

Newsletter

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Inside this issue:

Lessons to be Learned: Life after the Tragic Fire in the Social Care Home "Regi"

Inspections of Institutions

Inclusion in Germany:
Daheim statt Heim

Seminar of the European
Coalition for Community
Living 2007

Update from ECCL's
Management Committee

European Disability Forum

ENIL's Strasbourg Freedom
Drive

News & publications

Join ECCL

Word from the Editorial Team

Dear Readers,

This issue comes two months after our seminar in Zagreb, at which we were happy to meet many of you. Judging from the positive feedback we received from participants, this seems to have been an informative and useful event.

For those of you who were not able to attend, we have included an article about the seminar further on in the Newsletter. The full report and all the presentations can be downloaded from ECCL's website www.community-living.info.

In our last editorial, we wrote about the incident in a social care home (an institution for people with disabilities) in Latvia, where on 23 February 2007 a fire broke out and killed 23 residents. In this issue, we bring you an update about the situation in Latvia, the actions taken by the Government following the incident and the planned changes in the system of social services for people with disabilities.

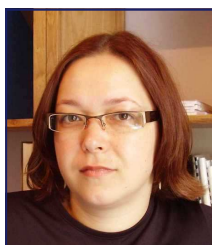
As we have noted on many occasions, thousands of people with disabilities across Europe still live in large institutions, excluded from their communities and vulnerable to different forms of abuse. While ECCL's focus is primarily on the development of community-based services, we recognise that it is necessary to protect those individuals who still live in institutions and will remain there until alternatives become available. For this reason, this edition includes an article about the work of one of our members, the Mental Disability Advocacy Center, to promote the establishment of independent bodies to monitor the quality of care provided to people placed in institutions.

Finally, we would like to encourage you to support EDF's **1million4disability** campaign and **Daheim statt Heim** campaign in Germany. You can find more information about both campaigns inside this issue. In addition, we would like to remind you to send us your feedback, as well as your contributions to the Newsletter and the website. We especially welcome examples of good practice in the provision of community-based services, which can be shared within our network.

If you support our work and would like to join ECCL, please download the application form from our website and send it completed to coordinator@community-living.info. The average membership fee is 60 or 100 EUR per year, and you can receive additional information about joining ECCL by writing to the address above.

We look forward to hearing from you!

Editorial Team (Ines Bulić, John Evans and Camilla Parker)



Lessons to be Learned: Life after the Tragic Fire in the Social Care Home "Regi" *By Ieva Leimane-Valdmeijere, ZELDA*

Just three months ago we were shocked to find out about the terrible death of 26 people with mental disabilities - residents of the social care home "Regi", which was one of more than 30 social care homes located in the western part of Latvia. Out of 90 residents almost one third died. The appalling accident has made Latvian society question whether institutional care is the best option for people with mental disabilities.

Institutional care for people with mental disabilities¹ is still pre-dominant in Latvia, where in 2006 social residential care was provided to 4646 people with intellectual disabilities and/or mental illness by 33 social care institutions. According to data from the Ministry of Welfare, around 90% of the social care budget is allocated

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to social care homes. (In 2007, 28.8 million Euros will be used to fund 33 social care homes.)

There is still a long waiting list - around 680 persons are waiting for a place in a social care home. This is because residential community services for people with mental disabilities are still a dream for many families. Currently, only a few group homes operate in Latvia - mainly for people with intellectual disabilities and almost none for people with mental illness. The Latvian Government plans to provide up to 50% of funding to cover the costs of establishing and running group homes for people with mental disabilities and promising. However, the amendments of Law on Social Services and Social Assistance concerning the funding of group homes only came into force in January 2007 and funding has not yet been allocated. The likelihood is that this will not now happen until next year. From 2008, the Ministry of Welfare estimates that it will provide co-funding for the establishment of two half-way houses and three group homes every year.

The current range of community based residential services for people with mental disabilities is very limited. By the end of 2006, only 10 group apartments, for people with mental disabilities, had been established in Latvia. Currently (according to the data as at April 2007), the Government co-funds residential community services for 70 persons. The Ministry of Welfare estimates that by 2010 this number will grow to 350 persons. Government efforts have also resulted in the creation of three half-way houses, opened on the grounds of three social care homes and providing social rehabilitation for 59 persons with mental disabilities. Another three half-way houses for 57 residents will be opened in 2007. The aim of a half-way house is to help those residents who are about to leave an institution to acquire independent living skills before they move to community based group homes.

