

Newsletter

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Message from the Editorial Team

Dear Readers,

The second issue of ECCL's Newsletter this year brings you information about some developments and initiatives in several European countries related to the promotion of community living.

This issue opens with an article by Yana Buhner Tavanier, a journalist from Bulgaria, on institutions for adults with intellectual disabilities and mental health problems in Bulgaria, Romania and Serbia. We have reprinted the full-length version of the article, written after a four-month long journalistic investigation. The article highlights the appalling human rights abuses that take place on a daily basis in institutions for people with disabilities in the three countries and the lack of real progress towards developing community-based alternatives. The European Commission's response to this article is available at: <http://dumpinggroundsforpeople.wordpress.com/read-the-investigation/ec-and-country-responses/european-commission-answers/>.

In the article by Tobias Buchner from Lebenshilfe Austria, we learn about the availability of community-based services in Austria. Having ratified the UN Convention on the Rights of Persons with Disabilities (the CRPD), the Austrian Government is obliged to take steps to ensure that persons with disabilities can enjoy the right to live independently and being included in the community (Article 19). However, as the article explains, access to independent living and adequate support is still denied to people with high support needs.

On 14 September, during ENIL's Strasbourg Freedom Drive, we launched our Focus Report on Article 19 of the UN Convention on the Rights of Persons with Disabilities. The report aims to provide a clear explanation of the scope and purpose of Article 19 and makes recommendations to Governments and the European institutions on how to implement the right to live independently and be included in the community. The report has already received positive feedback from a number of organisations that promote and monitor the implementation of the CRPD in their countries.

Earlier this month, the Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care (ECCL is a member of this group) was published by the European Commission. The Report makes a series of recommendations to the EU Member States and the

European Commission on how to facilitate the transition from institutional to community-based care. Finally, we have included in this issue a brief update about the slow progress in the development of community-based alternatives to institutions in several European countries. ECCL has brought this information to the attention of both the Council of Europe and the European Parliament during the Strasbourg Freedom Drive.

We would like to invite you to let us know what is going on in your country, so that we can ensure that the relevant authorities (such as the European Commission and the Council of Europe) are aware of the barriers to the effective implementation of Article 19 of the CRPD. Likewise, we would appreciate receiving any examples of good practice or activities that seek to promote the CRPD. Thank you in advance.

To join the European Coalition for Community Living, please visit our website www.community-living.info or write to coordinator@community-living.info.

We look forward to hearing from you,

Editorial Team (Ines Bulić, Camilla Parker, John Evans, Ayla Alasgarova)

Foreword to the article ‘Institutions Remain Dumping Grounds for Forgotten People’

By Judith Klein, Director of the Open Society Mental Health Initiative

Having worked for almost 15 years in Central and Eastern Europe supporting the development of community-based services for people with intellectual disabilities and mental health problems, I applaud Yana Buhner Tavanier’s article on long stay institutions in this region. Buhner Tavanier provides an in-depth look at an issue that governments in the region would prefer to ignore.

The Open Society Mental Health Initiative (MHI) has successfully supported the development of person centered, quality, cost effective community-based services such as supported housing, day programs, crisis intervention and supported employment in many Central and Eastern European countries. The target group for these programs is people with mental disabilities, including the most severely and multiply disabled people, and these programs are often held up as models of contemporary practice by national governments. Therefore, it is difficult to understand how governments can continue the unjustified and inappropriate life long institutionalization of people with mental disabilities when the community-based services offer viable and sustainable alternatives that respect the rights of the individuals receiving them.

I have two theories for why the segregation of people with mental disabilities, which is a very severe human rights violation in itself, is allowed to continue. One theory is that society as a whole fails to make the connection between the people incarcerated in institutions and what we expect for ourselves, our family, friends and fellow citizens. This is because, as Buhner Tavanier’s article portrays so movingly, the residents of these institutions are systematically dehumanized. They are dehumanized by government practices, by staff in the institutions who have no time to treat them as individuals, and by the general public who prefer not to think about this issue. I think of this as the ‘us and them’ mentality. People with mental disabilities are regarded as ‘less than human’, an inferior form of being. Couple this with the widespread and ingrained stigma and prejudice against them. The result: large, remote institutions where people spend their lives, dying of abuse and neglect, marginalized and forgotten. The bitter irony of this theory is that similar treatment of animals would be an immediate public scandal. This cannot be right.

The other theory is there is a lack of **real** political will in Central and Eastern Europe to take action necessary to end this appalling practice. At the global level, where deinstitutionalization has been successfully implemented on a large scale, there has, in every case, been strong political will from the central government to support it.

In Central and Eastern Europe, while ‘deinstitutionalization’ has become a popular turn of phrase in policy circles, the truth is that not one government in this region, including the new EU member states, has concrete plans or financing mechanisms to develop networks of community-based alternatives to institutions, which are an absolute prerequisite for successful deinstitutionalization. Alarming, new institutions for people with mental disabilities continue to be built across the region, often with European taxpayer funding.

