

A Life Worse than Imprisonment: Meeting Bulgaria's Mentally Disabled

by Theresa Freese-Treack*

The dreadful stench was the first thing that hit me. As I began to adjust - both to the smells and to the darkness - breathing deliberately, trying to maintain my composure and preparing for what lay ahead, I recognized groups of women huddled together in filthy conditions, forming an assembly line. One group stood in front of a trough frantically rubbing their hands under jets of water streaming out of the faucets. There was no soap to assist the women in their task. Puddles of water already formed on the cement floor were now turning into a pool. One woman stood dipping a loaf of bread into the water, making it soft, eating it over a faucet. Then, the women moved into an adjacent room -- small, dank, mouldy and already three-inches thick in water. The women briefly waited, crammed into this tight area and enveloped in darkness, until they were moved on.

Next stop: the canteen. Here, residents grabbed a bowl of cold soup and a plate with a sausage and mashed potatoes handed out from a kitchen window. Women were sitting, standing or walking around aimlessly, holding plates of food in their hands. Many were eating directly from the dishes. Some were awkwardly using cutlery recently acquired by the home. Others just used their hands. A few women sat screaming for no apparent reason. Scuffles broke out every couple of minutes. Some sat alone cowering. Most ate rapidly then left the canteen to wander outside and lie on the grass.

Within half an hour most of Razdol's 107 residents had eaten. I had witnessed what was the conclusion of residents' second organized activity of the day. The next -- dinner.

I was appalled and felt helpless. As I surveyed the situation - a scene I had seen so many times in still photographs and read about in numerous reports while campaigning for Amnesty International - and as I listened to the screaming, watched women rocking idly in front of their plates, eating soup with their hands, or sitting isolated in a corner, starting in apparent fear whenever anyone approached, I began to comprehend the horror of living in such an institution.

The Razdol home for women was my first stop along a stream of visits to Bulgarian homes for mentally disabled children and adults. Ahead of me lay Tri Kladentsi, Mogilino, Kachulka, Samuil. All were situated in remote locations scattered across the country, approachable only by dilapidated roads, which in winter months are often unusable or, on a good day, can take one-and-a-half hours to reach by car from the nearest highway or urban centre.

After lunch, I followed the remaining residents outside the canteen. I was immediately surrounded by women touching me and my colleagues from the Bulgarian Helsinki Committee, begging for cigarettes or money. Many lay on the ground staring at us with empty eyes. Others, curled up in balls, lay motionless, barefooted and in tattered clothes. Only those who were communicative, and later showed us they carried some responsibility in the home because, as they explained, they were not like "the others", were dressed

fairly well.

We handed out cigarettes quickly, filling open hands and appeasing pleading eyes. Some discretely hid the cigarettes in secret places throughout their clothes. A few quickly put out their hands with a smile for more. Others thanked us and remarked that we should keep the remaining cigarettes for ourselves - "they are expensive and we will take them all".

A trip to the lavatory was unbearable. It required a long trek to the end of a dark and windy corridor for the bedridden. The stench was daunting. A quick peak inside was all I could manage, holding my breath just long enough to enter and make it back around the corner to the main corridor where the smell was not so sickening. Stalls were streaked with faeces - although staff had run water over the floors upon our arrival. I wondered what it might be like on a normal day.

One elderly resident, Kalinka, took my hand, guided me around the home, and relayed to me how she had come to Razdol from a children's institution. The story Kalinka told was a typical example of a common practice whereby individuals with mental disabilities are abandoned by their families - usually at birth - and institutionalized for life.

Unfortunately, what I experienced in the Razdol home was merely a brief representation of the inhuman and degrading treatment of residents that I was about to witness, in many peculiar shapes and forms, throughout the rest of my visits. Neglect and systematic abuse confronted me every step of the way.

In the Tri Kladentsi home severely disabled children languished under lock and key, stuffed in a room. No toys, no games nor any sign of activity were available to engage them. Children simply rocked back and forth, screamed or beat themselves and others.

In the Mogilino home bedridden children lay in crib-lined rooms surrounded by flies and staring blankly. Staff did not know children's names or conditions and instead, like any visitor, referred to personal information cards. When I gave children the smallest sign of affection, they came to life, giggling at the slightest touch upon their faces or arms. At that moment, I realized that, chances were, those who survived would end up in homes like Razdol - nameless, hopeless people without a life to speak of. Playing with the Mogilino children, I realized what a vicious cycle institutionalization was.

