



Update of findings in Kosovo – December, 2004

SUMMARY

Mental Disability Rights International (MDRI) made visits to Shtime Special Institution (SSI) and several of the protected and semi protected apartments in Kosovo in 2004. However well intentioned, both the refurbishing of Shtime and the building of apartments in the community for people with mental disabilities has not alleviated glaring human rights abuses perpetrated against this population (see *Not on the Agenda: Human Rights of People with Mental Disabilities in Kosovo*, August, 2007, which advised against the policy of investing further in a segregated system of mental health services). Shtime residents still live isolated from society and arbitrarily detained – some for decades. Without meaningful human rights oversight or any effort to remove past abusers from the staff, patients remain under constant threat of physical violence and sexual abuse.

Many of the so-called “integration homes” (apartments being built by the Kosovo government and international donors) are so geographically isolated from the community that they themselves are mini-institutions. In some instances, children receive completely segregated education from other children and virtually never leave their newly built home. And in another we found residents locked in a hallway and who had not been allowed to leave their apartment for six months.

Recently, at the urging of MDRI, the World Bank funded a disability advisor to the Kosovo government. The resulting report concurred with previous MDRI recommendations and called for the closing of Shtime and real community supports for people with mental disabilities.

The government and donors are moving in the right direction with the construction of homes in the community for this population. With a better understanding of what constitutes integration and rights protection, homes can be built and staffed in such a way that truly supports full citizenship and community participation of people with mental disabilities in Kosovo

INTRODUCTION

Mental Disability Rights International (MDRI) is an international human rights group dedicated to the protection of people with mental disabilities. Headquartered in Washington, DC, with an office in Prishtina, Kosovo, MDRI promotes the human rights and full participation in society of children and adults with mental disabilities worldwide.

In August 2002, MDRI released its report, *Not on the Agenda: Human Rights of People with Mental Disabilities in Kosovo*, which described serious human rights violations and abuses perpetrated against people with mental disabilities in Kosovo. In addition, the report made recommendations to the United Nations Mission in Kosovo (UNMIK), the government of Kosovo and international donors which included the closing of Shtime Special Institution and the development of a comprehensive system of community services and support.

The government of Kosovo, in an effort to provide housing in the community for people with mental disabilities who lack the means or family support to live independently, has embarked on an ambitious plan to build 14 protected or semi-protected apartments. Staffed by nurses, these apartments – which are now being referred to as “integration homes” - are 10 bed units which typically sit on 7 to 8 acres of land. Average construction costs are estimated at 120,000 to 200,000 Euros for each building. Thus far, a combination of international donor support – primarily Switzerland, the Principality of Liechtenstein and Denmark – coupled with funds from the Kosovo government budget, has paid for the construction. The individual municipalities where the apartments are located donate the land. The Kosovo Ministry of Health (MoH) has jurisdiction over apartments which house people with psychiatric disabilities while the Ministry of Labor and Social Welfare (MLSW) is charged with administering housing for people with developmental disabilities.

Over the summer and fall of 2004, MDRI staff visited several of these newly occupied homes as well as several sites where construction is underway. In addition, we again visited the Shtime Special Institution.

MDRI FINDINGS

Programs Under the Authority of the Ministry of Health

Semi Protected Apartment in Prizren

This home is located on what is referred to as the “transit road” approximately 4 to 5 kilometers from the center of Prizren. It is geographically isolated both from both the town and other neighbors and residents have no access to a vehicle or public transportation. The house is surrounded by a tall metal fence with a padlock.

MDRI investigators made an unannounced visit to the house on a weekday afternoon. We found residents locked in a bedroom hallway. We were told that they were locked in the hall because this was their rest time and it also prevented them from spending too much time outside smoking. We asked that the residents be let out of the hallway so that we might speak with them.

Although the residence has a 10 person capacity, only 8 beds were occupied. Seven staff work in three shifts, yet there was only one staff person working during our visit. Staff controls such activities as when residents go to bed, can have coffee or a cigarette and when or if they are allowed to leave the house.

Residents who talked with MDRI reported that they had only been into the town once in the past six months and they do little or nothing all day long. Several residents, who had spent years in psychiatric institutions in Serbia and Kosovo, stated that “living here is the same as living in an institution” and “this is the same as Shtime, only smaller.”