Clearly, there is much work to be done. Thank you, Ms. Buhrer Tavanier for bringing people with mental disabilities in Central and Eastern Europe out of the shadows. MHI will continue its work to enable them to be reunited with their local communities, where they have always belonged.

Institutions Remain Dumping Grounds for Forgotten People

By Yana Buhrer Tavanier in Sofia, Goren Chiflik, Svilengrad, Radovets, Oborishte, Belgrade, Kulina, Churug, Bucharest, Mocrea and Gura Vaii



An institution in Bulgaria, Goren Chiflik. A girl dips her bread in a puddle next to the toilets. © Yana Buhrer Tavanier

Reform is coming too slowly to institutions for adults with intellectual and mental health disabilities in Bulgaria, Romania and Serbia, where chronic neglect, filthy conditions, and the use of physical restraints and high-dosage drugs to control behaviour remain routine.

Someone is screaming.

Someone is screaming her head off in what seems a desolate part of the yard. There is a fence surrounding some shacks and, with each step taken towards it, the shrieks get louder. Ten more steps and there's a gate in the fence. Another ten and all hell is let loose.

There is the screaming woman – barefoot, skinny and dressed in rags.

There is another woman, unable to walk, rolling on the ground outside. She is literally covered in flies – fifty, perhaps a hundred flies on her face, filthy clothes, bare feet, hands and the two chunks of bread she's holding.

There is also a girl, who dips her dry bread in the dirty puddle in front of the outside toilets. And then eats it.

No-one pays attention.

It is lunchtime in Goren Chiflik, an institution in a remote village in eastern Bulgaria, housing 90 women with intellectual and mental health disabilities. It was renovated recently, but the place of horrors, the shacks for the “most disabled” residents, was left untouched. It is well hidden; so well hidden, in fact, that the head of the regional directorate for social protection says she has never seen it, despite having paid numerous visits to the institution. The 30 women here are not allowed to eat with the others. Instead, they are given their food behind the fence that is usually locked, effectively turning it into a cage.

This investigation, mostly conducted undercover in institutions for adults with intellectual and mental health disabilities in Bulgaria, Romania and Serbia, uncovered evidence of human rights abuses, inhuman and degrading treatment and appalling neglect. It showed that reform in this field remains patchy and slow, and too often leaves the most vulnerable behind.

Bulgaria and Romania, both EU members since 2007, and Serbia, which seeks the same status, have a grim track record when it comes to institutional care. This investigation suggests that they are still failing to meet international standards. Inadequate policies result in underfunding and a failure to recruit qualified, motivated staff. Residents are not being treated so much as controlled. Many are gradually destroyed by constant exposure to harmful, high-dosage medication. People do not leave their beds for years. Children are being kept tied down for most of the time. Living conditions are appalling beyond imagination. And the process of deinstitutionalization is as phlegmatic, that death still is the only reliable way out.

Two out of three governments showed no readiness to talk about policy. The recently elected Bulgarian government was the only one ready to answer questions – but in writing. Much is at stake for these countries if they do not improve things. The European Commission has said it may suspend payments under the European Social Fund in case of serious irregularities in Bulgarian and Romanian institutions. As for Serbia, many important voices insist that the EU must demand a better human rights track record from future candidate countries. However, in practice, Brussels has been turning a blind eye to such abuses for years.

People in institutions

3,700 in Bulgaria's institutions for adults with intellectual and mental health disabilities.

5,700 in institutions under Serbia's social ministry.

4,800 in the chronic wards of Romania's mental hospitals.

Tied up with drugs

In the institution for adults with mental illnesses in Radovets, I meet 76 unusually lethargic men. Too many hands are trembling, faces stiff and movements heavy. I am about to find out why.

Radovets is a tiny village in southeast Bulgaria. Like most institutions, this one is as remote as can be. Attracting qualified personnel here is practically impossible.

Officially, I am in Radovets as a researcher for the Bulgarian Helsinki Committee, BHC, the country's most influential human rights NGO. This was the way I chose to gather most information for this investigation, as journalists make institutions nervous. The time needed for a journalist to get a permission to enter an institution gives the staff the necessary weeks to "cover their traces" – which could include cleaning, dressing people up, telling them what to say, untying people, making them appear "busy" in the day rooms, even hiding neglected and malnourished people in locked rooms. That's why it's important that visits are either unannounced, or announced shortly beforehand – otherwise appalling living conditions and inhuman practices could be hidden, or at least made seem not so bad.

Although almost all the residents are diagnosed with schizophrenia, Radovets does not have a full-time psychiatrist. The director of the institution, Krayo Kraev, says just one such specialist works within a radius of 50km, and he only visits once a month.

One consequence of this neglect is that *all* the men in Radovets are on the *same* therapy, haloperidol, in every medical record we see. No matter what the diagnosis, current condition, or concomitant illnesses are. The director confirms this. "All residents have been prescribed haloperidol by the psychiatrist," he says. He sees nothing wrong with this state of affairs.

