Romania: Including the Excluded

How a self-help initiative proved that institutionalization and exclusion are not the only options for the intellectually 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.

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The communist regime in Romania went to great lengths to make those suffering from mental illness and intellectual disabilities suffer even more.

As in most communist countries, the official government policy towards the disabled was to try and hide their existence. Communist governments were loathe to admit that their countries had the same proportion of people with psychiatric conditions or mental disabilities as Western countries.

The regime offered two "solutions." The least violent was for them to stay with their families, who would hide them away from neighbors' eyes. Or they would be warehoused—and largely abandoned—in state institutions, where the quality of life could sometimes be on par with that of a prison camp.

Fourteen years after communism disintegrated, these institutions are still being used as a dumping ground for people who have mental, intellectual, and physical disabilities. While conditions in some state institutions have improved somewhat, in one vital sense they remain unchanged: their primary function is still to keep their residents away from "normal" people.

The Timisoara Exception

But there is some good news.

It may have taken about five post-independence years to happen, but since the mid-1990s, organizations have sprung up in every region, to challenge the idea that people with mental disabilities are damaged goods to be left on the shelf in some backroom store. Some focus on advocacy, others on reintegrating former patients and users of mental-health services.

When it comes to alternative approaches to dealing with people with intellectual disabilities (such as Down Syndrome and autism), the leader in the field is perhaps the Pentru Voi Center, an NGO based in Timisoara, a city of 330,000 in western Romania.

Pentru Voi was started by a group of parents of children with intellectual disabilities. Frustrated at the lack of care and sensitivity that their children were receiving, they launched a self-help initiative. It became a battle against traditionally hostile attitudes towards the handicapped.

Their initial plan wasn't terribly ambitious. It was simply to create a day-care center, says Laila Onu, the executive director of the foundation. "We bought a three-room house in an outlying neighborhood of Timisoara. Then we needed more space, and we extended our building. At the same time, the children were becoming adults; and we realized that we also need to introduce services for this age category."

Now everyone in the center's programs is an adult.

Onu, herself the parent of a child with disabilities, has been the driving force of the institution since its creation. "It was difficult, especially in the early years," she recalls. "We would have not been able to do all we have done without support from several foreign institutions and the families."

The turning point came in 1997, when Pentru Voi managed to persuade Timisoara's city council to cover basic operating expenses: wages, food, heating, water, electricity, and even the gas for the minibus that carries the centers' clients.

This municipal support makes Pentru Voi unique. “Timisoara is the only town were the public budget provides money for an alternative [community-based] organization," says Onu.

From Learning about Hygiene to Finding a Job

A lack of clear legislation governing public-private partnerships can complicate cooperation with the city. However, support from the Timisoara city council and international donors—ranging from Inclusion International and the Open Society Institute to the European Commission—means that Pentru Voi can offer the kind of personal support that huge, state-run institutions cannot.

Zina Costin, one of the Pentru Voi Center's instructors, says the ratio of staff to “beneficiaries” —as she calls the disabled—is one to five; a good ratio, in Romania. But by Western standards, “we are still too few, as they work mostly one to one. And we feel it everyday," she adds.

Staff turnover is high. The pay is as low as public-sector wages, and only 30 percent of the original employees, who were trained by Dutch specialists, are still on staff. "It's very difficult to find qualified personnel in this area," says Onu, the center’s director. "So we have to train our own people, knowing that, sooner or later, they will be going to a better-paid job. Their departure has a negative impact on the beneficiaries."

But the job does offer important non-monetary compensation. Zina Costin says, "We are proud to teach them how to express themselves.” When “clients” first come to Pentru Voi, “many don't know how to write or read and their language skills are underdeveloped— as are their notions of personal autonomy and hygiene."

Pentru Voi teaches its clients much more than that: it offers training in social and practical skills, and provides some of its clients with support to find work in the open market and housing in the community.

The 110 clients are divided into five groups, according to their abilities, with 11 instructors. Some groups learn how to sew clothes and bags, to make candles, carpets, cards, and to work in a garden and a kitchen. Another group is taught to operate copy machines and to use computers. The production of the center’s magazine “Pentru Voi” is entirely their work, from writing to layout.

Manuel B. began with basic carpentry skills, then moved on to making bags, before starting to work with copy machines. Eventually he found he excelled on computers. He spends almost all day in front of a PC, editing images and writing. "The computer is my hobby now," he says, and it takes a long look to spot that he is different from your usual computer geek. "I would like now to get a job outside the center, but that would probably be difficult, since I am pretty slow."

Others, though, have indeed gone on to find work outside Pentru Voi. The center itself runs a copy shop, and sells products produced by its members. "Some are now working in a copy center, while others are able to make business cards, badges and even brochures," explains Roxana Damaschin, the center's assistant manager.

The clients cannot make a living working in Pentru Voi. The revenue they generate is not paid out in wages, says Damaschin, "because the law stipulates that any revenue they earn would cancel out part of the [disability] allowance they get from the state."

Instead, some of the money is spent on buying raw materials and tools. Sometimes the money is used to fund a group field trip.

