the child concerned. A randomly selected report, examined by Amnesty International's delegate with the assistance of the educator, indicated that the child had benefited from a total of only 9 sessions of each activity in the first five months of 2004. Other reports appeared to be completed in a very similar fashion. All entries appeared to have been completed at the same time as the writing, pen and handwriting appeared to be the same. Assuming that these records were accurate they indicate an appallingly inadequate frequency of activities, many of which can be realized only on a one-to-one basis, as most Dzhurkovo children have complex needs and require regular, frequent and diverse physical stimulation and activity. Although it was not possible to establish how long each session lasted, it is not likely, given the number of staff and their training, that these sessions were appropriate for their specific needs. A specially equipped playroom and a gym, as on a previous visit, did not appear to be in effective use.

The individual rehabilitation plans were reportedly prepared by the educators according to a 1997 methodology. For each month of the year there were three different activities that the child would engage in. For instance, in January 2004, many plans contained "development of non-verbal

communication" as one of the three subjects of their programme. Other activities included: "development of skills for self-servicing and independence", "playing with toys", or sunbathing and walks (but only in summer months).

At the time of the visit practically all 43 "bedridden" children were in bed and not engaged in any activity. It is evident that they spend most of their time in this way. A girl with Down's syndrome who is eight years old and had been observed two and a half years earlier chewing the sides of her wooden cot was found still chewing on the cot, driven to this activity from lack of attention and means to occupy herself. Her situation was described in our 2002 report yet nothing had changed in the way she was being treated.



An eight-year-old girl with Down's syndrome, Dzhurkovo, June 2004 © Al

³ Individual activity plans and rehabilitation programs should be designed, implemented and periodically evaluated and reassessed by a range of specialists in different fields, procedures which the staff of Dzhurkovo are evidently not able to comply with.

Response of the Bulgarian authorities

In September 2004 Amnesty International received a letter from the State Agency for Child Protection, regarding its concerns about the children of Dzhurkovo, described in an appeal published in August 2004. The letter states that a survey of conditions and care in specialized institutions for children in Bulgaria was finalized in May 2004. With regards to Dzhurkovo, the survey concluded that the institution "could be modified for children from 10 till 18 years old". This conclusion is based on the arguments that "For children under 10 [adjustment to]... the cool climate is very difficult because of their physical disabilities. [Moreover]... after arriving in the institution, the children under 10 become victims of violence [perpetrated by]... older children." One of the general recommendations deducted from the survey is "to ensure appropriate transportation means, which will compensate the negative impact of the location of institutions".

Amnesty International welcomed the efforts of all authorities involved in the above mentioned survey. However in light of its own findings, Amnesty International was concerned to learn that the commission, which conducted this survey, noted as a positive aspect of care in Dzhurkovo the fact that every child has an individual care plan but did not appear to scrutinize the appropriateness of those plans and the way in which they had been drafted. Amnesty International is also concerned that the commission apparently failed to scrutinize whether the present staff, in view of their number and training, would be capable of providing the appropriate care and rehabilitation in implementing individual plans. In addition, despite the negative assessment of the institution's location, the commission failed to recommend a transfer of all children from Dzhurkovo to a more appropriate location. The recommendation that only children younger than 10 should be transferred to a more appropriate location does not adequately address the needs of the children of Dzhurkovo. Amnesty International considers the location of the institution to be unacceptable for any type of year-round institutionalized accommodation be it for children or adults. In September 2004 Amnesty International wrote to Minister of Labour and Social Policy, Christina Christova, and to the Chairperson of the State Agency for Child Protection, Shirin Mestan, requesting additional information and urged them to take all necessary steps to ensure that the needs of Dzhurkovo children are appropriately addressed. No reply has been received at the time of publication of this report.

According to reports a criminal investigation into the death of 14 children in Dzhurkovo in the winter of 1997 was reopened in September 2004. Their death had reportedly been attributed to "acute heart failure", but was widely believed to be the result of neglect, hypothermia and malnutrition. Amnesty International welcomes this belated step to establish all circumstances which led to the death of children in Dzhurkovo.

Conclusions and recommendations

Amnesty International wishes to reiterate its concern that depriving children with developmental disabilities in Dzhurkovo of thorough individual assessments, adequate medical care and appropriate rehabilitation amounts to cruel, inhuman and degrading treatment and thus violates international law, including Bulgaria's obligations under the Convention on the Rights of the Child, as well as the International Covenant on Civil and Political Rights and the UN Convention against Torture. The consequences of such neglect for the children of Dzhurkovo are life-threatening in some instances. Children who have been neglected and deprived of adequate rehabilitation suffer the consequences for the remainder of their lives. Depriving a person of the opportunity to develop his/her potential denies them their fundamental right to life with dignity and respect.

The children of Dzhurkovo need appropriate developmental and educational programmes, physicians, therapists, educators, nurses, social workers, and other professionals to assist them to develop their full potential and provide them with the opportunity to gain independence and full inclusion in society. This can only be achieved if they are brought down the mountain and provided with appropriate care and rehabilitation in a major urban centre where they will have access to all relevant specialists.

⁴ Worldwide Appeal Bulgaria: children in care home need help (The Wire) August 2004.