This investigation, mostly conducted undercover in institutions for adults with intellectual and mental health disabilities in Bulgaria, Romania and Serbia, uncovered evidence of human rights abuses, inhuman and degrading treatment and appalling neglect. It showed that reform in this field remains patchy and slow, and too often leaves the most vulnerable behind.

Medical experts maintain that haloperidol, an old antipsychotic drug, has extremely strong side effects, including tardive dyskinesia – involuntary movements of the face, hands and feet; akathisia – manifested in rocking while standing or sitting; lethargy and sleepiness. Because of its sedating effects, the US have massively used haloperidol during deportations of aliens, until the press found out about this in 2008.

The men in Radovets have taken haloperidol every day, sometimes for years. Records show that doses are high and the drug is given without consent. This means tranquil residents and untroubled staff. Though what it really means is blurred minds and harmed bodies.

“This is not treatment, but taking control of people,” Krasimir Kunev, head of the BHC, says. “I’ve never seen side effects so widespread.” At that moment we observe the men having dinner. Many hands are trembling. Holding a full spoon seems like a devastating challenge.

During our visit, the men either sleep or sit in the yard doing nothing. Hristo is one. “I have no energy to do anything”, this 32-year-old, once an award-winning chess-player, says slowly: “I wake up, have breakfast, take my pills, but they suck all my energy out and I fall asleep. I wake up, go to lunch, thankfully we are not given pills then, so I play some chess; dinner comes, I take my pills, I am exhausted, I go to sleep.”

As this applies for all the residents, it becomes clear why the old isolation unit – a tiny closet under the stairs – no longer has to be used. Drug-based restraint has become a substitute for physical restraint.

Challenged about the therapy, the director of Radovets says he will look into the issue. But he states he is very worried that if he has to stop using the services of the current psychiatrist, he won’t be able to find a new one at all.

“In these places, it’s the staff that de facto administer medication. As the psychiatrist is not around to monitor, the staff tell him who ‘needs’ more sedation,” Kunev says. “The staff in these institutions are, by default, unqualified and insufficient. Thus, it’s a temptation to turn medical treatment into a method of controlling behaviour.”

The Bulgarian government says the remote location of so many social care homes is a key factor behind the lack of qualified staff. “A great deal of the specialized institutions for people with disabilities are located far away from big cities [...] This is why very often it is not possible to ensure enough qualified personnel to take care of the residents. This [remoteness] also hampers their access to the necessary health services”, reads the official position of the Bulgarian social ministry. It says it is committed to solving this problem.

The men in Radovets are not the only ones kept restrained with high-dosage tranquillisers. It is the same in Oborishte, a care home for adults with intellectual disabilities, situated in eastern Bulgaria, one-third of whose 98 residents have a mental illness.

A look at the medical records in Oborishte also reveals the widespread use of haloperidol. Many residents have been on 9mg per day for years. Professor Toma Tomov, a leading psychiatrist, says such strong doses should only be given for short periods and for acute conditions.

Professor Tomov asks the part-time psychiatrist at Oborishte why such high doses are routinely given to people who do not need them. “At night, we have only one guard and one nurse and it’s scary,” she says, visibly embarrassed.

Her answer confirms that here, too, people are over-medicated with potentially harmful drugs to guarantee peace for the insufficient staff.

The director of the institution, Ilcho Goranov, defends the use of the drug on the grounds that “it is being administered by a professional”. He has made it clear that he has no plans to change dosages. Even though the existing practice of overmedication is in direct contradiction with Bulgarian medics’ ethics code, and the country’s public health law.

“Institutions are places where people are stored, not treated. These are not hospitals. Residents are not there till they get better. They are put in institution for an undetermined period of time, usually for life. The stay is therefore aimless. In a situation like this emotional reactions of protest and aggression could occur – and this is what makes staff use high doses of anti-psychotics, such as haloperidol”, professor Tomov says.

The mayor of the nearby town Vulchi Dol, Mr. Veselin Vasilev, who is de facto responsible for the institution in Oborishte, is unaware of any problems with the medical treatment. “We have established a monitoring mechanism. And there have been numerous checks by the social services. Nobody has found anything wrong”, the mayor insists. And then adds: “we should always bear in mind that the work in these places is extremely unpleasant and difficult”. The mayor is very happy with Mr. Goranov, the new director of the institution – “he is young and capable, able to write projects, the living conditions are much better now”. The head of the regional social support directorate shares his feelings.

There is a document, placed on the wall of the medical room in Oborishte, which reads that everyone has the right to file a written complaint to the director, who has to register it in the book for complaints, and then inform the mayor. The director of Oborishte, who has signed the document, laughs out when I ask him to show me the book for complaints. It does not exist. “No one could complain here, I accept only praise”, the director giggles.

Telling the difference

Intellectual disability is usually present from birth and refers to an ability that is lower than average to process information, learn new skills, and cope independently. Mental illness on the other hand occurs at a later age and does not affect the intellect of a person; common mental illnesses are depression and schizophrenia. There is a big difference between the two conditions, and the care provided also should be very different, explains Antoaneta Mateeva, a clinical social worker and lecturer at the New Bulgarian University. People with intellectual disability need developmental therapies, education and support adjusted to their needs to be able to live included in society. Mental illness can be cured or stabilised with medication, psychotherapy or other support systems.

