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International Forum on Discrimination of People with Mental Disabilities Opening remarks by Irene Khan, Secretary General, Amnesty International Sofia, 10 October 2002

CHECK AGAINST DELIVERY

The film has shown us in visual and compelling terms the plight of people with mental disabilities in social care homes in Bulgaria: and this is happening here in the heart of Europe, at the beginning of the twenty-first century, in a country which is aspiring to join the European Union.

Today is International Mental Health Day - and so it is very appropriate that we mark the day with this film - and with the launch of Amnesty International's report on **Bulgaria: Far from the eyes of society - systematic discrimination against people with mental disabilities**. This report describes our concerns regarding the way in which people with mental disability - men, women and children - suffer serious violations of their human rights in social care homes and psychiatric institutions.

This report is the product of five research missions over a period of some 12 months by Amnesty International, the Bulgarian Helsinki Committee and Mental Disability Rights. They visited three state psychiatric hospitals, and more than 16 social care homes, including five for children. They spoke to the residents as well as the Bulgarian authorities, administrators and professional staff of the institutions, NGOs and human rights activists.

Our research has been meticulous, our conclusions shocking.

We are outraged at the systematic discrimination, stigmatisation and isolation of people with mental disabilities in Bulgaria. They are the victims of prejudice at all levels of society. They are victims of the policy of institutionalisation and segregation. They are practically the last in the line to receive social assistance in a country that has limited resources. By putting them in institutions, often in remote locations, not only are their rights ignored and violated, their very existence is being conveniently forgotten by government as well as by society. They are left to perish far from the eyes of society: out of our sight, and out of our minds.

The objective of this report is to tear apart the veil of complacency and ignorance, and to force all of us - government officials, international donors, civil society organisations and ordinary Bulgarians - to

recognise the terrible injustice that is being inflicted on people with mental disability. We must confront the reality. And this reality is that:

- First and foremost, the Government of Bulgaria has failed in its obligations under international law to respect and ensure the rights of all its people on an equal basis.
- The legal provisions and judicial provisions of compulsory treatment in psychiatric hospitals and social care homes violate international provisions against arbitrary detention and on fair trial - people are locked away without a second medical opinion or judicial review - treated worse than criminal suspects. Complaints of ill treatment or death in suspicious circumstances are not investigated.
- the conditions in many of the social care homes for adults are appalling. In eight of the ten institutions we visited the conditions and treatment of the people were inhumane and degrading - clearly in violation of international human rights standards. In some of these social care homes the mortality rate is around 20% - much higher than that of the local community. People in these institutions died of pneumonia, hypothermia and malnutrition - unheard of in the local community. So, how would one explain discrepancy? Only by acknowledging severe discrimination and gross neglect on the part of the authorities towards those living in these institutions.
- most strikingly, care for people with mental disabilities, whether adult or children, is marked by a systematic lack of assessment, treatment and rehabilitation by therapists, psychologists and physicians. The objective is to control behaviour, not to treat it, far less to rehabilitate the people into society again. Let me quote what the consultant psychiatrist said in the report: "People have been abandoned by society with nothing to do and nothing to hope for ...excluded from society on the basis of diagnosis which are questionable, founded on assumptions which are outdated and seldom reassessed." Imagine the condition of those with learning disabilities that we found are being given strong sedatives. Imagine the total despair of the five year child who actually chewed through the wooden bar of her cot because she had nothing else to do. Imagine the future of children who continue to be placed in social care homes on the basis of inadequate diagnoses and without proper monitoring or reassessment. Unless action is taken urgently, these children risk being permanently and severely affected, condemned to spend the rest of their lives in social care homes.

If that is reality, what has been the reaction of the authorities?

Let me start by saying that we appreciate the cooperation that we have received from the authorities in preparing this report. We were given free access to the institutions. We take this as an indication of the commitment of the government to engage with us in a constructive dialogue to change the situation.

We also appreciate the assistance we received from the administration and staff of the institutions we visited, who are working in difficult conditions with chronic understaffing, very limited resources, and inadequate training. Many of them are keen to improve the situation and we believe this is not only commendable but deserves support.

During our research we raised with the Government our concerns about the situation in the social care homes at Sanadinovo and Dragash Voyvoda, and the Government responded positively to them.

But I must also underline that the response has been short-term and limited. The problem cannot just be solved by repainting the walls, repairing the toilets, or building more seclusion cells, as has been done at Radovets, in clear breach of international human rights standards and professional best practices, or even shutting down one institutions and moving the residents to another institution - which deals with the problem in the short term but is not a long term solution.

We shared with the government our report in July 2002 but have not heard formally from them as yet. Yesterday we met with Madam Kristova, the Deputy Minister of Labour and Social Policy, and with Dr. Petar Tenchev, the Deputy Minister of Health who informed us of legislative reforms which are on the table. We are pleased to see Madam Chritova join us here today - I hope Madam that you will take fully

into account our recommendations as you and your colleagues considers the proposals for change.

Our detailed recommendations are in the report - and so I will not repeat them here. What I would like to emphasise four points:

- First, we believe that what is needed is comprehensive reform, not cosmetic change. Measures, such as the Ministry of Education's Order No. 6 that recognises the right to education of children with disability, or the proposal of the Ministry of Labour and Social Policy to amend the law on social assistance, are important but they are not enough. Not only has the National Programme for Mental Health been disappointingly slow, it does not cover the situation in social care homes where many of the people with mental disabilities - both children and adults - actually are. So let me emphasise: the government must look at fundamental reform and that means de-institutionalisation and ways to increase the capacity of the community to support the rehabilitation and reintegration of people with mental disabilities. The Government must initiate a long-overdue comprehensive programme of reform of mental health, social assistance and education services for people with mental disabilities that will ensure Bulgaria's full compliance with international standards.

- Secondly, in the immediate and short-term, before winter sets in, we call on the government to make sure that all the institutions have the resources for heating, food, clothing and bedding so that more people do not die. The mortality rates in winter at Dragash Voyvoda, Radovets, Razdol and Oborishte are unacceptable. Improving the appalling situation for the men, women and children in social care homes may be a matter of life and death for some of them this winter. And to avoid any confusion, let me clarify that addressing this immediate, life-threatening situation should not in any way divert attention from the issue of fundamental reform, which should be a topmost priority.

- Thirdly, responsibility for human rights extends beyond national boundaries - and calls for international solidarity and support. We recognise that reform and improvements will require resources - and we call on the international community, particularly the European Union, to help provide these resources. But we believe that these resources should not be invested in propping up over a system that is by its very nature gravely flawed - international funds should be used to encourage and ensure that the Government of Bulgaria undertakes a comprehensive reform in compliance with its international human rights obligations.

- Fourthly, and most importantly, there must be public acknowledgement of the discrimination and the denial of human rights of people suffering from mental disabilities. We need to change social attitudes - and that is done through public awareness, social mobilisation and political leadership. It is everyone's responsibility. But I must underline that it is also a very special responsibility of the political leaders to give a clear and unequivocal message that people with mental disabilities are people like us, they have the same rights as all of us, and that the government will do everything possible to combat prejudice against them. Such a statement requires no additional resources, it requires political will. We call on the Prime Minister and his senior ministers to show that political will.

Amnesty International remains committed to this issue. We look forward to the debate and particularly to the ways in which we can all work to bring about change. Let us join forces to campaign to protect the rights of people confined in psychiatric and social care institutions in Bulgaria, to put an end to the discrimination, neglect and despair that they suffer every day, and to ensure that they can lead their lives with human dignity, develop their potential and be fully integrated into the community - like all of us.

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