Reactions to the tragedy

The tragedy of 23rd of February generated a great deal of media interest. It was the first time that mental disability issues received so much attention. Local NGOs, together with several international human rights organisations, wrote an open letter to the Latvian Government, asking the Latvian Government to shift the focus of support for people with mental health problems and people with intellectual disabilities from institutional care to community-based services. In addition, ECCL sent a separate letter, asking the Latvian Government to prioritise the development and provision of comprehensive, quality community based services for all people with disabilities and to stop new admissions into existing institutions. The Ministry of Welfare responded to both letters in May 2007, by explaining that local municipalities have not been active in the development of community based services.

During the public debate in Latvia, two issues were raised:

1. If Latvia has real plans to go forward with deinstitutionalisation, what are the Government's intentions regarding the development of community based services and what should be done right now to proceed with these plans?
2. What about the quality of care and human rights protection in the existing institutions?

Developments three months after the incident

- The findings of an internal investigation of the Welfare Ministry were published on 5 April 2007. It was announced that the Director of the social care home "Regi" would be dismissed. This was because illegal construction of the attic had been carried out at "Regi" social care home, without the required State Fire and Rescue Service inspections;
- In mid May, the Investigation Commission of the Ministry of Interior informed the news agencies that the most probable cause of fire was an electrical fault in the recently built attic;
- Immediately after the tragedy, the Minister of Welfare instigated an audit of the efficiency and functions of provision of social services. During the audit, the division of functions between the Ministry of Welfare and Social Services Board (the body responsible for inspecting the quality of care in social care institutions) was evaluated. However, the results have not been publicised as yet;
- The criminal investigation is still under way and therefore all the information is confidential and not available to the public.

In the meanwhile, the Ministry of Welfare has started to discuss what should be the minimal number of staff necessary in each institution. The Ministry has also created a working group, which until October has to evaluate the current situation in the field of social services. The working group will gather information on problems and will develop recommendations for improvements of the social care system.

Although several local and international human rights NGOs have stated that plans to build another institution are unacceptable, the Ministry of Welfare is already planning to ask the Government for funding in order build a new social care home. The ministerial proposal for a new institution has to be submitted to the Government by 1 July 2007.

While the Ministry of Welfare designs its plans for a new institution, Latvia has received another reminder that a new institution should not be built. In its recent Concluding Observations² on Latvia's initial report on the implementation of the International Covenant on Economic, Social and Cultural Rights, the UN Committee on Economic, Social and Cultural Rights expressed its concerns "that institutional care continues to be dominant form of care for mental patients, and that community-based services are still underdeveloped", adding that "the Committee urges the State party to allocate increased resources and undertake effective measures for treatment of, and care for, persons with mental illness, with a view to moving towards deinstitutionalisation in favour of community-based care."

The only promising change is the intention of the Health Ministry to adopt a new Mental Health Care Strategy in line with the WHO Helsinki Declaration. The Mental Health Strategy, which is currently being reviewed by the Cabinet of Ministers, plans serious investments in the development of community mental health care services, including residential services such as half way houses and group homes. The next step will be the development of an Action Plan with a budget for the Strategy. However, to reach these goals of the new mental health policy both Ministries - the Welfare and the Health Ministry - should coordinate their activities, in order to develop the health care sector and social care services in the best interest of users.

Looking ahead

It is clear that Latvia urgently needs a new mental health and social care policy with a clear Action Plan containing a strong intention to start the process of deinstitutionalisation. Both groups - people with intellectual disabilities and people with mental illness - need social services. Therefore, the two relevant Ministries should coordinate and join their efforts. Unfortunately, there is a lack of awareness among decision makers that independent living is not only about group homes, but about the creation of a system which is responsive to the individual needs of each service user and ensures that they are at the centre of service provision.

Ieva Leimane-Veldmeijere is the Director of the Resource Centre for People with Mental Disability "ZELDA" in Latvia.

Institutional care for people with mental disabilities is still pre-dominant in Latvia, where in 2006 social residential care was provided to 4646 people with intellectual disabilities and/or mental illness by 33 social care institutions.

¹ The term 'people with mental disabilities' refers to people with intellectual disabilities and people with mental health problems.

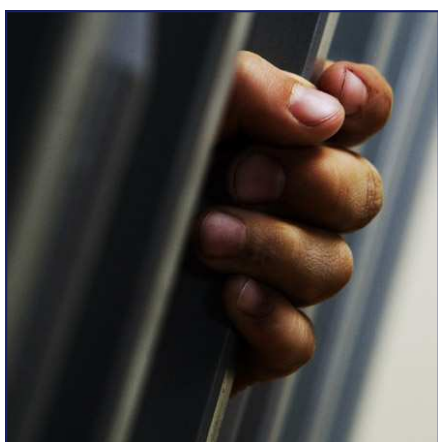
² UN ECOSOC, Consideration of Reports Submitted by States Parties Under Articles 16 and 17 of the Covenant, E/C.12/LVA/CO/1, 22 May 2007, http://www.ohchr.org/english/bodies/cescr/docs/ec_c12_lva_co1.doc

Inspections of Institutions

By Oliver Lewis, MDAC

Institutions exist. Several NGOs, including MDAC, are calling for the right to live in the community to be made a reality. This will involve both the development of a range of community-based services and the closure of long-stay institutions. Sadly, the situation in many European countries is that hundreds of thousands of children and adults with disabilities are detained in institutions, and despite the best efforts of NGOs (and in part as a result the European Commission's chronic failure to take sufficient action) some people will remain in institutions for very many years.

