

Newsletter

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Message from the Editorial Team

Dear Readers,

Our first Newsletter of 2010 includes information about ECCL's recent activities and various initiatives aimed at promoting the right of children and adults with disabilities to live and participate in the community as equal citizens.

This issue opens with an interview with Ludmila Malcoci, the Director of the Community for All project in the **Republic of Moldova**. The project aims to develop a range of community-based services for residents of a long-stay institution in Orhei (an institution for boys with intellectual disabilities and mental health problems), and to contribute to the overall reform of care and social policies.

In 2009, ECCL contributed to several important initiatives that highlight concerns about the situation of people with disabilities in long-stay residential institutions. In the previous issue we wrote about the report of the **Ad Hoc Expert Group on the Transition from Institutional to Community-based Care**, which is now also available in Croatian, Romanian, Bulgarian and Hungarian. Copies of the report are available on the ECCL website www.community-living.info. In this issue, you can read about another two European initiatives - a project of the **EU Fundamental Rights Agency** on people with intellectual disabilities and mental health problems and **WHO Europe's** draft Declaration and Action Plan on children with intellectual disabilities. In addition, we have included some information about the public consultation on the preparation of a new **EU Disability Strategy 2010 – 2020**.

Following the launch of our Focus Report on Article 19 of the UN Convention on the Rights of Persons with Disabilities in September 2009, we have sought to disseminate it as widely as possible and to ensure that it becomes available in more European languages. (The Spanish, Slovenian and Italian translation is available on our website.) We presented the report and its recommendations at a workshop on Article 19 organised by Inclusion Europe. We also discussed the report at our meeting with the Council of Europe Human Rights Commissioner Mr. Thomas Hammarberg in January this year.

Each year, new members join ECCL. This is very easy to do - by simply completing the online form on our website. Members of ECCL are able to share information and good practice with other ECCL members who are involved in similar initiatives across Europe as well as learning about European developments that could help with the advocacy work that they are doing in their countries. We would like to invite new organisations and individuals who promote the right of people with disabilities to live in the community to join us, and to keep us informed about the concerns we should raise with representatives of the EU institutions and the Council of Europe.

Finally, we would like to inform you that on 24 March 2010 we are convening a seminar on how European Union funding can be used to support the transition from institutional to community-based care. The one-day seminar will take place in Brussels. To register, please write to coordinator@community-living.info.

We look forward to hearing from you,

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

Developing Community-Based Services in the Republic of Moldova

Interview with Ludmila Malcoci, the Director of the Community for All Project, Keystone Human Services International, Moldova

ECCL spoke to Ludmila Malcoci, the Director of the Community for All Initiative to find out about the deinstitutionalisation efforts in the country and the opportunities and challenges faced by people with disabilities in Moldova.

The Community for All Moldova Initiative is a partnership between civil society and government aimed at initiating the shift from large residential institutions to care in the community for people with mental disabilities, in a sustainable manner. Community for All Moldova is funded by the Open Society Mental Health Initiative and implemented by Keystone Human Services.

About the Community for All project

Q: Can you tell us a bit about the Community for All project?

The Community for All initiative was established through a joint effort of the Open Society Mental Health Initiative, the Soros Foundation Moldova, Keystone Human Services International, Hope and Homes for Children and the Ministry of Labor, Social Protection and Family of the Republic of Moldova.

The objective of the Community for All project is to contribute to the reform of care and social protection policies, with the aim of facilitating the social inclusion of people with disabilities. This will be achieved through the development of community-based services for residents of an institution for boys with severe mental disabilities¹ from Orhei, and by establishing a legal framework for the provision of alternative, community-based services for persons with intellectual disabilities.

Q. What is the approach of the Community for All project to de-institutionalisation?

Our project combines the bottom-up and top-down approaches. Based on a Memorandum of Understanding, we are supporting the Ministry to develop legislation that promotes the social

inclusion of persons with disabilities and the regulatory framework for community-based social care services for persons with intellectual disabilities. Up to now, the Project has supported the Ministry in developing the draft Strategy for social inclusion of persons with disabilities, the draft Law on social inclusion of persons with disabilities and the draft Standards and Regulations for shared living and supported living services. We are also working with the public administration at the district and community level and non-governmental organisations (NGOs), in the process of reuniting children with disabilities with their families and developing new community-based services.