At the Samuil home for women with severe mental disabilities, an unusually communicative and coherent young woman, Tania, described her tragic life in Samuil and revealed to me one of the worst abuses I witnessed during my visits: a windowless seclusion cell with iron-barred doors where one woman lay. Tania detailed how staff beat residents, gave them an injection and placed them in this cell as punishment for misbehaviour.

At the Kachulka home a female resident, entirely naked, with the exception of an open shirt on her back, and in a very distressed state, greeted us at the entrance to the institution. Another woman lay similarly exposed on the ground outside the main dormitories, in full view of all staff, residents and visitors.

At the end of the week, driving back from Kachulka to Sofia - a six-hour drive, I reflected on everything I had experienced, with hundreds of miles under my belt, and the enormity of the problem facing me like a brick wall. What I had witnessed in one week was merely a terse overview of an endemic problem. Over 100 such institutions exist throughout the country.

Bulgaria faces a legacy, inherited from the pre-1990s Communist period, of keeping the mentally disabled far from the eyes of society. Today, as a Bulgarian Helsinki Committee representative explained, conditions in social care homes are worse than those in Bulgarian prisons or police custody. Unlike prisons, which are placed in the centres of towns and cities as a deterrent to crime, social care homes for the mentally disabled were placed in distant mountain villages or small towns bereft of a proper infrastructure or professionals trained to care for people with special needs - and away from the attention of potentially concerned citizens who could pressure for change.

The inhuman treatment residents receive is also a reflection of the general population's attitudes toward the mentally disabled, whose lives currently are not deemed worthy of more attention. For a country economically distressed following the collapse of Communism, these issues simply have not been a priority.

The discrimination against people with mental disabilities, however, is not unique to Bulgaria: Mental Disability Rights International has documented similar conditions in places as close to Bulgaria as Kosovo and Hungary and as far away as Mexico. And such problems are known to be prevalent in countries situated throughout the world.

In this context, bringing abuses to light is not sufficient - although it is an important first step. Most urgently, and especially during winter months, residents need adequate food, clothing, toiletry items, including personal toothbrushes and toothpaste. Staff need basic training on methods of hygiene as well as recreational and rehabilitative activities they could provide: from reading stories to residents and taking them for walks to using existing and new facilities properly. Substantial investment in de-institutionalization and public awareness programs is also necessary. And, to ensure that all residents of social care homes are treated humanely and with respect for their basic human rights, the Bulgarian authorities need to institute promptly standards of treatment and care appropriate for persons with mental disabilities and institute an independent monitoring mechanism for all homes.

It is important to remember that, as demonstrated by the transfer of residents from the Sanadinovo home for women in June 2002 - 48 went to the Kachulka home, seven to the Razdol home while roughly forty remaining residents stand unaccounted for to date - closing institutions alone is not an answer. Until there is international action and real, as well as visual, improvements on the ground, Bulgarian residents will continue to languish in these institutions.

Fortunately, the Bulgarian authorities are in a good position for affecting change in this area. Not only have many institutions, such as the World Bank, the World Health Organization and the Geneva Initiative on Psychiatry begun financing programs or sponsoring events to improve the lives of people with mental disabilities in countries dotted throughout the world, but the international community is making this issue a priority as economic social and cultural rights -- in addition to the traditional work on civil and political rights - becomes a priority.

Moreover, the United Nations is currently developing a convention on the rights of persons with disabilities that could provide firm standards for governments and international institutions working to provide people

with mental disabilities with their basic human rights.

With a concerted and informed effort, the Bulgarian authorities as well as a unique coalition of local and international institutions can effect change for the better. To date, the Bulgarian government's receptiveness to Amnesty International and Bulgarian Helsinki Committee appeals offers a promising start.

As part of Amnesty International's effort, on 10 October 2002 (United Nations World Mental Health Day) Irene Khan, the organization's Secretary General, is presenting Amnesty International's concerns and recommendations regarding the discrimination against people with mental disabilities in Bulgaria at an international forum in Sofia, which has been organized jointly with the Bulgarian Helsinki Committee, and with participation from representatives of the international community. At that time, a 20-minute documentary and a report on Amnesty International's visits will be released.

Amnesty International's work in this area could provide insight for the United Nations as it develops its important convention as a standard for the international community to abide by. Moreover, when complete, the convention will provide important standards not only for Amnesty International but for all human rights organizations to refer to as they embark on similar projects throughout Eastern Europe, and indeed the world.

Meanwhile, the men, women and children of Bulgaria's social care homes wait.

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