In Bulgaria on paper there are 15 institutions for adults with mental illnesses, and 28 for adults with intellectual disabilities. For years the government did not maintain this separation – people were put wherever there was place. This policy has changed in recent years – but as a heritage of the past institutions still often combine the two types of patients.

Those most in need get least

“Why is this child tied up?”, I ask after I’ve abruptly opened a closed door in Kulina. Up to this moment I’ve been only shown “approved” rooms in this institution in southeast Serbia housing 500 adults and children with intellectual and developmental disabilities. “Because this is a very self-abusive child. We are doing this to protect it”, a startled staff member answers. But medical experts agree that self-abuse occurs because of lack of human contact or stimulation. Children prefer to feel pain than to feel absolutely nothing. And loving attention, not tying up, is the best way to prevent it.

In most institutions in Bulgaria, Serbia and Romania, one problem is that those who need help most get least. There is not only a lack of financial and human resources and good medical care. There is a lack of understanding. As a result, people in the gravest conditions tend to suffer most.

In all the institutions visited, reform is patchy. Most have some renovated buildings and some “transitional facilities” for a handful of residents. But improvement in overall standards of care, the provision of therapies apart from drugs, and programmes preparing people for a return to the world all seem a long way away.

Kulina offers one of the striking examples. The institution got international attention in 2007, when Mental Disability Rights International, MDRI, which promotes human rights in this field, published a damning report on Serbia, highlighting habitual use of physical restraints, seclusion, lack of staff, degrading treatment, lack of medical care and life-threatening physical conditions in Serbian care homes.

Serbia’s authorities angrily rejected the accusations and still seem in a state of complete denial. Asked to comment on the current state of its care homes, Serbia’s ministry for social affairs merely forwarded its emotional reply to the 2007 MDRI report to me.

“We identified what we consider to be torture [...] Children tied down to beds. A man, who was in bed for eleven years. The question is whether those abuses have been brought to an end. I do not know the answer”, says Eric Rosenthal, executive director of MDRI, when I meet him in Belgrade this June.

The answer is no.

When I visit Kulina a month later, there is some evidence of improvement. An attractive new building for “supported living”, housing ten adults, has been erected. There is also a new sports field and day rooms, where less disabled children can draw and play.

But, as in so many of these institutions in the region, parallel universes operate in Kulina.

The “severely disabled” children spend their time motionless in bed – sometimes physically restrained – or tied to chairs in empty day rooms. Some rock back and forth on the floor for lack of attention. To spend your entire lifetime without the opportunity to move, or to feel – that’s what many human rights activists call torture. I see many such forgotten children. Bed-ridden teenagers look no older than four. Children in cribs are horribly thin, arms and legs atrophied from disuse. “You will often hear from government officials or from staff members that “they are simply like that, this is part of their condition”. But children and young people lying in cribs became like that, because they had no stimulation, no activities”, says Dragana Ciric, country-director for Serbia of Mental Disability Rights International. “And these who hurt themselves are the ones that didn’t give up. The next step is to give up and let yourself die. In Kulina there was a girl, a teenager, lying in a crib, she was very self-abusive. And then suddenly stopped. Her eyes became blank. She has given up, wanting to die”, Mrs. Ciric adds.

In the two-storey pavilion for immobile residents, there is no elevator. Upstairs, I find people tightly packed in dark rooms, their world defined by the four sides of the bed. Teenagers and elderly, men and women – they are never taken out. Each room looks and feels like the next. It is dead quiet.

“Two years ago we saw a man who had not left his bed for eleven years. We were appalled, but the staff told us – “don’t worry, he’s so severely disabled that he is not aware what’s going on”. But then the staff also said that this young man cries every time his mother comes to visit, once a month. So that should oppose their thinking that these people don’t feel the difference. Of

course they do. But they are not given the opportunity to feel it”, MDRI’s Dragana Ciric comments.

Churug, a Serbian institution housing 206 men and women with mental illnesses, is another example of reforms that leave the most vulnerable behind. Churug contains three pavilions, of which two have been renovated. The third, housing “severe cases”, has not. It is an old army building with dirty, dusty, stinking rooms. The manager says the people here take a “collective shower” once a week. They receive no therapy apart from drugs. Activities in the day rooms are reserved for the “more able” residents. The “less able” could “pick up leaves, or help with the laundry”, I am told. The director of Churug, Mr. Miodrag Mijatovic, says he doesn’t believe that a renovation of the building will happen any time soon – “but we are persistent in our efforts to get funding”. He doesn’t mention involving the people in the third pavilion in occupational, art or psychotherapy.

In the home for women with mental illnesses in Svilengrad, Bulgaria, it is the same story. A cosy new transitional facility (for four) coexists with a pavilion for the immobile. There, it is the stench that hits you – the sickening smell of floors and mattresses drenched with urine and faeces. Women are packed in bare rooms. One woman is quietly crying. She is lying in her own excrement.