When working at community level, the project is focused both on enabling persons with disabilities to move out of institutions, and preventing institutionalisation of other persons with disabilities. We do this by working with partner organisations in the communities where the person is living (or in the case of the residents of the institutions, the communities where they originally lived).

Plans for the integration of children and adults into their own families or into other community-based services are based on a person-centred approach. We work to establish groups who can provide support to each person with disabilities. These community support groups usually include family members, representatives of local authorities, social workers, pedagogues, community doctors, etc. In a participatory way, the support group develops a person-centered plan and an intervention plan for the individual. The intervention plan includes different activities oriented towards the person's integration into the community and uses community, family and project resources. Examples of the support communities can provide include: regular health supervision by a family doctor, pedagogical support to facilitate school inclusion, minor work to renovate the house where the person is going to live, and providing other essentials such as food and clothes.

In cases which require the development of new community based services such as community homes and supported living, the local public administration share the operational costs of these services. The project also supports the most pressing needs of the child which cannot be met by the family or community, and can act as a barrier to his/her reintegration within the family and social inclusion. In this context, I would like to mention that during a six-month period, thanks to project interventions and support, 17 children and young adults moved from the Orhei institution into their community and 14 of them were reunited with their biological families. All these young people are provided with support in the community. Five children are going to schools or kindergartens.

The project also works with the local mayor's offices in the communities where the residents of institutions originally came from, to develop in a participatory way a community plan to prevent the institutionalisation of other persons with disabilities. This plan is then integrated into the overall plan of the community (known as the "strategic socio-economical development plan").² Other members of the community (local public administration, NGOs, school representatives, social service providers etc.) also receive training on disability issues, the social inclusion of persons with disabilities and new community based services for persons with disabilities. Up to now, the project has helped to strengthen the capacity of more than 500 community actors to promote the social inclusion of persons with disabilities.

The project also serves as a gatekeeping mechanism for the prevention of institutionalisation of other children, and we now have 21 children in the prevention program. The prevention program responds to urgent cases, where a person would otherwise be placed in an institution. The Ministry of Labor, Social Protection and Family refers the person to the project, which then works to provide the support that the person needs in the community. On page 5 is an example of how the project supports families to look after their children at home and to overcome the difficulties involved in doing so.

Quality of services

Q: How does Community for All define good quality community-based services for people with disabilities? What criteria do such services have to satisfy?

For us, good quality community based services are based on the services users' needs, which is probably the most important criterion. Other criteria that services should satisfy include:

- ◆ Involving persons with disabilities in all decisions related to their life;
- ◆ Providing enough community support to persons with disabilities to facilitate their development and growth;
- ◆ Facilitating the integration of persons with disabilities into their community (by providing family support, school integration, etc);
- ◆ Ensuring a high level of satisfaction by persons with disabilities and their families.

Q: How do you evaluate and monitor the quality of services you are providing? Do you involve service users in the evaluation of services?

Since we are only beginning to provide new services, we are still in the process of developing a monitoring and evaluation mechanism. Involving service users in evaluating the quality of services will certainly be a part of it. This will be done through, for example, users' report cards or focus group discussions. We will also try to involve community support groups (consisting of pedagogues, doctors, friends and family of the person with disabilities) and users' families in the process. It is important to involve community support groups, as these people are a part of the process, they know what is going on, they can help develop recommendations and they will support the implementation of these recommendations at community level.



De-institutionalisation in Moldova

Q: How do you see the process of de-institutionalisation in Moldova in relation to both children and adults with disabilities?

In Moldova, there are around 7,500 adults and children with disabilities living in long-stay residential institutions. Institutions are under the Ministry of Labour, Social Protection and Family and the Ministry of Education. Overall, deinstitutionalisation is new to the country. If we look at the issue from the perspective of the institution for boys with severe mental disabilities in Orhei, we are only at the beginning of the process of deinstitutionalisation. We very much appreciate the commitment of the national and local government in this process. I would say that the political will is the most important factor in ensuring that it is a success. Now that we have the commitment of the Government, we can discuss both the closure of institutions and how to prevent people from being institutionalised. This would not have been possible several years ago.

My mother by Victor Chiriac (top) and *My class* by Dumitru Ceban (bottom)

However, there are still major challenges ahead; among them, the lack of legislation for community-based services, outdated financial mechanisms that continue to favour institutional care, the economic situation in Moldova, the scarcity of community-based alternatives to institutions, and the fact that these are operated mostly with donor funding.

