

Newsletter

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Dear Readers,

We have decided to devote this issue of the ECCL Newsletter entirely to our Annual Seminar, which took place last month in Norway. We hope that the presentation and articles included will be of relevance to those who did not have the opportunity to attend the Seminar, as well as to those that took part.

The focus of this year's Seminar was on the **UN Convention on the Rights of Persons with Disabilities**. We were particularly interested in how the Convention relates to our agenda - the promotion of quality community-based alternatives to institutions for disabled people in Europe. We would once again like to thank all the speakers, chairs and participants for making the event a success and to the Open Society Mental Health Initiative for their financial support.

In our last Newsletter in April, we reported that only four European countries ratified the Convention - Hungary, Croatia, Spain and San Marino. Since then, only two additional countries are added to this list - Slovenia and Austria. Other countries, such as the UK and Romania, have announced that they intend to ratify by the end of the year. In September, the European Commission submitted a proposal to the European Council to ratify the Convention and the Optional Protocol and this is expected to happen soon.

At the Seminar in Norway, ECCL conducted a survey among participants on the Convention. Our intention was to find out more about developments in different countries and receive suggestions about what ECCL can do to support the work carried out at national level. The survey consisted of four questions, namely *What is the level of awareness about the Convention in your country?*, *What are the key opportunities and barriers to the ratification and implementation of the Convention in your country?*, *What are some of the activities you are undertaking to get the Convention ratified or implemented in your country?* and *What can ECCL do to promote the Convention?* We would like to invite the readers of this Newsletter to send us their answers to the survey as well, in order to get a more comprehensive picture about the situation in Europe. We will bring you results of the survey, as well as some information about translations and reservations to the Convention, in the next issue of our Newsletter in December this year.

In this issue, in addition to the report from the Seminar, you will find a note of the presentation given by Mr. Johan Ten Geuzendam, the Head of the Disability Unit at DG Employment, Social Affairs and Equal Opportunities at the European Commission. You can also find information about ECCL's advocacy workshop 'Strengthening Local and National Campaigns for Community Living', which took place a day before the Seminar.

Finally, we would like to inform you about the results of the European Parliament Written Declaration on the discrimination and institutionalisation of children with disabilities in the European Union, which we wrote about in the last issue of the Newsletter. Unfortunately, the Declaration did not receive the necessary number of signatures by MEPs that would require it to be adopted by the European Parliament (the required number of signatures was 400 and the petition was signed by 213 MEPs). The petition was an opportunity to highlight the need for the EU to reassert its commitment to advance the rights of children with disabilities. Although we were not successful in achieving its adoption it will hopefully have raised the issue amongst MEPs. ECCL would like to thank all those who contacted their MEPs for support and will continue bringing issues of concern to the attention of the European Parliament.

As always, we would like to encourage you to send us your contributions for the website or the Newsletter. We would particularly welcome your answers to the Survey on the Convention, which can be sent to coordinator@community-living.info (for your answers to be included in the next issue of the Newsletter, we need to receive them by 5 December 2008). Thank you!

We look forward to hearing from you!

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

ECCL
European Coalition
for Community Living

c/o NCIL
4th Floor Hampton House
20 Albert Embankment
SE1 7TJ London, UK
T: + 44 20 7587 3982
F: + 44 20 7582 2469
coordinator@community-
living.info
www.community-living.info

Facilitating the Implementation of the UN Convention

By Johan Ten Geuzendam

Disability policies are essentially the responsibility of each Member State. So, why did you invite me to speak?

Because there is an added value of the European Union in the disability area. Let me explain: The Community has gone from assistance to rights: Disability is a rights issue and not a matter of discretion. It is clear from article 13 of the EC Treaty on which I will come to speak, but also from the fact that the EC is a party to the UN Convention of the Rights of Persons with Disabilities.

People with disabilities have the same rights as non-disabled persons and should have access to them in practice: enabling people with disabilities to enjoy their rights is at the centre of the EU actions.

This requires adequate policy and actions defined together with people with disabilities themselves. Mainstreaming is a crucial methodology, allowing taking into account the needs of people with disabilities at all stages of development of various policies.

The EU has currently a Disability Action Plan with as priorities for 2008-2009:

- 1) Actions for inclusive participation through accessibility: fostering accessibility of the labour market, boosting accessibility of goods, services and infrastructures, and consolidating the Commission's analytical capacity to support accessibility.
- 2) Actions towards full enjoyment of fundamental rights: facilitating the implementation of the UN Convention and complementing the Community legislative framework of protection against discrimination.