“Reform in Bulgaria is supply-driven, rather than demand-driven. It is patchy, certain changes are made to absorb funds, not to achieve a real improvement in the life of all institutions’ residents”, says the BHC director Mr. Krasimir Kunev.

Goren Chiflik, the Bulgarian institution introduced at the beginning of this article, offers perhaps the most shocking case of parallel universes. The small new transitional facility, the main building, an empty new pavilion and the horrifying stables, where 30 women are locked up, are all in the same yard.

Director Stanislav Enchev is not planning to move the women from the old stables to the new pavilion because he fears that “they’ll break everything”. He admits that “this place is our sore” and says the authorities should grant funds to build one more pavilion.

But Borislav Natov, the local mayor, says such funds will not come from the municipality. “We have no budget to ensure normal living conditions for these people,” he says.

Maria Chankova, head of the regional social support directorate, promises “urgent measures”. She has paid numerous visits to Goren Chiflik, but says she has never seen the women in the old stables.

I find Liliana in the old stables, covered in flies. She is paralysed, crouched like a grasshopper, the skin on her legs yellowish-blue. Liliana, even though she is as big as her pillow, is 62. She looks malnourished, her face too pale, her body strikingly thin. “I think this woman is about to die”, I say. “No, no, she is like that”, says the sanitary worker standing next to me. “But you know, she used to look better, she does seem very pale lately”, interrupts the other one. “Do they ever leave their beds? Do you take them outside?”, I ask. The first sanitary worker gives me a sad smile. “Usually I am alone here, and I have to take care of 30 women. There’s no time. There’s no way”. Liliana is a victim of this lack of care since 1999.

According to the Bulgarian Helsinki Committee at least five of the women in Goren Chiflik are in dire need of hospitalization, and there’s a risk for their lives.

Another place where care is provided for some and not others is Mocreia psychiatric hospital in western Romania. 70 out of its 160 patients are chronically ill. The institution has recently been renovated and physical conditions of the buildings have drastically improved. Other changes are

also coming – a sports room, a therapeutic garden... However, about half of the patients are effectively prisoners, locked in their rooms, only allowed out under supervision for 30 minutes at lunch and 40 minutes for a walk. The resident psychiatrist explains that some “might run away”, and that others are “very aggressive”. I am not answered why then not have more guards and a change in the medical treatment. For a huge part of its residents, Mocrea is nothing more than a shiny prison.

In another Romanian institution, Gura Vaii, there is not even consistent access to running water. “For five years our sanitary system is practically non-existent”, says Dr. Aneta Vladioiu, the manager of the Gura Vaii ward. She explains that the county hospital in Turnu Severin doesn’t have the money to allocate for solving the problem. The 56 patients take a shower once a week. The toilets on the first floor are unusable.

Despite numerous promises, the Romanian health ministry never answered a series of questions about the conditions in Mocrea and Gura Vaii.

“We insist that the Gura Vaii ward is closed down”, says Georgiana Pascu from the Center for Legal Resources, the most influential Romanian NGO working in the field. But not the dreadful living conditions are the biggest concern in Gura Vaii. The real problem is the complete standstill in this place, the total lack of care. There’s nothing to do. The two day rooms are locked and unused. There’s no physical or occupational therapist – even though Dr. Vladioiu says they are desperately needed. There even are no pencils, or paper.

“Is anything else going on here apart from medication?” I ask.

“Well, the music outside,” the manager answers, referring to the loud sound of the radio blaring in the yard. Equally shocking is the manager’s statement that most of the patients in the chronic psychiatric ward are not mentally ill but intellectually disabled, suffering from dementia or simply homeless. In the yard, they rock back and forth or stare into space.

And by the time I leave, even the music outside has stopped.

Numbers

According to latest data, provided by the Ministry of labour and social policy, in Bulgaria the budget for social services has tripled in the last four years – from 60 million leva (or 30 million euro) in 2006, to 176 million leva in 2009. Serbia has also spent much on renovation of institutions and establishing social protection (more than 765 million dinars, or 8.2 million euro, between 2004 and 2007), as well as for creating alternative services – as stated in the country’s reply to the MDRI report. As of 2006, Romania allocated substantially more funds to carry out reforms in the system – according to data published by World Health Organisation regional office for Europe some 15 million euro were allocated in 2006 and 2007 for the development of community mental health centres.

Getting away with murder?

“The European Commission is fully aware of the current problems in Bulgarian and Romanian institutions [...] substantial progress has been made, but the Commission is aware that still more remains to be done” the EC said in response to my questions.

This spring EC has warned Greece that if it does not come up with a road map for psychiatric reform, EU funding will be cut from social projects across the board. Regarding the question could this happen to Bulgaria and Romania, the answer was “there is always a possibility of payments being suspended under the The European Social Fund in certain cases, basically

serious deficiencies in management, serious irregularities, or a serious breach of obligations under the ESF regulations”.