It is our hope and belief that the existing political will and the combined efforts of the government and civil society will help bring to an end the era of segregation and exclusion of people with disabilities.

Looking with hope to the future

Dumitru³ and his mother Vera live in a small village in the north part of the country with a total population of around 1000. Vera gave birth to Dumitru when she was only 17. When the boy was diagnosed with mental retardation, Vera's husband left the family for good. As Dumitru grew up, his intellectual disabilities were accompanied by challenging behavior, and Vera's family and neighbours advised her to send Dumitru to the Orhei institution and to begin a new life. When she refused, the family asked her to leave the house. Vera did not have any qualifications, was not employed and there was no one who could help her and her son financially. She therefore decided to place her child in the institution.

When Dumitru's case was referred by the Ministry of Labor, Social Protection and Family to the Community for All Project, a team composed of a social worker and psychologist assessed the community and the family and developed a person centered plan (PCP) for Dumitru. Based on the PCP, intensive social, psychological and material support was given to Dumitru and his mother. First of all, the project team supported them in finding a place to live. The behavioral specialist developed a plan of interventions for Dumitru to help improve his behavior. The plan involved everyone in contact with Dumitru. Dumitru was also included in a day care centre. Arrangements were made for Vera to train to be a cook at a vocational school. She is now described as one of the best students by the school principal. The team is also helping Vera find a job. Vera said: "This is the first time in our life when we feel safe and happy and look with hope to the future".

Q. Has orientation towards joining the European Union been helpful in encouraging the development of community-based services for people with disabilities?

The goal of joining the European Union has most certainly contributed to the development of community-based services for persons with disabilities in Moldova. I have been working in this field for around 10 years. During my time at the Moldova Social Investment Fund I was involved in the development of the first community-based services for children at risk, including those with disabilities. Moldova has taken a big step forward in the last decade. Initially, the process was mostly driven by NGOs and the most progressive local authorities. Now we also have the political will at the central level. In this context, I would like to mention the following developments:

- ◆ the adoption of the social protection policies for persons with disabilities by the Ministry of Labor, Social Protection and Family;
- ◆ the Draft Strategy for Social Inclusion of Persons with Disabilities;
- ◆ the efforts of the Ministry of Labor, Social Protection and Family to develop the Law on Social Inclusion;
- ◆ the legal framework for integrated social care services;
- ◆ the approved strategy on reforming residential institutions; and
- ◆ the Memorandum of Understanding with the Ministry to develop community-based services for residents of the Orhei institution for boys.

Q: What do you see as the main barriers and opportunities to the process of deinstitutionalisation in Moldova?

I would say that the main opportunities are the efforts of the Moldovan Government to join the European Union, as well as the commitment to the process on behalf of the Presidency, Parliament and the Government of Moldova. Of course, the fact that Moldova has signed the UN Convention on the Rights of Persons with Disabilities is also an opportunity for improvements in this area. The experience of neighbouring countries which have some positive experiences in the

field of deinstitutionalisation and the existing external donors' support to the process of deinstitutionalisation are also positive factors.

As to the barriers, I would highlight the following:

- ◆ the commitment to social inclusion still remains mostly at discourse level;
- ◆ the lack of legislation and mechanisms to implement the policies in practice;
- ◆ the lack of alternatives to institutional care and the poor geographic coverage of the existing ones;
- ◆ the fact that most of the community based services are run by NGOs and funded by donors; and
- ◆ the financial commitment of the government to making the shift from large residential institutions to care in the community still remains at a low level.

I would add also the political instability that we experienced throughout 2009 and the international financial crisis, which imposed a 20% cut on the public administrative budget for 2010. This will certainly have an effect on the social protection projects as well.

UN Convention on the Rights of Persons with Disabilities

Q: Will the UN Disability Convention be helpful to organisations – such as Keystone Human Services – working towards creating equal opportunities for people with disabilities and other groups at risk (such as children and the elderly) in Moldova?

Yes, because, the Convention protects the right of persons with disabilities to live independently and participate fully in all aspects of life. According to the Convention, persons with disabilities have a right to individual autonomy and independence and the freedom to make their own choices, including regarding where to live, how to spend their time, etc. Persons with disabilities should be fully involved in the making of decisions about policies, programs and services that concern them. I would say that Keystone provides a positive example in this case and that we try to implement the Convention when developing models of community-based services in Moldova.