The UN Convention is the end of a long way and the start of another long period. The Community signed the Convention on 30 March 2007. As the Convention and its Optional Protocol entered into force on 3 May 2008, and the Optional Protocol has not yet been signed by the European Community, a Decision concerning its accession is needed. The Commission has already adopted the relevant proposals to enable the Community to conclude these two instruments. The proposals define the areas where the Community is competent (declarations of competences pursuant Article 44.1 of the UN Convention and Article 12.1 of the Optional Protocol) as well as the mutual relationship between the Community and its Member States when implementing the Convention and its Optional Protocol.

At the first EU informal ministerial meeting on disability issues in Berlin on 11 June 2007, Ministers undertook to further develop policies so as to ensure the full implementation of the UN Convention in a coherent and coordinated way and called on the European Commission to ensure that the new priorities of the European Disability Action Plan contribute to the effective implementation of the Convention.



Johan Ten Geuzendam

At the second annual ministerial meeting on 22 May 2008 in Slovenia ministers endorsed:

- The significance of quick ratification/conclusion in all Member States and by the European Community;
- The importance of the principle of close cooperation between the Community and Member States;
- The relevance of the European Disability Action Plan 2008-2009 for the implementation of the Convention and its focus on accessibility as a priority for active inclusion and on fostering accessibility of the labour market, boosting accessibility of goods, services and infrastructures, consolidating the Commission's analytical capacity to support accessibility, facilitating the implementation of the UN Convention and complementing the Community legislative framework of protection against discrimination;
- The Council Resolution (2008/C75/01 of 17th March) on the situation of persons with disabilities in the European Union where the Commission and Member States are invited, in accordance with their respective competences, to ensure that people with disabilities enjoy their human rights in full, by further developing a comprehensive policy mix of all appropriate instruments with a view both to eliminating discrimination and to including

persons with disabilities in society, based on the human rights approach and the mainstreaming of disability and examining any gaps that may exist in the current Community legislative framework of protection against discrimination, in particular on the grounds of disability, and considering appropriate and targeted responses.

The conference held on 22 and 23 May 2008 in Kranjska Gora about future challenges in promoting the rights of persons with disabilities in European Union Member States also strengthened the vision that new possibilities in the community and accessible community services and facilities are of the highest importance to ensure persons with disabilities to be included in the society.

Based on the information provided by the Member States and the discussion at the Disability High Level Group, the following actions can be seen as of common interest and providing added value for a quick and effective implementation of the UN Convention:

1. The development of consistent and comparable data, targets and indicators.
2. The compliance of non-discrimination legislation with the Convention's provisions (See below on Art. 13 proposal of the Commission).
3. A common approach in the preparation of the Conference of State Parties, including the nominations for the Committee on the Rights of Persons with Disabilities, but without prejudice to Member States freedom of action at this level.
4. Exchange of good practice on the work of the independent mechanisms, required by the UN Convention as well as discussion of ways to encourage cooperation among these bodies.
5. Common approaches and formats for the reporting to the UN from Member States and the Community, in particular where there are shared competences.
6. Exchange of experiences, information and good practices, starting with the following priorities in relation to the articles of the UN Convention: accessibility, legal capacity, access to justice, **independent living**, voting rights, monitoring mechanism and empowerment of people with disabilities.
7. Cooperation and coordination in the production of accessibility guidelines and standards for products and services while making use of existing European infrastructures and resources.

Today we speak here about an independent living and being included and as you just have heard it is one of the areas identified for common actions (action 6).

Today in Europe, well over one million people with disabilities still live in some form of institutional care. Quality of life in these institutions varies greatly and dignity of life of its inhabitants is not always guaranteed.

Our Chairman, Prof Jim Mansell presented yesterday the findings of a study financed by the Commission on the development of services in the community for people with disabilities in Europe ('Deinstitutionalisation and Community Living - Outcomes and Costs'). The report confirms that institutional care is often of an unacceptably poor quality. Indeed, sometimes the conditions in institutional care may represent serious breaches of internationally accepted human rights standards. Disabled persons living in closed residential institutions are the most invisible European citizens with regards to access to basic human rights and satisfaction of fundamental needs. This is all about life in dignity and of being recognised as an active subject rather than a mere object of care. In this seminar we are again seeing many examples showing that community-based services, when properly established and managed, can deliver better outcomes in terms of quality of life and ensure that disabled people can live as full citizens. Services in the community are not more expensive than institutional care once the needs of residents and quality of care are taken into account in calculating the costs.