The home has a living room, dining area, kitchen, laundry and bedrooms. The bedrooms have two to three beds each. Residents had no personal items in their rooms except for a few articles of clothing. There was a computer in the house but we were told that residents were not allowed to use it, nor were they allowed to use the laundry room because “they don’t know how to use them and they will break them.”

There was no landline telephone in the home for emergencies or for residents to communicate with family or friends.

Protected Apartment in Gjilan

The home in Gjilan is located in a congested neighborhood with many other homes nearby and a 5 minute walk to the center of town. Although this apartment was also surrounded by a fence, there were no locks and the gates were open.

At present, there are nine residents and seven staff. In stark contrast to Prizren, we found residents engaged in a variety of activities - some were outside, some were watching sports, some were listening to music, resting in their room, some having coffee and cooking. Several visitors dropped by while we were there. Bedrooms were filled with personal items such as televisions, radios, music tapes, flowers, photographs and posters. One woman proudly showed us the clothes she purchased at the shops in town – “These are my everyday clothes and these are my fancy clothes for when I go out to restaurants and with my friends.” Residents had control over their money and had the freedom to walk into town whenever they wanted to.

One former resident had met a man in the town and had gotten married. She lives nearby and stops in to see her friends often. Another woman, who had spent many years in an institution before moving to the protected apartment, was able to eventually move back home with family members to his community of origin. Another resident shared with us his hope of getting a paid position with a company he is presently volunteering at.

Programs Under the Authority of the Ministry of Labor and Social Welfare

Home for Children in Gračanica

In the spring of 2004, MDRI staff visited what was described as “temporary housing” for eight children who had once lived in Shtime. An older home, it was located near the center of town with many neighbors nearby. Six of the eight children attend school with all other children in the enclave, while two children described as “autistic” and “severely disabled” do not. These two receive no habilitation or therapy and do not leave the house. Staff said, “There is nothing we can do with them.”

When MDRI toured the home, several of the children were eager to show us their rooms. They were filled with many personal items such as toys, art supplies, photographs and

stuffed animals. And while we were there, several children left for the village center to meet with their friends and play. Because of the close proximity of the home to the center, children were able to walk to school and visit friends without being accompanied by staff.

When MDRI staff returned to Gracanica in October 2004, the children had been moved to their newly built facility. The home is located high on a hill, at the end of a dirt road, on the very outskirts of town. There are virtually no neighbors. Because of the distance of the house to the town, the only time children go out is when they are picked up by a van to attend school or about once a month when staff bring them into town to get supplies for the house. According to the staff, the children are frustrated because of the isolation and are showing signs of depression and aggression. “They miss their friends, they miss their freedom. They want to go back to the other house.”

Staff stated that the children will probably need additional medication because of their feelings of sadness and frustration.

Two new children are expected to move to the home by the end of the year. Both children will be coming in from the community rather than transferring from Shtime or another institution.

Shtime Special Institution

When MDRI visited the institution in May 2004, there were 179 patients living in the institution with one recent admission from the community. During our visit to Shtime, we found the majority of people idle – sitting in empty rooms on chairs and on the floors. Many were in their beds. There was virtually no activity or rehabilitation being provided. As we toured the facility, many of the residents requested that we help them get out of the institution or help them by contacting a friend or relative. In one ward, we observed feces smeared on the wall and floor where staff was serving lunch to the patients.

Home for Children in Shtime

This home is adjacent to the Shtime Special Institution (SSI). Eight of the ten children in this home were formerly housed with the adult population at SSI. The other two children are recent admissions from the community. Children attend school on the grounds of SSI and get their health services at the clinic in the adult institution. There are no habilitation programs for the children and MDRI observed that at least one of the children had no developmental disability whatsoever. Rather, he used a wheelchair for mobility as a result of losing his legs in a train accident. During our visit, while some children were attending classes, several were in their beds. Staff confirmed that the children rarely, if ever, leave the grounds of the SSI.

Homes Under Construction Visited

MDRI visited the home under construction for adults with developmental disabilities in Shtime. Due to open in the next month or so, it is located directly across the street from the Shtime Special Institution and the Shtime Children's Home.

A home for adults with developmental disabilities is also under construction in Kamenica. Although this home was only about one kilometer from the center of town, it was very difficult to reach even by car. The roads were not paved and they were filled with mud and ruts. We expect it will be even more difficult to traverse in winter, especially on foot. Additionally, it is surrounded by woods and there are no homes or neighbors nearby.