For those able to take the next step—to set up a life away from their parents’ homes—the Foundation offers protected housing. Another program offers help finding work. Ten of the 30 people currently in the advanced program have already been hired as janitors, cooks' assistants or construction workers on the open market.

“I’d be Living in the Sewers”

Although Timisoara is the only local council which is so deeply involved in community-based projects with NGOs, an increasing number of Romanian patients are being “de-institutionalized.”

“I think that about 25 percent of the mentally disabled people that are taken care of by institutions in Romania are now part of the alternative system,” Laila Onu estimates. This figure includes people with intellectual disabilities who now live at home in their families. The level of support offered by these new community-based services can vary widely.

Pentru Voi itself is trying to bring some of the other 75 percent out of state-run institutions. This has meant adding special programs. Most of the clients who use Pentru Voi come to the center during the day, and return to their families

in the evening. But when the center brings intellectually disabled people out of state institutions, it also needs to provide some form of sheltered housing, and paid work opportunities.

Pentru Voi runs two programs specifically designed to help integrate the formerly institutionalized into the community. Although some of the center's clients are working on their own, they still need support. Some are in a protected work program, like the six men who work under supervision in a bakery, built with help from the Co-Operating Netherlands Foundations for Central and Eastern Europe.

Ghizela Ghereben was one of first people to move from a state institution to Pentru Voi. Her impoverished parents had turned her over to an institution when she was very small, and she spent almost two decades there. Now 22, Ghereben lives in an apartment with two other women and works as an assistant cook.

"Two years ago, I met my mother for the first time. Now, I visit her every weekend," she says.

Doinita Duma also spent years in an institution. Her memories of the orphanage where she lived are not pleasant: "They beat us there every day," she remembers. "The food wasn't so bad, it was pretty clean, but the personnel beat us with broomsticks."

She now works as a janitor in Pentru Voi's sheltered housing. "If it were not for Pentru Voi," she says, "I would be living in the sewers."

The Challenges of Caring

Pentru Voi may have a model of care that is vastly better than in most places, but staff members say the sheer variety of diagnoses they are confronted with can be frustrating. It is particularly difficult to make progress with severely disabled people, some of them both mentally and physically handicapped.

A life spent in a state institution can sometimes compound the problems. The physical abuse that Doinita Duma recalls is commonplace. So too was sexual abuse, say Pentru Voi staff.

Problems like these make aggression a potential danger, and this has prompted the center's managers to introduce everything from aromatherapy to physical exercise to singing when seeking to calm the center's users.

Care-workers also find that dealing with adults with disabilities makes their job harder. "Working here is not as rewarding as working with children," says Costin. "Children usually progress prettily easily, whereas adults can sometimes regress. But, generally speaking, the improvement is more than obvious, and more and more families are willing to use our services."

In fact, the waiting list for inclusion into the regular program is two to three years. In an effort to meet the need, Pentru Voi opened up an afternoon care center that caters to people with medium and severe disabilities.

The Challenges

The interest of families in Pentru Voi's services suggests that (at least in Timisoara) some of the social stigma of having a child with disabilities is being eroded. According to official figures, the percentage of Romanians with intellectual disabilities is two times smaller than in EU countries. The difference is thought to reflect the shame that Romanian families feel in acknowledging a disabled relative. In an effort to reach out to a group in which disability is a second reason for marginalization, Pentru Voi has hired a Romani staff member. Many of the 110 the center's "beneficiaries" are Roma.

However, stigma and prejudice can make dealing with families difficult. "There are families we work with really well, but some are not very cooperative," says assistant manager Damaschin. Some parents are suspicious. Some send their children to the center, then withdraw them, and then bring them back. Others would like their other, healthy children to benefit from the center's services—particularly the meals.

The greater difficulty comes with families who put their children into state-run institutions. When those children come to Pentru Voi, the parents often try to reestablish a relationship. Usually, the motive is financial gain. When they see that their child has been "adopted" by the center, they mistakenly assume that they are eligible for some kind of monetary benefit, and re-establish relations with their son or daughter. When they realize there is no money to be had, they drop out of the child's life again. Once again, their children have to face the trauma of separation.

Pentru Voi's own relationship with the traditional care system has evolved over the years from negative, to neutral, to almost positive. Every once in while, someone from a state institution shows up at the center to see how Pentru Voi does things.

"But old-fashioned ideas still play an important role" in dealings with state-run institutions, says Onu, Pentru Voi's director.

There are, though, situations in which Pentru Voi cannot cope. On very rare occasions, there are people so severely troubled that managers remove them from the center. "It has happened on maybe five occasions, that we couldn't cope with a very difficult disabled person," Onu says. "It's a very hard decision, but when you have staff and beneficiaries being beaten, and an entire group seriously disrupted, there is no alternative."

In these instances, the client is sent back to their family. Staff members say that these are by far the most painful moments that they face.

It is, presumably, deeply painful for the families too. Parents may choose to turn to the state. "In Romania, the only alternative for a family that can't deal anymore with such a severe disability is the psychiatric hospital." There, she says, the person may simply be locked into a room.

Pentru Voi is leading the way in providing community-based care and reintegrating those released by state institutions. Onu says her hope is one day to be able to set up a service for those it cannot help, those with both intellectual disabilities and violent, deeply troubled personalities.

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