This Commission study, based on solid data, will help Member States and stakeholders transform services for disabled people from institutions to services in the community. This transformation will for the Member States be an essential part of meeting their responsibilities under the UN Convention on the Rights of Persons with Disabilities. Faced with the conditions in institutions, we should combine our efforts to rapidly replace them with quality social services in the community. Exchange of experiences, information and good practices in this area are very useful but not enough.

We are already working on the subject. We are now finalising a Toolkit for Managing Bodies and Beneficiaries



Prof. Jim Mansell and Johan Ten Geuzendam

of the EU Structural Funds. This will be a practical tool for both managing bodies and users during the preparation, implementation, monitoring and evaluation of Structural Funds programmes and projects. This toolkit does not only focus strongly on accessibility requirements. It also clearly establishes that investing EU funds in solutions which oppose and unable the community living of disabled people would be acting against the UN Convention and a violation of fundamental rights of people with disabilities leading to more exclusion. The European Structural Funds have to be used to support inclusion as one of the key common values of the European social model.

Another of the seven actions identified by the Ministerial meeting for the effective implementation of the UN Convention was the support to the Commission proposal for a legislative initiative based on Article 13 (TEC) adopted on 2 July 2008.

The Commission proposal for a directive provides for protection from discrimination on grounds of age, disability, sexual orientation and religion or belief beyond the workplace. This new draft directive aims to ensure equal treatment in the areas of social protection, including social security and health care, education and access to and supply of goods and services which are commercially available to the public, including housing.

The proposed Directive will create a level playing field across the EU as some Member States already have very extensive national anti-discrimination protection in place. Calls for such a horizontal proposal came repeatedly from the European Parliament while the Heads of State and Government in December 2007 called on Member States to strengthen their efforts to combat discrimination.

Once adopted, this Directive will prohibit direct and indirect discrimination as well as harassment and victimisation. For people with disabilities, non-discrimination will involve general accessibility as well as the principle of "reasonable accommodation" which is already used in existing European legislation. It will, however, avoid imposing a disproportionate burden on service providers by taking account of the size and resources of the organisation, its nature, the estimated cost, the life cycle of the goods and services and the possible benefits of increased access for persons with disabilities. The directive will only apply to private persons in so far as they are performing their commercial or professional activities. To ensure effectiveness of the proposed measures, national equality bodies will give advice to victims of discrimination while civil society organisations will also have the possibility to help victims in judicial and administrative procedures. We consider this draft directive to be an important step forward to protect people with disabilities from discrimination, so that they are fully included in the society on an equal base with the others, therefore we ask for your support to get it adopted by the Council.

Now what is the relation between this new proposal for a directive based on Article 13 and the UN Convention?

As such, the UN Convention does not create any obligation for the Community to provide for new legislation covering the matters it governs, as it applies to the Community only within the limits of already existing Community competence. Nevertheless once the new Directive is adopted it will imply new competences for the Community *vis à vis* the UN Convention.

The Convention is a Human Rights instrument that is legally binding. Once in force, the Convention will require its parties be it the EC or its individual Member States to take measures to protect against discrimination and to make adaptations for disabled people in certain areas, such as education, health services, employment, social protection, public housing, culture, sport etc. Some of these areas might be covered in a new Directive. In a number of cases, Member States will have to legislate to comply with their new obligations under the UN Convention. In this regard the new EC legislation ensures in the EU a more uniform approach to putting in place the minimal protection resulting from the obligations of the UN Convention.

In conclusion, both the adoption of the draft directive and of the Council Decisions enabling the conclusion of the UN Convention and the Optional Protocol will be of great importance for the understanding and implementing of the UN Convention on the Rights of Persons with Disabilities in the European Union.

For people with disabilities they will also contribute significantly to making living independently and being included an ever more realistic option.

Thanks for your attention.

Johan Ten Geuzendam is the Head of Unit for EU Integration of People with Disabilities at DG Employment, Social Affairs and Equal Opportunities at the European Commission. This presentation was delivered at the Seminar of the European Coalition for Community Living on 13 September 2008.