I am sure that every ECCL member agrees that this widespread institutionalisation is outrageous. We must, however, acknowledge this to be the situation, and we have a duty not to neglect those human beings who are currently inside these institutions. Social care homes, homes for children with intellectual disabilities, special residential schools, psychiatric hospitals, special hospitals or prisons... all of them are institutions full of people whose human rights we should care about.



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Every person detained in an institution is vulnerable to abuse. Physical abuse, violence, forced "treatment", physical restraints, seclusion, rapes, starvation, abuse of sexual and reproductive rights, lack of education, denial of the right to work, removal of legal capacity, lack of advocacy services and denial of the right to seek justice before courts. Institutions breed these types of abuses, and MDAC is working to combat them.

It is fundamentally important that in each country there are effective monitoring mechanisms (or "inspectorates") of such institutions. The effective functioning of such inspectorates will help ensure that people with disabilities and detained in institutions will become less vulnerable to abuse and neglect; they will become more visible to the protective gaze of society, their voices will be heard, services consequently improved and abuses remedied. So too will States themselves benefit. They will be able to rest in the knowledge that they are constructively contributing to the fulfillment of their duty to both respect and protect the human rights of some of their most vulnerable citizens.

In November 2006 MDAC produced a report called *Inspect!* The report offers clear guidelines as a framework for establishing and maintaining inspectorates and measures the current practice of six European countries against these guidelines. These six countries are the Czech Republic, Estonia, Finland, Hungary, the Netherlands and the United Kingdom. This review allows an assessment of common or innovative, as well as deficient, practices from which lessons can be learnt.

MDAC's *Inspect!* report aims simply to raise the profile of mental health and social care inspectorates. In so doing it hopes to stimulate discussion, to facilitate transfer of best practice and to encourage concrete and embedded State action, all geared towards strengthening the effectiveness of inspectorates and thus a reduction of human rights violations. *Inspect!* lays out in point-form eight requirements for the establishment and effective functioning of inspectorates. These requirements are based upon international legal standards, agreed following debates in domestic, regional and international forums, with active participation by State, inter-governmental organisations and civil society. They also draw on the groundbreaking work of the European Committee for the Prevention of Torture (CPT - see www.cpt.coe.int). The eight requirements are:

1. Ratify the UN Convention against Torture (OPCAT)

States should ratify and thereafter effectively implement the OPCAT. Compliance with the OPCAT requires State provision of effective monitoring of places of detention by the establishment of a system of regular visits to such institutions carried out by independent international and national bodies.

2. Establish inspectorates with a legal mandate

States should establish inspectorates by law, with a mandate to conduct regular unannounced and announced visits to institutions. Inspectorates should have the right to speak to patients, residents and their representatives of their own choosing in private. They should have the legal right to view documents. Inspectorates should have unobstructed access to all institutions upon demand and be able to react to complaints from people in institutions to the inspectorates. The inspectorates should make recommendations to public authorities with the aim of improving protection of human rights, and comment on existing and draft legislation and policy.

3. Ensure inspectorates are independent

States should ensure that inspectorates are independent from the executive and from visited institutions. They should specifically allow inspectorates to control a budget which is sufficient to effectively carry out its mission, and allow inspectorates to hire its own staff, and maintain office space separate from the executive or institutions. There should be clear policies in place to prevent conflicts of interest or corruption among inspectors.

4. Recruit qualified and experienced inspectors

States should ensure that inspectorates recruit people with disabilities, including people with psycho-social or intellectual disabilities as inspectors. The inspectorates should ensure an ethnic, gender and professional mix, and invite experts on an ad hoc basis. Inspectors and their secretariat staff should receive ongoing and high quality training and professional development.

5. Ensure that visits are effective

States should guarantee that inspectorates regularly carry out both unannounced and announced visits. They should generally inform institutions and its staff of the objectives of visits and, vitally, ensure that each institution is visited at least once a year. The inspectorates must have access to and visit all parts of an institution. During the visits the delegation from the inspectorate should conduct interviews in private, with patients, residents and any other person who the inspectorate believes may supply relevant information. They should make sure that procedures are in place to prevent perceived or real retribution (punishment) against patients and residents who communicate with inspectorates. The inspectorate should view all documentation without justification or explanation (including health documentation and court records), whilst observing confidentiality and protecting privacy of patients and residents.