Q: Assuming that Moldova will ratify the UN Disability Convention in the near future, what do you think the Government's first steps should be?

I think that the first thing the Government should do is to develop legislation compliant with the provisions of the Convention, mechanisms for its implementation, and to allocate financial resources for this work. The next thing to do would be to develop a mechanism for the monitoring and evaluation of the implementation of the Convention. At the same time, some existing legislation will have to be amended so that it complies with the Convention, such as the Law on Social Protection, the Law on Children's Rights, and the Law on Education. It is also important to work with the public and the authorities, in order to promote the Convention at all levels.

Q: What role should the Moldovan disability community play in implementing the UN Disability Convention, especially in relation to the right to independent living (Article 19)?

The disability community should certainly play a role in empowering persons with disabilities to advocate for their rights, as well as promote and advocate for the right of persons with disabilities to live in the community. They should work towards changing the attitudes of families and communities towards persons



Barriers by Victor Chiriac

with disabilities, their rights and role in the society; and they should continue to advocate for the development of community based services for persons with disabilities. Finally, the disability community can play a part in developing mechanisms for monitoring the implementation of the Convention, and by acting as a watchdog.

Q: What role could the EU institutions play in implementing the UN Disability Convention in Moldova?

The EU should support Moldova in the development of a regulatory framework for the implementation of Convention, such as amendments to the old legislation, the drafting of new legislation and the development of regulations and standards for new services, and provide expertise in the development of a monitoring mechanism. Given the experience in delivering community based services in the EU Member States, they should also support us in the development of community based services.



Orange peels by Andrei Cataveica

Q: What could initiatives such as ECCL do to help?

Some of the things that it already does, such as sharing best practice in the development, delivery and evaluation of good quality community based services for persons with disabilities. It would help if ECCL could also support us in making connections with other organisations and projects developing community based services, and help develop advocacy strategies and action plans. Support in finding donors for the development of community based services would also be very useful.

Endnotes

- ¹ The term 'mental disabilities' is used to refer to intellectual disabilities and mental health problems.
- ² The community plan is developed in a participatory way by all the stakeholders, such as representatives of the local public administration, NGOs and community leaders. This is done during a 5-7 day workshop, after which it is discussed at the general community meeting and approved by the local council. Usually the strategic plan covers a 3-5 year period. It includes different components: economical development, social development, development of community infrastructure, health, social protection etc.
- ³ The names were changed to protect the persons' identities.

Photos: All the photos were taken by project beneficiaries (persons who were integrated into their families) and were a part of the exhibition organised at the Ministry of Labor, Social Protection and Family. The photos show the world from a perspective of persons who spent years living in institutions and are now discovering it again. Before taking the photos, they went through a training on how to use a camera.

Keystone Human Services International is a family of nonprofit organisations working together to serve the community. Keystone's mission is to create opportunities for the social inclusion of people with disabilities. This includes ensuring that disabled people can make their own decisions in life, and that they become valued and active members of their communities. To this purpose Keystone provides comprehensive community-based services, including early intervention and children and family services, for children, young people and adults with intellectual disabilities, autism and mental health problems, and their families. In addition to working in the U.S., Keystone is engaged in initiatives in Russia and Moldova.

The Open Society Mental Health Initiative (OSHMI) aims to ensure that people with mental disabilities are able to live as equal citizens in the community and to participate in society with full respect for their human rights. OSMHI focuses on ending the unjustified and inappropriate institutionalisation of people with mental disabilities by advocating for the closure of institutions and the development of community-based alternatives. *ECCL would like to thank Raluca Bunea for her contribution to this interview.*

ECCL members in the Republic of Moldova:
Woman and Child—Protection and Support (Criuleni), Public organisation SOMATO (Balti) and ACASA—Association for Charity and Social Assistance (Chisinau)

Towards Community-Based Support and Better Health for Children with Intellectual Disabilities and their Families in Europe