Question and Answer Session with the Head of the Disability Unit at the European Commission

After Johan Ten Geuzendam's presentation at the ECCL Seminar in Drammen, Norway, a question and answer session followed, in which a number of important issues were raised. This is a summary of the main points raised by participants and Mr. Ten Geuzendam during the discussion.

Several questions dealt with the scope and purpose of the Toolkit for the Structural Funds, and its potential to prevent the use of Structural Funds for renovating and building of new institutions for people with disabilities. Mr. Ten Geuzendam clarified that the Toolkit is in the final stage of the preparation and is likely to be issued by the end of the year. Its scope has not yet been fully agreed. He emphasised, however, that there are important funds that are managed outside DG Employment and Social Affairs, particularly the European Regional Development Fund (ERDF). When it comes to infrastructure financing, ERDF is much more important than the European Social Fund (ESF), which is managed by DG Employment and Social Affairs. He also pointed out that many of the risks for new investments into institutions lie outside of the ESF. DG Employment and Social Affairs, however, wants to make sure this area is sufficiently covered, and it is one of the main reasons why the toolkit is being developed.



Seminar participants

On the question of whether the ERDF Regulation will be revised in light of the Toolkit, Mr. Ten Geuzendam pointed out that this is not the purpose of the document. As its name suggests, its aim is to provide practical assistance to individuals designing projects. It does not add to or revise the existing regulations. He added that, if the intention is to change ERDF Regulation, other means should be used.

The second set of questions and comments dealt with personal assistance. Firstly, a question was asked about whether the new anti-discrimination Directive will cover social care and if yes, will it refer to the right to personal assistance.

Mr. Ten Geuzendam stressed that social services are in the scope of the new proposed Directive, but that it is an anti-discrimination Directive. This means that, when it comes into force, the principle of non-discrimination will have to be respected in access of people with disabilities to services. Discussions on the proposed Directive have started in the European Council, but personal assistance has not been mentioned so far. However, there will still be substantial work on further clarifying the definitions and the Disability Unit will seek to ensure that this aspect is given attention. However, Mr. Ten Geuzendam stressed that it is not the intention of the Directive to ensure harmonisation within the EU. When it comes to access to personal assistance, there are huge differences between the Member States and they will not necessarily be affected by the Directive.

Another one of the participants commented on the importance of portability of personal assistance between the Member States, if EU citizens are to enjoy the right to free movement. Mr. Ten Geuzendam added that, while EU has very limited competence in the area of social services, the implementation of the Convention in Europe is likely to have a favourable impact on the further development of personal assistance schemes.

Concerns were once more raised about misleading translations of the Convention, in particular Article 19, and a question was raised about the possible influence of the Commission on this issue. Mr. Ten Geuzendam pointed out that the Commission has prepared its own translations of the Convention and encouraged participants to check whether these are correct.

Finally, the Head of the Disability Unit announced that over the coming year, a new EU disability strategy will be developed. The strategy will, among else, put more emphasis on the implementation of the Convention and build more on the need to have a process among the Member States which resembles the Open Method of Coordination.

Report from ECCL Seminar 2008: Living Independently and Being Included

12 - 13 September 2008, Drammen, Norway

The third annual seminar of the European Coalition for Community Living took place in Drammen, Norway on 12 - 13 September 2008. The topic of the Seminar was 'Living Independently and Being Included: Understanding and Implementing the UN Convention on the Rights of Persons with Disabilities' ("the Convention"). The aim of the Seminar was to discuss how we can use the Convention to facilitate the development of quality community-based services for people with disabilities in Europe. The Seminar also created opportunities for exchange of good practice in community living, especially between Northern European countries and countries of Central and Eastern Europe.



Opening Panel

The Seminar was hosted by the ULOBA - the only Norwegian cooperative¹ on personal assistance at their headquarters in Drammen. ULOBA was founded in 1991, and its work is based on the principles of empowerment, full citizenship and human rights. It is owned and run by people with disabilities according to the philosophy of independent living². ULOBA covers the whole of Norway and runs 27% of all personal assistance programs in the country. ECCL chose ULOBA as its partner organisation for this year's seminar in order to give the participants an opportunity to engage with a group of individuals who have developed a truly innovative service and learn how support services can be provided in a way which facilitates people's independence and participation in all aspects of life.

