Latvia: A Cat at the Window

An advocate for community-based health care tells how NGOs, health professionals, and village authorities are working to establish Latvia's first group home for the mentally disabled.

Note: The following article is one in a series commissioned and published by Transitions Online (TOL) and the Mental Disability Advocacy Project (MDAP), a part of the Open Society Institute's Public Health Programs. Each article addresses the situation in an individual country or region in Central and Eastern Europe and the former Soviet Union, focusing on emerging trends in alternative services and ongoing challenges for the social inclusion of people with mental disabilities.

By Ieva Leimane-Veldmeijere

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The psychiatric hospital in Akniste is, in every sense, the last stop for many in Latvia. Far from the cities, poorly served by public transport, this 450-bed facility is where many people with severe mental disabilities end up. It is a place for the "hopeless cases."

Yet this apparently unpromising institution is known for its open-minded staff and for this reason was chosen by non-governmental organizations from both within and outside Latvia for a series of pilot programs to boost community-based care for people living with chronic mental disabilities. It's the most elaborate scheme of this kind in Latvia. Those of us involved in these projects see them as a laboratory for other partnerships, involving cooperation among public, private, and non-profit agencies.

Looking for a Way Out

A key goal for the project—which is co-sponsored by my organization, the Latvian Center for Human Rights and Ethnic Studies—is to establish a group home in the village of Garsene. While this is the first for people with mental illnesses and one of the first group homes of any in the fundraising stage, for two years a few patients have been able to take the first steps toward independent living in the "training apartment" near the hospital.

One of the original tenants to try out the apartment, Ainars, says he "put up both hands against it" when we asked if he would like to live there after spending 11 years in a hospital ward.

"I had 55 reasons to say 'no,'" he says—but now he's thankful to project leader Skaidrite Pudane for finding the right responses for his "no."

Some 62,000 Latvians are officially registered as having "mental disabilities." Under this heading are included people with disorders such as schizophrenia and neurological problems, as well as intellectual disabilities. More than a third of those 62,000 people spend time in mental hospitals, or in one of 30 social-care homes funded from the state budget. Two of the country's nine psychiatric hospitals (including that in Akniste) are for long-stay patients. Ainars is one of the few who've been offered a chance to re-enter the life of the community.

There are almost no alternatives to these institutions. As a result, long waiting lists are the rule for placement in a social-care home. Here (and in other ways), Latvia's psychiatric patients still lack the protection of a modern law on mental-health care.

The government has prepared a draft law and plans to send it to parliament early in 2004. If approved, this law would finally bring the country's legal protections for those with mental-health problems in line with the Council of Europe's European Convention on Human Rights.

The Latvian government and health-care agencies have not been blind to these concerns. They have passed laws to reform the social-care homes and raised the bar for staff qualifications; some psychiatric institutions have even spent their own funds to renovate facilities.

What is lacking is a developed policy of community-based support for people with mental illnesses. People with intellectual disabilities have a group home in Riga, and a supported employment program. This may not be much, but it is more than the community-based support offered to people with mental illnesses.

Latvia is hardly alone in facing these obstacles to modernizing its support systems for the disabled. Here, as in other EU accession countries, those of us involved in building new community services run up against similar barriers to progress: the need for extra funding in the initial stages of a project; a lack of trained staff for community-based programs; and a lack of expertise in moving from institutional to community-based care.

For these reasons, in Latvia and elsewhere, international foundations (rather than cash-strapped state budgets) have funded most initiatives to develop community services.

The projects at Akniste are no exception. The main financial support comes from the Open Society Institute and the Soros Foundation-Latvia, who work together with the Latvian Center for Human Rights and Ethnic Studies. These organizations have embarked on a step-by-step program to help the first patients from the hospital move back to the community.

These projects and others like them, whether you call them “reintegration,” “deinstitutionalization,” or “the user-centered approach,” are all designed for individuals, not institutions; for local authorities and local people, rather than government ministers and agency chiefs.

We say that our efforts at Akniste apply “the user-centered approach.” We use this term because the core idea underlying all the projects is to help the “users” of health-care and social-support systems to live in their communities. This can only happen successfully when the users have access to community-based mental-health services, legal aid, occupational training, and the guidance and counsel of other independent disabled people and care professionals.

Beginning in 2001, we initiated a number of projects at Akniste—from the launch of a monthly newsletter produced by the hospital patients' council, to the training apartment and the future group home. The first step was to win support for the activities of the council. The second was to revitalize patients’ connections with their families.

Reconnections

Many patients have spent years at Akniste. We began the family-ties project with a questionnaire sent to patients’ relatives. Encouraged by the high number of positive responses, we bought a van and began taking patients to visit their families.

At the end of the trial period, there had been 92 patient visits, and the project has since continued with the financial support of the hospital. Several families say they are now willing to bring their relatives home and give them the necessary care.

Our next step was to initiate a life-skills program, to provide patients with information and skills they will need in the community. Patients learned about planning their leisure time, budget planning, medications and their side effects, and recognizing and dealing with anger and the first signs of crisis.