6. Publish comprehensive reports

States should ensure that inspectorates publicly release detailed reports which identify root causes of problems, and they should formulate SMART (specific, measurable, achievable, realistic and time-bound) recommendations to institutions and to the authorities which have power to implement them. The reports should not only focus on negative aspects, but also highlight best practice, including promoting alternatives to institutionalisation.

7. Ensure maximum impact

States should oblige inspectorates to present annual reports to parliament, and in doing so alert legislators to life inside institutions. Inspectorates should enter into dialogue with authorities on implementation of report recommendations and carry out follow-up visits: this is the only way to ensure recommendations are implemented. The inspectorate should respond proactively and appropriately to inspectorate reports and report on actions that they have taken to meet recommendations.

8. Coordinate activities

States should ensure that inspectorates maintain cooperation and coordination with other bodies responsible for the promotion and protection of human rights, including other inspectorates and complaint mechanisms. Such cooperation results in effectiveness, coherence of methodology and standards, mutual reinforcement and avoids duplication of work, inconsistency or contradiction. Finally and crucially, inspectorates must focus on disseminating their reports to civil society stakeholders and relevant international and regional human rights bodies.

Most States already have in place some sort of a monitoring mechanism of mental health and social care institutions. What is also clear is that the inspectorates across Europe differ greatly in their development, quality and effectiveness. MDAC hopes that by providing a clear structure, its eight requirements, against which these practices can be measured, it will further this process by encouraging focused debates.

The most obvious starting places for such debates include: inadequate resourcing of inspectorates; a lack of both perceived and actual independence from government control; and inadequate formal participation of persons with disabilities and civil society generally. All of these are the result of, and contribute to, the pervasive invisibility and vulnerability of persons with disabilities removed from society. Effective inspectorates can contribute to social reform by ensuring that States respect and promote the right to live independently and to be included in the community.

The effective functioning of [...] inspectorates will help ensure that people with disabilities and detained in institutions will become less vulnerable to abuse and neglect; they will become more visible to the protective gaze of society, their voices will be heard, services consequently improved and abuses remedied.

*Oliver Lewis is the Executive Director of the Mental Disability Advocacy Center (MDAC). To download the *Inspect!* report and to find out more, please see MDAC's website www.mdac.info.*



Inclusion in Germany

Daheim statt Heim: The closing of institutions and inclusion of older people and people with disabilities, by Silvia Schmidt MP

Daheim statt Heim ("living at home or in supported living instead of institutions") is a federal initiative facilitated by Silvia Schmidt and launched in December 2006. Silvia Schmidt is a member of the Social Democratic Party (SPD), a representative and a delegate for people with disabilities in the German Parliament. The initiative is gaining more and more popularity and is supported by professionals, experts, representatives of associations of disabled people and politicians from a range of parties in the Parliament.

Too many people in Germany live in specialised institutions. Instead of institutions, more and more people with disabilities and older people want to live in their own homes (e. g. in supported living). Therefore, we do not need institutions, but community-based services for older and disabled people. We need community care and supported living.

Daheim statt Heim consists of a petition¹, which has already been signed by more than a thousand people (incl. associations with more than 500 000 members). The petition demands the closing of long-stay institutions, foster homes and such for older and for the disabled people.

Daheim statt Heim is based on personal needs and human rights (e. g. self-determination and participation) and is similar to processes towards community living in other western countries, such as Sweden, Denmark, Great Britain, USA or Canada. It relies on the Disability Action Plan (DAP) of the European Commission and the UN Convention on the Rights of Persons with Disabilities. The right to self-determination and participation are also prescribed in the German legislation from 2001. The law SGB IX focuses on self-determination and participation and its key feature is the possibility for people with disabilities to use a personal budget (a direct payment system).

Daheim statt Heim seeks to make the human rights of older people and of people with disabilities core concern of the State and social services. Its key aim is to provide older people and people with disabilities with the opportunity to live independently in the community, in small group homes (with a maximum of 5 persons) or individual housing, with adequate support based on each person's needs. Support for older people and the disabled must be based on the individual's views and needs. The *Evangelical Foundation Alsterdorf* and the *Evangelical Foundation Hephata Mönchengladbach* offer examples of best practice in this area.

A central demand of **Daheim statt Heim** is the closure of long-stay institutions, in which people who have been labelled as dependent are inappropriately isolated, segregated or compelled to live together. The initiative also demands the shifting of funds from long-stay institutions to community-based services, and legislative reform to support this. Another key message is that deinstitutionalisation and the promotion of at-home-care should in no way go hand in hand with cost reduction on the part of the State. On the contrary, providing people with quality alternatives to institutional care and promoting their integration into social life could trigger higher costs. An indicator for State expenses must be the needs of each individual.