Although many experts think the EU should require better track records on human rights from candidate countries, as one of the Copenhagen criteria for accession is respect for human rights, the Commission has refused to comment on this assertion.

“Bulgaria and Romania were quite literally getting away with murder. People were, and are still, often subject to the most grotesque neglect and abuse”, Oliver Lewis, executive director of international human rights organisation Mental Disability Advocacy Center, says. “When Bulgaria and Romania were joining, it was blatantly obvious what the situation was, there was no lack of information about the human rights abuses in institutions. The situation was even mentioned in the progress reports of the European Commission. But the Commission failed European citizens by totally ignoring this situation. There has been no change since these countries joined the EU, and there are few mechanisms for the Commission to improve the rights of people in its Member States”, Mr. Lewis adds.

Laura Parker, who worked as social policy advisor for the European Commission in Sofia before Bulgaria joined the EU, says: “It is clear that the decisions about enlarging the EU were primarily political ones. The almost total disregard for elements of the Copenhagen criteria also reflects the fact that human rights are simply not an EU priority.”

Parker was one of those responsible for collating the information which was used to draft the EC’s Regular Reports. “[We] tried to reflect the reality of the situation. And I know that senior EC officials were fully aware of what was going on as they personally visited some institutions.[...] But by the time they had been edited by various EC officials, the final official Regular Reports did not accurately represent the situation”, says Mrs. Parker, who is currently head of the Bulgarian office of Absolute Return for Kids, an international charity.

“The life-threatening, degrading conditions, the torture, the arbitrary detention, the stripping away of legal capacity without due process – those are all issues that can be solved immediately and the EU has the capacity to do so. Immediately. If they insist on it”, says Eric Rosenthal from MDRI.

Far from the eyes of Brussels and the minds of national governments, institutions housing the most vulnerable citizens in Bulgaria, Romania and Serbia remain no better than dumping grounds for forgotten people.

The graveyard of Radovets is a metaphor for this state of neglect. This is where the loneliest men are buried. For about half a century, the institution has had its own plot – for the residents no one wants to take care of, even after death, and dozens of former inmates lie beneath this overgrown field. However, there are only a couple of tombstones. Anonymity in death is a logical end to a life spent without rights or identity.

This article was produced as part of the Balkan Fellowship for Journalistic Excellence, an initiative of the Robert Bosch Stiftung and ERSTE Foundation, in cooperation with the Balkan Investigative Reporting Network, BIRN.

What you can do to help?

If you would like to help bring attention to the situation of people living in institutions in Bulgaria, Serbia and Romania, please visit www.dumpinggroundsforpeople.wordpress.com. In addition to reading more about Yana Buhner Tavianier’s investigation, you can find out what you can do to help.

Community Living for people with intellectual disabilities in Austria

By Tobias Buchner¹

International studies and publications on deinstitutionalisation and community living for people with intellectual disabilities have so far failed to report on the situation in Austria. This article aims to provide a brief overview of the current situation. The first section deals with the federal government and federal state (Länder) disability policies² for the Austrian system of care over the last two decades. It then considers policies and services at the federal state level. The third part draws on research undertaken in the field of housing in Austria, followed by final conclusions on the topic.

Disability policies at the federal and state level

In Austria, housing for people with intellectual disabilities falls within the remit of the nine federal states. This means that although policies may be adopted by the federal government, their implementation is carried out quasi-autonomously by the federal states. There is no federal (national) law on care for people with disabilities; instead, federal states establish their own laws in this area.

While federal states are responsible for the operational level of care, an analysis of federal policies is also of interest, because federal government policies are seen as “recommendations” to the federal states. They have had at least some impact on the organisation of care in the past.

Several disability policies include guiding principles, such as integration and normalisation, self-determination, participation and ‘equal opportunities for all’. When it comes to accommodation for people with disabilities, some housing policies refer to the Austrian model of “community-based living” (“Gemeinwesenintegration”). This is described as an alternative model of care to challenge the traditional institutional model. Based on the principles of integration and normalisation, the housing options include single apartments with ‘mobile support’, shared living arrangements (with support from staff) and small group homes. However, the policies fail to provide either a detailed description of the “community-based living” model or exact measures for its implementation.

In addition, information on housing for people with disabilities is not available at the federal level and this field has traditionally been neglected in national and international reports. For example, in the recent report on the situation of people with disabilities (2008), published on a regular basis by the Austrian Ministry for Social Affairs, the issue of housing is not even mentioned.³

Housing at the federal state level

Similar to the situation at the federal government level, most federal states either lack data on housing for people with intellectual disabilities or do not publish them. Information on the type of accommodation for people with disabilities is only available from Styria, Vienna and Vorarlberg. While data on the number of services in the field of housing were published by Carinthia, Upper Austria, Styria, Vienna and Vorarlberg, this was not disaggregated by age, gender or type of disability.