We then developed a second life-skills module with materials and training sessions for sex education and health, including HIV/AIDS. Both parts of the life-skills program have been adopted by other institutions in Latvia.

Life at George’s

When Ainars and fellow Akniste patient Peteris were chosen as the first tenants of the training apartment in January 2002, life outside the regimen of the hospital was an eye-opener. After two months in the apartment, Ainars wrote in the patient newsletter, there were so many decisions he had to make every day: what to have for breakfast, how to do laundry, how to budget.

Where before, he used to spend his disability pension only on cigarettes, suddenly he found it difficult to make ends meet. He tried to find work to cover expenses. It was a shock to discover how much the economic situation had changed during his years at Akniste, he wrote. But, he said, he had gotten used to “George’s apartment,” as patients dubbed it (after the financier and philanthropist George Soros, whose Soros Foundation-Latvia provided funding for the apartment).

Since Ainars’s and Peteris’s six-month stint in 2002, four more patients have spent three to six months in the apartment, finding their bearings for life outside the hospital. The apartment is a short walk from the hospital, in a building where hospital staff and local people also live. Patients are provided with a mobile phone, and can call on the services of a social worker who lives in the building, to help arrange for heating, hot water, and other practicalities.

Both Peteris and Ainars were more “open-minded,” after their stay in the apartment, patients’ council head Eriks remarks. They now spend their pension money more wisely, and think more practically about their needs, rather than buying only coffee and cigarettes. They have proved they can live independently, Eriks thinks.

Skaidrite Pudane, a rehabilitation nurse, says the training apartment and other alternatives for halfway housing are necessary, because many patients encounter problems about four months or so after leaving the hospital. These include drinking, difficulty sticking to their medication, and communication problems with fellow residents in their halfway house.

According to Skaidrite, a third of the 75 patients she sees daily could live in the community—if there were adequate state support and services. Chiefly, it would require day care, housing assistance, and employment assistance. She and Eriks both remark that the patients who spent time in the apartment showed greater self-esteem and got on well with their neighbors.

Space slots in the apartment are reserved for patients whose families have agreed to take them back. Unfortunately, neither of the two original tenants has been able to rejoin their families. Peteris moved back to the hospital, owing to a bout of depression after he stopped taking his medication. Next spring, he will be eligible to leave hospital and return to his old apartment. Ainars has been unable to find a place to live on his own. He is now resting his hopes on the group home.

In addition to the training apartment—and soon, the group home—there are other ways for patients, willing and able, to live outside the hospital setting. Last summer, two patients moved out of the hospital to live and work on a farm.

Next Steps

In spring 2004, we plan to open a small craft shop in the village of Garsene, five kilometers from the hospital. The shop will sell items made by patients, and will be run by patients and group-home residents. The 5,000 tourists who visit Garsene every year to walk its nature trails and tour its old castle are the most likely buyers of craftwork made by patients.

In addition, the village’s Protestant congregation has been awarded a small grant from the World Bank for a joint project with the Akniste hospital. The funds will be used to arrange lectures and visits by specialists for people with dependency problems.

The lack of suitable housing for the disabled remains the most formidable obstacle to community-based care. The hard reality is that many long-term institutionalized patients have no access to housing, because they have lost their apartments or have no close relatives. The Latvian government tried to address this problem in its Strategy for Psychiatric Assistance for 2000-2003. But to date, no funds have been allocated and no group homes for the mentally ill have been opened.

The challenge was taken up by a group of staff and patients at Akniste, who founded a non-profit organization, *Pasparne* (Refuge), for friends of people living with mental illness.

The major goal for Refuge is to make the group home in Garsene a reality. The municipality made available a house in the center of the village, next to the local pride--the old castle of Garsene. After renovation work is completed, the house will contain apartments for 10 single people and two couples.

There is a long way to go. Only about $14,000 of the estimated $90,000 cost has been met through donations from a construction company and the Soros Foundation-Latvia.

What will the group home mean for people who now have little choice but to spend their days in a hospital ward?

Ainars, who had at first resisted the proposal to live in the training apartment, explains what it meant for him to sleep in an ordinary bedroom:

“During all those years I spent in hospital, I forgot how nice it is to wake up without any commotion. Nobody running, nobody crying, maybe just a cat outside the window. You can just open your eyes, look at the clock—and if there’s nothing you need to do, just go back to sleep.”

***Ieva Leimane-Veldmeijere** is deputy director of the Latvian Center for Human Rights and Ethnic Studies (LCHRES) and director of the Soros Foundation-Latvia/LCHRES Mental Disability Program-Latvia.*

About Transitions Online (TOL):
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About MDAP:
The Mental Disability Advocacy Program (MDAP) is a part of the Open Society Institute’s Public Health Programs. MDAP supports projects that seek to address the massive over-institutionalization, lack of community-based services, and general exclusion from society of people with mental disabilities throughout Central and Eastern Europe and the former Soviet Union. Since 1995, MDAP has been supporting the development of community-based alternative services to facilitate the reintegration of people with mental disabilities into the community, as well as supporting the development of services to prevent institutionalization in the first place.