By Roger Banks

Mid December 2009 in London and the weather chilly and wet as a foretaste of the severe winter yet to come. The Novotel hotel near to St Pancras station served as host to a wealth of expertise, experience and enthusiasm that poured in via trains and planes from around Europe. This was the second meeting of the European office of the World Health Organisation's (WHO) steering group that is overseeing the development of a European Declaration for the health of children with intellectual disabilities and their families. The WHO Europe conference to launch this declaration will be hosted by the Romanian Prime Minister's office, the highest concerns being for those children and young adults who continue to live in appalling conditions in segregated institutions. The steering group, representing many key NGOs has been mindful of the need to improve the well being of children and families in all countries; poor physical and mental health, disadvantage, segregation, discrimination and lack of adequate and appropriate intervention and support can be demonstrated throughout the continent in varying degrees. A smaller drafting group has supported WHO to produce a declaration that has European applicability and is closely aligned to existing declarations and legislation on the rights and wellbeing of people with intellectual disabilities and their families. An important consideration throughout this process has been that of the need for an ongoing process of implementation of the priorities identified in any convention, declaration or action plan and it was with this in mind that the December meeting included representatives of a number of European NGOs and was hosted by the Children's High Level Group. The purpose and structure of the two day meeting were not only to give opportunity for comment and refinement of the declaration but also to think about how such organisations could enable a process of implementation of the actions necessary to achieve its objectives.

The meeting was supportive of both the content of the current draft of the declaration and also of the processes by which it had been achieved, in particular the bringing together of 'smaller voices' in the field and the involvement of people with intellectual disabilities and their families. The attendance of Tim, for example, a young boy with cerebral palsy from Sweden, together with his father, was an inspiration to the group. There was strong support for the emphasis in the declaration on prioritising support for the wellbeing of families and inclusion in communities as a means to eliminate the use of institutional and segregated care.

The priorities outlined in the declaration address such issues as: protection from harm and abuse, enabling children to grow up in healthy families, early identification of need and high quality health care delivered by an informed and skilled workforce.

The anticipated adoption and endorsement of this declaration by the Health Ministries of Europe, whilst a vital step, would not be the sole instigator of change for better health and better lives of children with intellectual disabilities and their families and whilst WHO has led the production of the declaration, it can only be one of a number of participants with a role in the process of implementation. It was encouraging therefore that the assembled NGOs gave a commitment to working together to find ways of bringing about real



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changes through such activities as awareness raising, organisational development, professional development and education, capacity building and research and development and above all, generating an understanding of the 'how' of positive changes. The Children's High Level Group volunteered to act as co-ordinators for this process and, together with a number of expert papers being produced to elaborate upon, and give good practice examples for, each of the identified priorities in the declaration, it is hoped that there will emerge a coherent and collaborative plan of actions across Europe.

The 'voice' of children with intellectual disabilities must be heard, and Tim's chuckles of delight as he played with a model London Bus amongst the documents and flip charts of the working groups, was a forceful reminder of the common goal to liberate all children with intellectual disabilities in Europe to a world of laughter, play and a real and valued presence in society.

Dr. Roger Banks is a member of the Drafting Group working on the European Declaration for the health of children with intellectual disabilities and their families. He works as a consultant/lead clinician in Psychiatry and Adult learning disability in Wales.

Council of Europe Calls for Deinstitutionalisation of Children with Disabilities

COE Press Release—Strasbourg, 4 February 2010

The Committee of Ministers has just adopted a text recommending that member states no longer place children with disabilities in institutional care and instead give preference to community living.

There are many concerns about the compatibility of institutional care with the exercise of children's rights. Barring exceptional circumstances, no children should be placed in institutional care. Moreover, institutional provision should be replaced with community-based services within a reasonable timeframe as part of a comprehensive approach.

The Committee of Ministers acknowledges that member states are at very different stages in this area and that deinstitutionalisation is an on-going, long-term process. The text therefore underlines the importance of safeguarding the rights of children with disabilities and vulnerable young adults in institutional care throughout the transition process.

Mechanisms should be established to involve children with disabilities and their families in the process of service development, as they are vital stakeholders.

The Council of Europe has been active for several years now in defending children's rights and helping to eradicate violence against all children, including children with disabilities.

It has adopted a ten-year plan for 2006 to 2015 aimed at bringing about a major change in perceptions of people with disabilities and in practices relating to them. A key aspect is protecting and promoting the rights and dignity of children with disabilities. In addition, one strand of the Building a Europe for and with Children programme is protecting children against violence.

Several million children and adults with disabilities live in long-term care institutions in the 47 Council of Europe member states.

The text of the Recommendation CM/Rec(2010)2 is available at www.coe.int.