Furthermore, according to **Daheim statt Heim**, deinstitutionalisation must not be limited to people with mild disabilities. It is unacceptable that only those individuals are offered an opportunity to live in the community, while people with more severe disabilities and a higher need for care are left behind in long-stay institutions. On the contrary, the initiative calls for deinstitutionalisation to start with people with more severe disabilities.

To conclude, **Daheim statt Heim** aims to promote integration in the widest sense. Integration and inclusion must be initiated from the very first years of life. Inclusion is not only about housing opportunities, but also about individuals' social life and their working environment. Participation should be promoted in all sectors of life under the motto: *nothing about us without us*.

¹ To sign the petition, please visit www.bundesinitiative-daheim-statt-heim.de

Highlighting the Central Role of People with Disabilities in Service Provision

Seminar of the European Coalition for Community Living 2007

In the first issue of our Newsletter in June 2006, we reported from ECCL's Right to Live in the Community Seminar in Brussels, which took place on 17 May 2006. This year we bring you the key points and conclusions from our User Involvement seminar, held on 20 - 21 April 2007 in Zagreb, Croatia. The seminar was organised by the European Coalition for Community Living in cooperation with the Association for Promoting Inclusion and the Association for Self-Advocacy, Zagreb.

The aim of the User Involvement seminar was to look more closely at the involvement of people with disabilities in the development, provision and evaluation of community-based services. During the one and a half day seminar, which was divided into five plenary sessions and six parallel working groups, participants had the opportunity to learn about good practices in user involvement, and to discuss challenges and ongoing developments in community living in Europe.

The User Involvement seminar brought together more than 130 participants, half of which were from Croatia and the rest from 21 other European countries. Participants came from disability organisations, self-advocacy and user organisations, service providers, academic institutions, ministries and residential institutions for people with disabilities.

The city of Zagreb was chosen as the venue for this year's seminar in order to encourage the development of community-based services in Croatia and support organisations and individuals involved in efforts to develop community-based services for people with disabilities in the country. It was also significant that a number of participants from the neighbouring countries (Bosnia and Herzegovina, Serbia, Slovenia, Macedonia and Kosovo) were able to participate in the seminar and discuss strategies for the development of community-based services in their countries.

Day 1: Quality assurance and ongoing developments in community living

The seminar was opened by John Evans (ECCL/European Network on Independent Living), who welcomed participants to Zagreb, adding that he wished for the seminar to facilitate exchange of good practice and challenge participants' thinking and organisation of community-based services in their countries. Words of welcome were also spoken by the co-organisers of the seminar - Borka Teodorović from the Association for Promoting Inclusion and Zdenka Petrović from the Association for Self-Advocacy, who herself spent decades living in an institution. The audience was then addressed by the Assistant Minister Dragutin Keserica from Croatia's Ministry of Health and Social Welfare, who spoke about the actions of the Croatian Government in the field of social inclusion of people with disabilities, providing some indication that his Government would support the recommendations arising from this seminar.

The first speaker, Christian Zechert (Dachverband Gemeindepsychiatrie, Germany) posed two questions to the audience - what is 'good quality' for people with disabilities and how can we ensure that 'user involvement' gives people with disabilities the opportunity to influence service provision. Giving the example of Germany, a country which does not yet have a system of comprehensive community-based services in place, he pointed out that, while quality assurance is an already established concept, the idea of user involvement is still at its very beginnings. Mr. Zechert further highlighted the differences between the 'real' and 'pseudo' user participation by asking who benefits from user involvement - whether it is the provider, for good presentation, the user, for good understanding of his/her interests, or both the provider and the user for better practice.

After discussing the relationship between ensuring quality and user involvement, the discussion turned to how to measure the quality of services. Michael S. Chapman (Chesapeake Management Consulting, the United States) started by asking what is quality and who defines it. He went on to compare the traditional approach to quality based on uniformity, consistency and compliance with the process, with the

"... all parts of [the seminar] were very useful and have made us think. Examples of good practice from other countries can serve as a roadmap for the reform of existing forms of care for people with intellectual disabilities [in our country]"
Participant from Croatia

"It is so important for organisations to come and hear about the wider picture of how people who use services are involved (or not)..." Participant from the UK



approach to quality as defined by people with disabilities. Mr. Chapman continued by pointing to different outcomes one can measure in order to evaluate the quality of a service. From the concept of quality, he turned to the concept of quality assurance and the difference between quality improvement, which is about choice, control and decision making, and basic assurances, focused mainly on health, safety and welfare. He stressed that, while basic assurances are preconditions for quality, they do not ensure good quality services.