An analysis of the available data about services at the federal state level shows that in general, there are five different types of housing facilities for people with intellectual disabilities:

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- ◆ Large residential houses with more than 15 residents
 - ◆ Small residential houses, offering space for 8 to 15 residents
 - ◆ Shared apartments for 8 to 10 residents
 - ◆ Small shared apartments for 2 to 6 residents
 - ◆ Single apartments

The support offered for these five types of housing can be roughly divided into the following categories:

- ◆ **Housing with full time support:** Services with 24h support, including nursing care (such as intimate care and basic medical care). Such support is usually available in large and small residential houses and in some cases in shared apartments.
- ◆ **Housing with part-time support:** support is provided during the day but not at night. This type of service is usually available in residential houses and shared apartments.
- ◆ **Training apartment:** Services are focused on fostering the independence of the residents (e.g. residents are taught how to cook). This category does not entail night service. Usually, this service is available in shared apartments and small shared apartments.
- ◆ **Mobile support:** Services providing support by the hour, available only in some small apartments and single apartments.

A closer look at the service descriptions shows that services are based on a 'competency model' (i.e. services are provided according to the independence of the users). In several policies, housing with full time support is described as a suitable support model for people with high support needs and a low level of independence. In order to "advance" to the next "level" of service category, a higher level of independence is required. Mobile support, offering assistance in a single apartment with the lowest number of support hours is the "end stage" of this model.

Housing with full time support is the category that is most often used. It is usually only provided in residential houses or large shared apartments. Most people with intellectual disabilities living away from their families live in residential houses with 8 to 15 (and more) other residents.

As a result of the "competency model", people with high support needs and intellectual disabilities have to live in large residential houses or shared apartments - it is not possible for them to receive a service with a high number of service hours in their own apartment.

Research on Community Living and Deinstitutionalisation

An analysis of the Austrian literature on Community Living, Deinstitutionalisation and Housing shows that there has been little empirical research on the subject so far. In most cases, the research that has been undertaken was focused on the process of the so-called 'de-hospitalisation' ("Enthospitalisierung" = the process of moving people with intellectual disabilities out of psychiatric hospitals). The findings of these few studies show that living in the community brought a general improvement in the quality of life for people with intellectual disabilities, compared to living in a hospital. However, some results indicated that in the areas of self-determination and social relationships, although there has been an improvement, considerable problems still remain. Furthermore, most studies failed to take into account the views of people with disabilities, because they interviewed only the support staff.

User evaluations have been conducted in some parts of Vorarlberg, Styria and Vienna, by ATEM-PO⁴. Findings of the evaluations are posted online, including the size, geographical aspects and other factors relevant to establishing the quality of life in single living units. These serve as an

information tool for people with intellectual disabilities looking for accommodation.⁵ However, this data has not been used to write and publish significant reports on outcomes of services concerning the quality of life.

Conclusions

It is impossible to provide statistics on the status of community living in Austria due to the serious lack of data and research. However, by analysing different policies and service descriptions, some trends can be identified:

1. The availability of support services depends on the level of independence of the user (known as a competency-based model).
2. Services are usually clearly linked with certain types of accommodation.
3. In most cases, the only option for people with high support needs is to live in a residential house or large shared living arrangements.
4. There is a clear dominance of residential housing.
5. Mobile support is limited to people with a high level of independence. Some federal states have just started to develop or offer this service to a small number of users.
6. Services are not based on individual need, nor provided in a person centred way.

In the field of housing the reality differs starkly from the guiding principles set out in Austria's disability policies. Although self-determination is a key policy at the federal government as well as at the federal state level, when it comes to choosing the type of housing, certain groups of people have no real choice. The guiding principle of "equal opportunities for all" seems to be very limited in the real world for people with intellectual disabilities.

In 2008, Austria ratified the UN Convention on the Rights of Persons with Disabilities. Article 19 sets out the right of persons with disabilities to choose their place of residence, and to decide where and with whom they want to live, with no obligation to live in certain types of accommodation. Moreover, people with disabilities must have access to community services, including personal assistance (United Nations, 2007). If Austria wants to ensure these rights and make community living with a good quality of life possible for people with intellectual disabilities, it will take a lot of more work and efforts in the following years.

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Endnotes

¹ This article is based on the paper "Deinstitutionalisation and Community Living for People with Intellectual Disabilities in Austria: History, Policies, Implementation and Research" by the same author, published in the Tizard Learning Disability Review 1/2009 (p 4-13).

² Ed. note: Austria is a federal republic, with nine federal states (Bundesländer).

³ The report on the situation of people with disabilities is published every five years and aims to provide a broad overview on the situation of people with disabilities.

⁴ ATEMPO is a company working with people with intellectual disabilities on the evaluation of residential services. All interviews are conducted by people with intellectual disabilities.

⁵ For additional information, please visit www.nueva-online.info.

What is happening in other countries?

On the occasion of ENIL's Strasbourg Freedom Drive in September, ECCL prepared **Briefings for the Council of Europe and the European Parliament**. They include information about progress in developing community-based alternatives to institutions in the Czech Republic, Latvia, Slovakia, Bulgaria and Germany. ECCL Briefings to the COE and the EP are available from www.community-living.info (under Resources > Statements of the European Coalition for Community Living).