Updates about the work of ECCL

EU Fundamental Rights Agency

On 25 November 2009, the EU Fundamental Rights Agency (FRA) held an initial networking meeting on the project Fundamental Rights of Persons with Intellectual Disabilities and Persons with Mental Health Problems. This meeting brought together organisations advocating for the rights of people with intellectual disabilities and mental health problems and representatives of the national human rights institutions from several European countries. The aim of the meeting was to help FRA define the priorities, the key stakeholders and possible activities for its work in this field.

The first part of FRA's project on Fundamental Rights of Persons with Intellectual Disabilities and Persons with Mental Health Problems started in 2009. It consists of legal research on the national and international human rights guarantees available to persons with intellectual disabilities and persons with mental health problems (carried out by a network of legal experts known as FRALEX). The main aim of the study, which will be completed in 2011, is to examine the existing legal instruments and their implementation in practice. The second part of the project will be a social study mapping the actual experiences of discrimination and human rights violations among the target groups (including those of people with disabilities in long-stay residential institutions). This will start in 2010.

Given that FRA's primary role is to provide evidence-based advice to the European Commission and the Member States, ECCL considers that an essential part of this project should be the identification of the problems that prevent, or hinder, the transition from institutional to community-based care. The identification of such barriers would help national Governments and the EU to better define what steps they need to take to achieve the social inclusion of disabled people.

More information is available at http://fra.europa.eu/fraWebsite/research/research_projects/proj_disability_en.htm.

EU Disability Strategy 2010 - 2020

The work of the European Commission on disability issues is based on a Disability Strategy, also known as the EU Disability Action Plan (DAP) 2003 - 2010. The strategy has been developed in two-year phases (the last one being 2008 - 2009), each of which identified policy priorities for the upcoming period.

In November 2009, the European Commission launched an online consultation on the forthcoming EU Disability Strategy 2010 - 2020, which ended on 4 January 2010. According to the European Commission, the aim of the online questionnaire was to identify the problems people with disabilities face in their daily lives and possible ways of solving them. However, a number of organisations, including ECCL, decided to submit a separate response, allowing us to propose a number of priority actions that should be included in the new strategy.

ECCL's response focused on the situation of people with disabilities living in long-stay residential institutions and the lack of quality community-based services. Our suggested priority actions were aimed at the implementation of Article 19 of the UN Convention on the Rights of Persons with Disabilities, which the European Community approved in November 2009 (without fully ratifying it, however). The key message of ECCL's response was that unless substantial progress is made towards developing community-based alternatives to institutional care, disabled people

across the European Union will continue being placed in long-stay residential institutions, often for life. ECCL has therefore called on the European Commission to make this issue a priority in the new disability strategy.

More information is available at <http://ec.europa.eu/social/main.jsp?catId=430&langId=en>. To receive a copy of ECCL's response, please write to coordinator@community-living.info.

Workshop on Article 19 of the UN Convention on the Rights of Persons with Disabilities

Last year, Inclusion Europe organised a series of capacity-building seminars on the UN Convention on the Rights of Persons with Disabilities ('the CRPD'). The seminars will continue this year, with the first event for 2010 focusing on making effective use of the monitoring mechanisms under the CRPD. This took place on 12 – 13 February in Prague. The seminars are primarily designed for members of Inclusion Europe, but they are also open to other organisations advocating for the rights of people with intellectual disabilities in Central and Eastern Europe, if places are available.

ECCL was invited to run several sessions at the seminar on Article 19 (Living independently and being included in the community), which took place on 20 – 21 November last year. The sessions covered the following topics: the scope and purpose of Article 19, opportunities and barriers to de-institutionalisation, other instruments at the European and international level that promote the right of people with disabilities to live in the community, and advocacy strategies for promoting the CRPD at the national level. In order to identify effective strategies for facilitating the implementation of Article 19, participants were invited to discuss barriers to community living in their countries and to identify conditions that need to be in place before the CRPD can be implemented (such as strategies for the prevention of institutionalisation, awareness about the rights of people with disabilities among members of the local communities, examples of good practice in the delivery of community-based services etc.)

With the help of Jan Siska from the Charles University in Prague and ATEMPO from Austria, participants also had the opportunity to discuss how to monitor services in their countries, how to make use of the best practice models in the delivery of community-based services, and how to carry out user-led evaluations of the quality of services in the community. All of these topics were discussed in the context of moving from institutional to community-based care.