Opening the second plenary session, Julie Beadle-Brown (Tizard Centre, UK) presented the Comparative Cost Analysis project (financed by the European Commission). The aim of the project is to provide scientific evidence to inform and stimulate policy development in the reallocation of financial resources to best meet the needs of people with disabilities, through a transition from large institutions to a system of community-based services and independent living. The following speaker - Angela Garabagiu (Council of Europe) - focused on the CoE Disability Action Plan 2006 - 2015 and the possibilities for the involvement of users of services and their representatives in policy development and decision making.

Day 2: Challenges and good practices

The second day of the seminar began with a presentation of the challenges and obstacles to the involvement of users in the planning and the delivery of services. Ingemar Färm (European Disability Forum, Sweden), presented the situation in Sweden and, referring to the right of a disabled person to choose his/her own accommodation, spoke about the difficulties in the implementation of this right in practice. By pointing to the gaps between policy and practice, he emphasised the need for continual quality monitoring and quality assurance.

Participants went on to attend two of the six parallel working groups, in which they had a chance to discuss in more detail some of the obstacles (focusing on Bulgaria, Hungary, Croatia) and learn about good practices from several European countries (focusing on France, Croatia, Serbia, Austria and the UK). The working groups were organised around the following topics:

- **Policy frameworks for community living** (Slavka Kukova, the Open Society Mental Health Initiative, Bulgaria and Neil Coyle, Disability Rights Commission, UK)
- **Self-advocacy as a precondition to inclusion** (Martine Dutoit, Advocacy France and Zdenka Petrović, Association for Self-Advocacy, Croatia)
- **Guardianship as a barrier to social inclusion** (Gábor Gombos, Mental Disability Advocacy Centre, Hungary and Neda Mišćević, Association for Promoting Inclusion, Croatia)
- **Community Living for All Initiatives in South Eastern Europe** (Ljubomir Pejaković, the Ministry of Social Policy Serbia and Vladan Jovanović, Fund for Social Innovations, Serbia)
- **Freedom and Independent Living through direct payments and personal assistance schemes** (Ivanka Jovanović, Centre for Independent Living Serbia and Tina Coldham, Mind UK)
- **Involvement of users in the delivery and evaluation of services on the national and local levels: good practices** (Klaus Candussi and Agyby Waltraud, Atempo Austria and Mandy Hooper, Commission for Social Care Inspection UK)

Closing the conference, John Evans summarised some of the main points made by the participants during the seminar and presented ECCL's proposal for the seminar statement. He stressed that, as users of services, people with disabilities must have a central place in the design, provision and evaluation of services for people with disabilities.

"[What I found most useful were] examples and experiences, especially from Serbia - the example of their strategic development, starting from principles and plans to drafting documents, securing funds for the development and provision of services in the community, ranging from donors to solutions provided by the state and the local community." Participant from Croatia

"It was a great honour and pleasure to participate in ECCL seminar [...]. We learnt a lot and we will use that knowledge to improve users' involvement in community-based services." Participants from Serbia

When speaking about stakeholder involvement, participants agreed that it is necessary to recognise that views of the different stakeholders should not have the same weight - it is the view of the user of the service in question that should count the most. During the seminar, the concepts of 'choice' and 'control' were brought up a number of times, as was the importance of different groups of people with disabilities working together.

In his final words to the participants, John Evans asked everyone to take the messages of the seminar back to their organisations, governments and service providers, as a step towards developing more and better quality community-based services in their countries.

The full Seminar Report and all the materials can be downloaded from www.community-living.info.

Update from ECCL's Management Committee

As a regular feature in the Newsletter, we bring you the main decisions of ECCL's Management Committee since the last issue in March 2007.

Policy paper on user involvement

Following up on the User Involvement seminar on 20 - 21 April 2007 in Zagreb, Croatia, ECCL will publish a Policy Paper on the same issue in the upcoming months. The paper will guide the work of ECCL and will be promoted among our member organisations. It will also be used in ECCL's advocacy activities at the European level. The draft policy paper will be distributed to member organisations for consultation before publication.

Structural funds

ECCL's Management Committee highlighted the importance of continuing to lobby for the investment of funds into the development of community-based services, rather than building new institutions. In the last couple of months ECCL has taken specific actions in relation to Romania and Latvia. These included writing to and discussions with the Commissioner for Regional Policy, the Commissioner for Equal Opportunities, the Disability Unit at the European Commission, the European Parliament and the representatives of the World Bank. ECCL has also signed an Open Letter to the Latvian Government sent by a number of Latvian and European organisations, and has written a separate letter to Latvian authorities. Activities in relation to these countries will continue, while at the same time information will be collected about planned investments in other countries.

Exchange of good practices

As was pointed out at the Zagreb Seminar, there is a great need for the collection of good practices in the process of de-institutionalisation and the development, provision and evaluation of community-based services. With the support of its members, ECCL will put additional efforts into the collection of good practices, some of which were discussed at ECCL's two seminars in Brussels (2006) and Zagreb (2007).