Altogether 93 participants from 26 countries gathered in Drammen. They came from local, national and European disability organisations, service provider organisations, research institutes, local and national authorities and the European Commission.

ECCL welcomed distinguished speakers from Ireland, the UK, Belgium, Croatia, Czech Republic, Norway, Bulgaria and the United States.

This report sets out the main points raised during the discussion and a summary of the Seminar conclusions, as presented by the Conference Rapporteur David Towell. Most of the presentations can be downloaded from the ECCL website at <http://www.community-living.info/?page=286>.

Day 1: Understanding the Convention

The Seminar was opened by **John Evans**, on behalf of the European Coalition for Community Living. After welcoming the participants, he invited everyone to use the next one and a half days to discuss how we can use the Convention to change the lives of 1,5 million disabled people in Europe living in long-stay residential institutions, whose rights are being denied on a daily basis.

Vibeke Marøy Melstrøm, Assistant General Manager at ULOBA, welcomed participants on behalf of ULOBA. She explained that the system of personal assistance in Norway is the result of disabled people's hard work and determination. She pointed out that, to sustain this revolution in how people with disabilities are supported, and to get society to embrace the social model of disability, we must work at all levels - from the local to European to the international. She concluded by acknowledging that in many countries disabled people are still not valued as equal members of society, and that we must therefore use the Convention as a tool to continue the fight for freedom and independence.

Lise Christoffersen, a member of the Standing Committee on Labour and Social Affairs in the Norwegian Parliament, began by referring to the limited accessibility of public transport in Norway as one of the barriers to social inclusion of disabled people. She briefly referred to the progress that *has* been made in improving the quality of life of people with disabilities, but again, placed emphasis on what still needs to be done to improve access of disabled people to education, employment, accessible housing, social and cultural life. Ms. Christoffersen informed the participants that, while Norway signed the Convention, it is unlikely to ratify it before 2010. Norwegian Government is planning to amend its national legislation (and enact new legislation) before ratifying, in order to ensure that it is in line with the Convention.

¹ ULOBA's stakeholders (owners) are people with disabilities, all of whom are users of personal assistance themselves.

² According to one definition, independent living is the "emancipatory philosophy and practice which empowers disabled people and enables them to exert influence, choice and control in every aspect of their life." Source: Frances Hasler, *Philosophy of Independent Living* (2003), available at:

www.independentliving.org/docs6/hasler2003.html

Donata Vivanti, a member of ECCL's Advisory Council and the Vice-President of Autism Europe, pointed out that the reason why there are still people living in institutions is the lack of adequate supports for community living. Before setting out objectives of the Seminar, she emphasised that the failure to protect human rights cannot be justified by the lack of resources.

David Towell, the Conference Rapporteur, set out the three main questions (see the box below) open for discussion and invited participants to give their suggestions on how to take the Convention forward.

Questions for discussion:

What is the level of awareness about the Convention in our respective countries among different stakeholders?

What are the opportunities and barriers to implementing the Convention (with a focus on community living)?

What can our respective organisations/institutions and ECCL do to promote the Convention?

Added value of the Convention

Two of the keynote presenters - Prof. Gerard Quinn (National University of Galway, Ireland) and Camilla Parker (Open Society Mental Health Initiative) focused on how to make use of the Convention, while Prof. Jim Mansell (Tizard Centre, University of Kent), presented the findings of a recent study 'De-institutionalisation and community living - outcomes and costs' (DECLOC)³.

Prof. Gerard Quinn, a leading expert on the Convention, focused on two main questions in his presentation: *Why is the Convention necessary?* and *What are the main challenges and opportunities to its implementation?* He emphasised that the Convention is not a magic bullet that will solve all the problems, but is something that if used wisely can help create a new dynamic of disability politics. *Prof. Quinn's presentation will be reprinted in full in the December issue of the ECCL Newsletter.*

Prof. Jim Mansell explained the scope of the DECLOC study, the main findings and recommendations. The study consisted of collecting, analysing and interpreting existing information on the number of disabled people in institutions in 28 countries, and analysing economic and policy arrangements required for transition from institutional care to community-based services. The findings of this study, in particular economic evidence on how to make the transition, can be used to support the implementation of the Convention.

Camilla Parker made a link between the two previous presentations and provided additional insight into how the Convention can help advance DECLOC's agenda for change.