ECCL hopes that similar capacity-building seminar will be organised across Europe, not only involving disability organisations, but also policy and decision makers, service providers and the media. ECCL's Focus report on Article 19 of the CRPD and our advocacy manual 'Creating Successful Campaigns for Community Living' can be used as resource materials to design and run such workshops. ECCL would be interested in working with you on this, so please do get in touch with us.

More information is available at www.inclusion-europe.org. To inquire about ECCL's publications, please write to coordinator@community-living.info.

Meeting with the Council of Europe Human Rights Commissioner

The Commissioner for Human Rights is an independent institution within the Council of Europe (COE), mandated to promote the awareness of and respect for human rights in 47 Council of Europe Member States. The current Commissioner is Thomas Hammarberg and his work can be

divided into three main activity areas: dialogue with governments and country visits, thematic recommendations and awareness raising, and promoting the development of national human rights structures.

On 26 January 2010, ECCL met with Commissioner Hammarberg in Strasbourg, in order to bring to his attention the existing barriers to de-institutionalisation in the COE Member States, and to suggest actions that should be taken by the COE and the national governments to address these barriers. The work of Commissioner Hammarberg is particularly important in those countries that are not members of the European Union, such as Serbia, Bosnia and Herzegovina, Montenegro, FYR Macedonia, Kosovo, Croatia, Turkey and the former Soviet Union countries (such as Russia, Ukraine, Moldova, Georgia, Azerbaijan and Armenia).

The Commissioner has issued several positions papers (known as 'viewpoints') on the rights of people with disabilities and is advocating for the ratification and implementation of the CRPD among the COE Member States. In relation to people with disabilities living in long-stay residential institutions, he noted that there is still too little data available and that far more attention is paid to the situation of children, while adults living in institutions are largely forgotten. Considering that the Commissioner regularly visits Member States and has the opportunity to meet with high level officials, ECCL plans to provide him with the information and questions that should be raised with the relevant authorities. ECCL will stress that the development of community based services is essential if the human rights abuses of disabled people in institutions are to be addressed. This is because the unjustified segregation of disabled people in institutions is in itself a serious human rights violation.

More information is available at www.coe.int/t/commissioner/.

ECCL website under construction

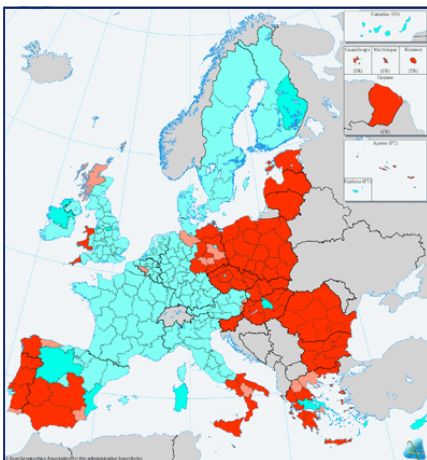
We are moving our website www.community-living.info to a new provider, which unfortunately led to it being offline for a period of time. We are doing our best to have it back online shortly and will continue updating it with the relevant news and resources. We thank you for your patience and apologise for these problems.

Funding exclusion while promoting inclusion?

The use of the European Union funding to maintain the institutionalisation of people with disabilities

24 March 2010 – Brussels (Thon Hotel Brussels City Centre)

The European Union has allocated substantial resources for projects that will improve the lives of European citizens. These funds, known as Structural Funds, have the potential to make a significant positive impact on the situation of people with disabilities by facilitating the development of community-based services as alternatives to institutional care. Yet, in some Member States, Structural Funds are being used to renovate existing, or build new, long-stay residential institutions. This practice perpetuates the marginalisation and social exclusion of disabled people. It is also in direct contravention of human rights standards and EU policies on promoting social inclusion.



Areas eligible for the EU Structural Funds (in red), as published by DG Regional Policy at the European Commission

On 24 March, the European Coalition for Community Living (ECCL) is organising a one day seminar on the use of Structural Funds. The seminar will highlight ECCL's concerns about the use of Structural Funds to maintain the system of institutional care and consider recommendations for reform. A particular focus of the discussions will be how Structural Funds can be better used to promote alternative services that would enable disabled people to live and participate in the community as equal citizens.