Future change of ECCL's legal status

ECCL's Management Committee has decided to formalise ECCL's structure (i.e. to formally register ECCL as a non-governmental organisation), in order to ensure the sustainability of the organisation and enable greater participation of member organisations in ECCL's work.

Meeting with the Head of the Disability Unit

On 22 May, ECCL's Coordinator and representatives of the Management Committee attended a meeting with the Head of the Disability Unit at the European Commission, Wallis Goelen. The main point discussed at the meeting was the investment of EU funds into institutions for people with disabilities in Romania. One of the questions brought up by ECCL's delegation was how can the Disability Unit support ECCL's efforts in this area, to ensure the implementation of the Commission's own Disability Action Plan. Among other issues discussed was the follow up to the Cost Comparison study, which is, in addition to other activities, collecting data on the number of disabled people in residential institutions in Europe and seeking to inform and stimulate policy development in the reallocation of resources from institutions to community-based services. Also discussed was the consultation on the next Disability Action Plan 2008 - 2009, which will be published at the end of this year.



Introducing the European Disability Forum

By Maria Nyman, Policy Officer

The European Disability Forum (EDF) is the representative European umbrella organisation of disabled people in the European Union. Its mission is to ensure disabled citizens' full access to fundamental and human rights through their active involvement in policy development and implementation in the EU. The membership of EDF is two-fold. Both European disability-specific NGOs and all national disability councils of disabled people

in the European Union are full members. This structure allows EDF to speak with one single and strong voice towards the decision-making institutions of the EU and other important bodies at European level.

EDF was established in 1997 and is therefore celebrating its 10th anniversary this year. Throughout these ten years, EDF has lobbied for strengthened rights of all disabled citizens within the EU. Although several legislative instruments of importance for disabled people have been adopted, disabled people are still being discriminated against in most areas of life.

Almost each EU decision and initiative has a direct impact on the everyday lives of European citizens with disabilities at all levels. Despite this, disability is still not automatically mainstreamed in EU policies. Therefore, EDF believes that there is an urgent need for a horizontal disability-specific legislation at European level, covering all areas of life. Discrimination of any citizen is unacceptable in a modern society, but all too common in practice. Legislation is necessary, but not sufficient. The greatest barrier a disabled person is facing is the attitudinal barrier. There is a great need for disability awareness-raising within society, starting already from childhood.

As EDF is celebrating its 10th anniversary and as it is the European Year of Equal Opportunities, EDF has launched a major campaign in January this year with the aim of collecting one million signatures of EU citizens who support a horizontal EU directive on non-discrimination of disabled people. The right to independent living and de-institutionalisation would be covered by such legislation. You can support this initiative by signing directly on-line at the campaign website www.1million4disability.eu.

Achieving the right to independent living is one of the most important objectives for the disability movement and the key to freedom for disabled individuals. ECCL has a very important role to play in this respect. ECCL allows for an exchange of information and best practice and the membership constitute together an invaluable joint expertise in the area of de-institutionalisation. Its committed and proactive work for high-quality community-based services will contribute significantly to achieve our common objective of a Europe where disabled people can participate as equal citizens.



ENIL's Strasbourg Freedom Drive

On the 4th until 6th September 2007, ENIL (European Network on Independent Living) are having a big Freedom Drive Lobby at the European Parliament in Strasbourg. ENIL will be campaigning for Independent Living, Human Rights and more Personal Assistance Schemes for disabled people throughout Europe, especially in the Eastern European Countries. Their campaign will also include demands to close institutions down in Europe in order to work towards a full inclusive European Society.



The Freedom Drive will involve a march through the streets of Strasbourg ending at the European Parliament, where later ENIL will make a presentation to the MEP Disability Intergroup. Individuals will also meet and lobby with their national MEP's, and there will be a meeting at the European Court of Human Rights. ENIL emphasises this will be a fun event as well as serious political lobbying.

ENIL is expecting over 100 disabled people, most of whom will be personal assistance users. There will be many European Countries represented. ENIL would welcome any support from the ECCL membership whether it is with letters of support, participation or helping assist disabled people from Eastern European Countries to attend.

Any further information can be received from Carmen Hernandez at secretariat@enil.eu.

News from our members

Employment opportunity at MHI

The Open Society Mental Health Initiative (Budapest, Hungary) is looking for a Development Manager to develop and implement strategies to support and

enhance the work of MHI's partner organisations in the region, with a particular focus on ensuring the sustainable development of organisations that provide high quality, user focused, community based services as alternatives to institutionalised care. The position is based in London, UK. Deadline for applications: 30 July 2007. Further information: www.osmhi.org

Publications

Needs Assessment of Users of Mental Health Care Services

Authors: Ieva Leimane-Veldmeijere and Uldis Veits

Publisher: Latvian Centre for Human Rights, 2006

Further information: www.humanrights.org.lv

The report demonstrates the views of users of mental health care services on the medical and social services available to them. It provides an insight into the human rights situation in psychiatric hospitals and social care homes for people with mental disabilities in Latvia, as seen by service users.