ECCL's Focus Report on Article 19 of the UN Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities ('the CRPD') is the first legally binding instrument to give explicit recognition to the right of people with disabilities to live and participate in the community. Article 19 of the CRPD recognises the equal right of all persons with disabilities to live in the community, with choices equal to others' and requires States to 'take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community'. Much more needs to be done to make this a reality for people with disabilities in Europe.

On 14 September, the European Coalition for Community Living (ECCL) published its report: **Focus Report on Article 19 of the UN Convention on the Rights of Persons with Disabilities**, which sets out the key steps for implementing the right to live in the community. It provides detailed commentary on Article 19, including its huge potential to bring about change to the lives of people with disabilities in Europe and possible challenges in achieving such change. The Report suggests specific actions that national, regional and local governments, the European Community and the Council of Europe should take to give effect to this right. It aims to assist individuals and organisations involved in promoting, implementing and monitoring the CRPD, such as policy makers, organisations of people with disabilities and service providers.

John Evans, one of the founders of ECCL, said: *'More than 1.2 million disabled in Europe are still segregated in residential institutions. Article 19 makes it clear that by putting disabled people in institutions, Governments are violating our human rights. It is crucial that action is taken NOW to ensure that like other citizens, we can be a part of society and can regain control over our lives.'*

No one should be forced to live in an institution because of the lack of alternative services in the community. Article 19 places an obligation on the Governments and the European institutions to accelerate progress towards community living in Europe, and ensure that people with disabilities can live and participate in the community as equal citizens.

ECCL's Focus Report on Article 19 is available at www.community-living.info (under Resources > UN CRPD) or by writing to the ECCL Coordinator.



Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care

The aim of this report, published by the European Commission at the end of September, is to encourage the transition from institutional care to community-based services in the EU Member States. It was initiated by the Commissioner for Employment, Social Affairs and Equal Opportunities Vladimir Špidla and was drafted by a group of independent experts, including the Children's High Level Group, the European Older People's Platform (AGE), the Confederation of Family Organisations in the EU (COFACE), the European Association of Service Providers (EASPD), ECCL, EDF, Inclusion Europe and Mental Health Europe.

The report focuses on children and adults with disabilities (including persons with mental health problems), children without parental care and the elderly, and begins by giving an overview of the extent of institutionalisation in the EU. It goes on to present the case for the transition to community-based services. This is followed by key challenges in the closure of institutions and the development of community-based services and a set of principles that will ensure that services developed enable people to live independently, and to be included and participate in their communities.

Finally, the report presents recommendations to the Member States and the European Commission on how to accelerate progress towards community living.

The conclusions and recommendations of the report have been presented to the Member States at the meeting of the High Level Group on Disability at the European Commission on 15 October. It can now be used as a tool by organisations advocating for community living across the EU and wider.

The Report of the Ad Hoc Group is available from www.community-living.info (under Resources > Policy documents)

Still waiting ... the unfulfilled promise of Olmstead

This report (referred to as the call to action) was issued by the Bazelon Centre for Mental Health Law on the 10th Anniversary of the US Supreme Court decision in *Olmstead v. L.C. & E.W.* In this landmark case, the Supreme Court held that “unjustified isolation” of people with disabilities in psychiatric hospitals, nursing homes and other institutions amounts to segregation, and is therefore illegal.

The aim of the report is to inform advocates, policy makers and the public about the role this decision has in enabling people with mental health problems to live in the community. However, as the report points out, too many people with mental health problems in the U.S. are still segregated in different types of institutional care, despite the fact that community-based services are more cost-effective and the right thing to do.

The Bazelon Centre report on the 10th Anniversary of the Olmstead case will be of relevance to all those campaigning for community living in Europe, as it highlights the positive impact, but also the shortcomings, of litigation in the process of closing institutions and developing community-based services for people with disabilities.

The Still waiting ... report is available from ECCL’s website www.community-living.info (under Resources > Thematic studies).

New resources on www.community-living.info

Campaigning resources—ECCL’s Advocacy Manual and other materials that can be used when providing a training on how to lobby and campaign for community living and the implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities.

Resources on community living and de-institutionalisation—includes a number of Thematic studies, reports on Children with disabilities, Country reports, Policy documents and materials on the UN Convention on the Rights of Persons with Disabilities.

Join the European Coalition for Community Living

Our membership is open to all organisations, institutions and individuals committed to the promotion, development or provision of community-based services as an alternative to the institutions. Membership of ECCL is free of charge.

The complete list of ECCL members is available on our website www.community-living.info.

If you would like to join ECCL, please visit our website and complete the ONLINE FORM. Please pass the invitation to join to any organisation, institution or individual who shares ECCL's vision of community living. Thank you!

Call for contributions

If you would like to inform ECCL's network about your events, projects or campaigns connected to community living, please send us a short description of such activities and we will include it in the next issue of our newsletter or post it on the website. Please send all contributions to the ECCL Coordinator at coordinator@community-living.info.

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