Prof. Jim Mansell's and Camilla Parker's presentations can be downloaded from the ECCL website.



Camilla Parker, John Evans and Prof. Gerard Quinn

Discussion

- The issue was raised about the impact of the Convention in countries like Germany, Spain or Italy, where services are decentralised and much depends on the regional structures. It was pointed out that, according to Article 4 of the Convention, its provisions 'extend to all parts of federal States without any limitations or exceptions'. This means that the State is always responsible and must oversee what happens at the local or regional level.
- Another issue raised by a Slovenian participant was the problem of misinterpretations of the concept of independent living in national translations of the Convention. The question asked was: 'Who can ensure that the meaning in national translations of the Convention is correct?' Prof. Quinn noted that translations can be problematic, as those that are not in the spirit of the original text can deflect States' responsibilities. The international monitoring body (the UN Committee on the Rights of Persons with Disabilities) should be encouraged to clarify what the term 'community living' means, but its recommendations will not be legally binding on States (although most States are expected to follow them).
- Participants were encouraged to raise the issue of wrong translations in the shadow reports to the Committee once it is in place.

³ Mansell J, Knapp M, Beadle-Brown J and Beecham, J (2007) Deinstitutionalisation and community living - outcomes and costs: report of a European Study. Volume 2: Main Report. Canterbury: Tizard Centre, University of Kent. Available at: <http://www.community-living.info/?page=268>

Practicalities of moving towards community living

The next set of presentations looked at 'where we are now' and 'how far do we have to go in order to make the Convention a reality', starting from the host country and moving on to Croatia, as an example of the situation in Central and Eastern Europe.

The session began with a presentation by **Christian Kielland**, from the Ministry of Children and Equality in Norway. About 20 years ago, Mr. Kielland acted as the project leader for de-institutionalisation of services for people with intellectual disabilities in the then Ministry of Social Affairs. He was therefore able to give a step-by-step account of the process of de-institutionalisation in Norway, the principles behind it and the role of the Government and the civil society.



Model of personal assistance presented by ULOBA

Helga Brun, from ULOBA, followed with a presentation on the personal assistance service for people with intellectual disabilities in Norway. As a mother of two daughters with intellectual disabilities who use personal assistance, she spoke about how personal assistance can be organised in order to give children and adults an opportunity to live a normal life and provide support to the families of disabled children. She also pointed to some differences in the support that disabled children get in group homes (which do exist in Norway as well), and when they are at home with their families. The latter option provides children and parents with the freedom to organise personal assistance based on their support needs, but also their interests and lifestyle.

Bojana Rozman, from the Association for Promoting Inclusion in Croatia, spoke about the practicalities of changing from an institutional to community-based model of care in Central and Eastern Europe. Asking participants to go back in time, she highlighted the main barriers to change and suggested what is necessary to drive forward progress in the country (and the region). She highlighted the impor-

tance of sharing models of good practice from other counties and keeping a personal capacity to remain outraged by the injustice and inhumanity of institutional care.

All three presentations can be downloaded from the ECCL website.

Workshop 1: Policy making and stakeholder cooperation

Workshop 1 was chaired by **Christy Lynch** from KARE, Ireland, who presented a project that aims to close down remaining congregate facilities and help people move to community-based provision in Ireland.

Among the barriers the National Steering Group, which set up the project, has experienced so far is parents' resistance to new services in the community, resistance by the service providers and staff, and the failure of the empirical evidence to influence personal opinions and attitudes (which tend to be distorted by vested interests). Some of the lessons that have emerged are the need to tie in spending and policy, the importance of using positive language (as opposed to talking about taking things away), not compromising on quality (even if it means the process will take longer) and making sure the process moves forward.

The presentation was followed by a discussion that raised questions and highlighted practices and experiences in other countries:

- To deal with vested interests, in the US, self-advocacy groups with no interest in the current system received funding to go into institutions to help with person-centred planning.
- Experience in Norway showed that strong leadership and commitment from Government throughout the process is very important.
- Regarding, re-training of staff: in Norway the same people who worked in institutions now work in community-based services. This often leads to institutional practices surviving in the new settings.
- Managing fear was a major issue in Norway too. It took a lot of resources to organise de-institutionalisation projects. Full time staff assisted the process to prepare individual plans.
- UK experience highlights the importance of ring-fencing existing funding⁴ in times of reforms.