From institutional life to community participation: Ideas and realities concerning support to persons with intellectual disability

Author: Kent Ericsson

Publisher: Uppsala Studies in Education 99, 2002

Further information: www.skinfaxe.se

The right for people with intellectual disabilities in Sweden to participate in community life has led to the closure of residential institutions. The publication deals with three questions: 1) why did this occur; 2) which services provide the alternatives and 3) has this transition led to community participation?

By the same author:

Establishing CBR for persons with mental retardation: A task for the Sweileh Integration Project in Amman

Proceedings from the International Seminar "Changing Services in a Changing Society" Amman, Jordan, 1998

Join ECCL!

ECCL is a cross-disability initiative and 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. The annual contribution fee for membership in ECCL is between 50 and 200 EUR.

The Management Partners of ECCL are Autism Europe, the Centre for Policy Studies of the Central European University, the European Disability Forum, the European Network on Independent Living, Inclusion Europe, Mental Health Europe and the Open Society Mental Health Initiative.

If you would like to join ECCL, please visit www.community-living.info for further information. Please pass the invitation to join to any organisation, institution or individual who shares ECCL's vision of community living. Thank you!

New members

Tizard Centre, University of Kent, United Kingdom • Rehabilitation Foundation "Speranta", Romania • "Woman and children - Protection and Support", Republic of Moldova • Center for Innovations in Education, Azerbaijan • Association for Social Inclusion of Persons with Mental Retardation Canton of Tuzla, Bosnia and Herzegovina • Brothers of Charity Services, Ireland • MDAC (Mental Disability Advocacy Center), Hungary • "Pentru Voi" Foundation, Romania • Association for Self Advocacy, Croatia • Association for Promoting Inclusion, Croatia • Steven M. Eidelman, United States • Klubi "Deshira" Clubhouse, Kosovo • Open Society-Georgia Foundation Public Health Programs, Georgia • Public organisation "Somato", Republic of Moldova • Hand in Hand Foundation, Hungary • European Network of (ex-) Users and Survivors of Psychiatry • Renate Weber, Romania • Regional Society for Support of People with Intellectual Disabilities, Bulgaria • Down's Syndrome Aid Society, Serbia and Montenegro • Association for the Psychosocial Health of Children and Adolescents (A.P.H.C.A.), Greece • Pierre Belpaire, Belgium • Erivajadustega Inimeste Toetusühing Tugiliisu (MTÜ Tugiliisu), Estonia • HADER, Kosovo • Association "Inclusion" of the Brcko District, Bosnia and Herzegovina • The Association for Help to People with Mental Handicap in the SR (ZPMR v SR), Slovak Republic • FDUV, Finland • CHANCE, Bulgaria • Interessenvertretung Selbstbestimmt Leben in Deutschland e.V. (ISL) - German Council of Centers for Self-Determined Living, Germany • Real Life Options, United Kingdom • Ado Icarus vzw, Belgium • Hungarian Society of People with Golden Heart, Hungary • St Anne's Service, Ireland • The Association for Helping Persons with Developmental Disabilities Gradačac - "Kutak radosti", Bosnia and Herzegovina • Stichting Pepijn en Paulus, the Netherlands • Mental Health Foundation, Armenia • The Latvian Centre for Human Rights, Latvia • Lebenshilfe Wien, Austria • NGO Riga city "Child of Care", Latvia • TIBP mbH, Germany • The European Association of Service Providers for Persons with Disabilities (EASPD) • Lebenshilfe Deutschland, Germany • Society of Social Psychiatry and Mental Health, Greece • Learning Disability Wales, United Kingdom • PUŽ - Association of Parents of Children with Special Needs, Croatia • Foundation Open Society Institute Macedonia, Macedonia • Quip - Association for Change, Czech Republic • Stefan Krusche, Germany • Forum selbstbestimmter Assistenz behinderter Menschen eV (ForseA), Germany

Please note that, in accordance with our privacy policy, we have not included those organisations/individuals who wished not to be named publicly.

CALL FOR CONTRIBUTIONS

If you would like to inform the 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 Ines Bulić, coordinator@community-living.info.

For more news and information about ECCL's activities, visit www.community-living.info and download the next issue of ECCL's newsletter.

Disclaimer: *The European Coalition for Community Living cannot accept responsibility or liability for contents of the authored articles in the Newsletter.*