The highlight of the Seminar will be the launch of ECCL's report on the use of Structural Funds, with findings from Romania and Hungary. The seminar will give participants the opportunity to consider ECCL's report and discuss key questions, such as:

- ◆ What are the human rights implications of using Structural Funds to maintain institutional care?
- ◆ What are the main barriers to the development of community-based services?
- ◆ How can Structural Funds be used to promote the development of community-based services for people with disabilities as alternatives to institutions?
- ◆ What role can civil society play in this process?

The seminar is organised in cooperation with the Open Society Institute Brussels and with the financial support of the Open Society Mental Health Initiative. ECCL's project on the use of Structural Funds was implemented in cooperation with the Institute for Public Policy, Romania and the Soteria Foundation, Hungary.

To register, please write to coordinator@community-living.info. The deadline for registration is 5 March 2010.

Draft Programme

9:00 – 10:00

Registration

10:00 – 13:00

Plenary session I

Chair: Jim Mansell, Tizard Centre, University of Kent

Welcome and introduction

John Evans, ECCL/Representative of the Open Society Institute Brussels

Opening words by representatives of the European Commission and the European Parliament

TBC/Ádám Kósa, President of the Disability Intergroup at the European Parliament

Setting up the context: the situation of people with disabilities in institutional care

Judith Klein, Open Society Mental Health Initiative

Launch and presentation of ECCL's report on the use of Structural Funds for the renovation of existing or the building of new institutions for people with disabilities

Camilla Parker, consultant ECCL

Presentation of key findings from Romania and Hungary

Elena Iorga, Institute for Public Policy Romania and István Sziklai, Soteria Foundation Hungary

Response to ECCL's response findings by MEPs and the national authorities, followed by discussion

Richard Howitt MEP and Mairead McGuinness MEP

13:00 – 14:00

Lunch

14:00 – 17:00

Plenary session II

Chair: Carlotta Besozzi, the European Disability Forum

Overview of the legal and policy context: disability and non-discrimination law and policies in the EU

TBC

Response to ECCL's report findings by representatives of the European Commission

Representatives of DG Regional Policy and DG Employment, Social Affairs and Equal Opportunities, TBC

How can the European Union support the transition from institutional to community-based care for people with disabilities?

Jan Pfeiffer, Chair of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care/Children's High Level Group

The role of civil society in the monitoring of Structural Funds: presentation of good practice

Javier Güemes, Fundación ONCE

Panel discussion with the speakers

Seminar conclusions

Gerard Quinn, Centre for Disability Law and Policy, National University of Ireland, Galway

Signature campaign

Sign the petition *Free Our People Now!*

Free Our People Now!



ENIL/ECCL campaign for deinstitutionalisation

On the occasion of 3 December, the European Day of People with Disabilities, the European Network on Independent Living (ENIL) launched an online petition calling on the relevant authorities, service providers, funding agencies and the public to support the transition from institutional care to community-based services for people with disabilities. ECCL is helping ENIL collect the signatures, which will be presented to the relevant officials during ENIL's Strasbourg Freedom Drive 2011.

Article 19 of the UN Convention on the Rights of Persons with Disabilities (the CRPD) recognises the right of all disabled people to live and participate in the community. Yet over 1.2 million people with disabilities in the European Union are still forced to live in long-stay residential institutions, without access to many of the CRPD rights. Despite commitments to social inclusion and de-institutionalisation, the number of disabled people in institutions in on the increase in a number of Member States.

The petition calls on the relevant authorities, service providers and funding agencies to actively develop quality, comprehensive community-based services and not to invest in the establishment or renovation of long-stay residential institutions for any group of disabled people. It also asks for new admissions to institutions to be stopped. Moreover, the petition calls on the civil society and the general public to support the right of all disabled people to live and participate in the community.

Institutions are not solutions. Only when quality community-based services are available to people with disabilities will countries be able to move towards implementation of Article 19 and other rights from the UN Convention on the Rights of Persons with Disabilities.

ENIL's petition for the right to live in the community can be signed on www.enil.eu or on www.community-living.info. Signatures will be collected until the next Freedom Drive in September 2011, when disabled people from all over Europe will gather in Strasbourg to campaign for their rights and to address their MEPs. The petition will be presented to the European Parliament and other authorities at the European and national levels responsible for implementing the CRPD.

Organisations and individuals who would like to support ENIL and ECCL in collecting the signatures should contact ENIL's Executive Director Jamie Bolling at j.bolling@enil.eu.

Go to www.enil.eu to sign the petition

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.

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

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