MDRI RECOMMENDATIONS

- The MoH should act immediately to stop the human rights abuses being perpetrated against the residents of the semi-protected apartment in Prizren. Residents should not be locked in hallways, rooms or the building. Due to the isolated location of the home, daily van or bus service must be provided into the town for socialization, job training, education or whatever residents freely choose. They should have access and control over their money. The home should be equipped with a landline phone available to all residents. And they should be supported in becoming self-determined and independent adults by being able to make day - to- day decisions about their lives.
- Housing built for children and adults with mental disabilities should be located in a geographically accessible location to all services in the community. Given that residents are unlikely to drive or have access to automobiles, all homes should be within walking distance from the center of the towns that they are located in. Homes should not sit apart or be isolated from neighborhoods.
- Municipalities should take into account the above recommendation when contemplating sites for construction of any other homes in the community for people with disabilities.
- The government of Kosovo and international donors should rehabilitate existing homes if land allocated from the municipalities does not meet accessible location criteria. MDRI urges immediate termination of any plans for future construction in remote or isolated areas.
- The children in the home in Gracinica should be relocated back into the village immediately, as their emotional well being is at risk due to the isolation of the facility. The children should not be put on additional medication as the answer to their imposed isolation.
- The children in Gracinica deemed "severely disabled" should be re-evaluated and provided with appropriate habilitation services, school and socialization in the community.

- Children living at the Shtime Children's House should not receive their medical care in the clinic at the Shtime Special Institution. Mental health professionals, who have worked with the children, report that most of the children formerly institutionalized at SSI show signs of having been sexually abused. Some of these children were abused at the facility, and the same staff that failed to protect them in the past likely remain in the employ of the institution. Continued association with the institution threatens their mental health. Every effort should be made to integrate the children into the community as fully as possible. Segregated schools and social activities – away from other children in the town – will only serve to exacerbate their disability and perpetuate stigma and discrimination.
- In an effort to close Shtime Special Institution, priority for placement in community-based homes should be given to its current residents. The creation of family support services and foster care should be instituted to prevent further abandonment of adults and children with mental disabilities. Transferring people from the community into protected/semi-protected apartments should only be considered after all other supportive measures have been exhausted.
- The Board of Visitors should be disbanded and an independent and freestanding human rights oversight board should be created to monitor the human rights protection for people in Shtime, the Elder House and the integration apartments. The World Bank Advisor on Disability in Kosovo has also made this same recommendation to UNMIK and the Ministry.

CONCLUSION

After years of misdirected efforts to rebuild Shtime and reinforce an outmoded system of institution-based services, MDRI has observed new efforts to support the creation of community-based housing for people with mental disabilities. The government of Kosovo and international donors should be commended for this shift in policy. International experience has shown that institutions such as Shtime Special Institution are not suitable environments for rehabilitation and are in fact a breeding ground for serious human rights abuses. Throughout the world there is a continuing shift from institution-based to community-based care for people with mental disabilities. And experience has shown that with the right combination of services and support, even children and adults with the most severe psychiatric or developmental disabilities can experience enormous improvements in the quality of their lives.

As MDRI has reported, misdirected dollars used to rebuild institutions or build housing that is in remote areas and segregated from the community, both geographically and programmatically, only continues to reinforce an outmoded and inherently dangerous institutionalized system. Under international human rights law, it is a form of

discrimination for mental health and social service system to keep people segregated from society when they are capable of living in the community.¹

The government of Kosovo and donors can look to the home in Gjilan for a model they should replicate. The home is located within walking distance of the town and with neighbors nearby. Residents are free to come and go and are encouraged to make the day-to-day decisions about their lives. They are supported and encouraged to learn life skills which will further assist in their reintegration into community life.

UN Security Council Resolution 1244 establishes that one of the primary tasks of the international civil presence in Kosovo is to “promote and protect human rights.” It is ultimately the responsibility of the United Nations to ensure that human rights oversight and enforcement systems are established to prevent further abuses in Kosovo’s institutions. It is also the responsibility of the UN to ensure that international funding is not used to rebuild and reinforce a service system that segregates people with mental disabilities from society. The issues identified in this report are fundamental human rights issues and MDRI urges the United Nations Mission in Kosovo (UNMIK) to take immediate action to ensure that the discrimination and abuse of people with mental disabilities is brought to an end.

¹ General Comment No. 5 to the International Covenant on Economic, Social, and Cultural Rights (1994). See discussion in Mental Disability Rights International, *Not on the Agenda* (2002) at p.31.