Christy Lynch's presentation can be downloaded from the ECCL website.

Workshop 2: Delivering quality services

Workshop 2 was chaired by **Milena Johnova** from the Czech organisation QUIP - Association for Change. She

⁴ The means that the budget allocated to running of an institution would be protected for the development of community-based services (while the institution is in the process of closure).

gave a brief overview of the situation in the Czech Republic, where the number of disabled people living in institutions is on the rise (21,000 people, out of population of 10 million). She focused on several major barriers to community living: lack of funding for the process of de-institutionalisation, the guardianship system, resistance by professionals to the closure of institutions and access to mainstream employment.

In the discussion that followed, participants were asked to reflect on the barriers to community living in their countries:

- In Slovenia, many strategies and plans still exist only on paper. There are legal obstacles (lack of adequate legal regulation) to setting up personal assistance schemes and at the moment only 8% of the funding for personal assistance comes from the State. At the same time, disabled people's organisations are running an experimental programme, which shows that supporting people to live in the community is cheaper than institutions. In order to demonstrate how personal assistance supports disabled people's independence, a disabled people's organisation invited election candidates to be personal assistants to disabled people for one day.
- In Bulgaria, what is lacking is person centred planning (for people with intellectual disabilities) and the real understanding among policy makers about the programs and documents they are developing, and which are supposed to lead to the development of services in the community.
- In Romania, a major barrier is the absence of services in the community, therefore at the moment institutions are the only option for many people. De-institutionalisation must be done well from the beginning, so as not to produce a negative effect. At the moment, group homes for 6-8 people are being created as a step towards community living.
- Many of the same arguments and barriers were present in Norway 15 - 20 years ago. It is important to develop one's own proposals, get the politicians to work with you (form alliances), use the mass media and alliances, and show the gap between what the politicians said they would do and what they are doing. At the same time, it is important to shape the public opinion and build up an agreement about the fact that the current situation is not acceptable. ULØBA presented their own solutions to politicians, who because of their lack of knowledge, used those to develop the new services.
- In Denmark, the Convention is being used to educate local authorities. The aim is to encourage development of local initiatives and policies.

Milena Johnova's presentation can be downloaded from the ECCL website.

Workshop 3: Managing the transition

Workshop 3 was chaired by Kapka Panayotova, from the Center for Independent Living in Sofia, Bulgaria. As a basis for discussion, she presented the case of institutional closure in the town of Stara Zagora, which was triggered by the documentary 'Bulgaria's Abandoned Children' (which revealed the abuse of disabled children in the Mogilino social care home). Responses to the documentary varied - from improving the state of institutions (supported by charity organisations) to elaborating plans for systemic change of the care system.

Ms. Panayotova pointed out vision, political will and implementing capacity as three components of the process of transition, after which participants proceeded to discuss ways of linking these three components in practice. Resources and public support were added as important elements, although a participant from Norway thought that public support was not crucial. Later in the workshop it was pointed out that it is not only the final vision that is important, but also the vision of what can go wrong during the process of transition, and having contingency plans in place.

The discussion that followed focused on whether group homes, even if only presented as a temporary solution, are the best alternative for disabled children leaving larger institutions.

Some of the issues brought up in the discussion were:

- A question of how realistic it is to expect that children would leave group homes after a large amount of resources was invested into setting them up.
- Importance of not going through intermediate solutions like group homes when developing services in the community.



Workshop 3

- A question of why children are not being placed into families as the first solution, rather than first going through a group home.
- The reality of the situation, which demands an urgent solution and the problem of placing a large number of children (who are leaving the institution) into families at the same time.

Plenary discussion: Wrapping up Day 1

The main thread running through the last plenary session of the first day was the question of why countries tend to repeat the same mistakes as others by replacing larger institutions with smaller ones. Despite the existence of best practice examples of supporting people with disabilities to live independently and participate in society, such models are often not replicated by policy makers or service providers.

Another point highlighted by a number of participants was the lack of resources as a justification for poor quality services; a justification that is used in rich as well as developing countries.

The need to grasp what ‘independent’ or ‘community’ living means was stressed by a number of participants, since the same description is used for services that segregate disabled people. The importance of translating the term ‘independent living’ (as preferred to ‘community living’) into other languages was pointed out, in order to make more people aware of this concept.

Picking up on other country’s ‘bad practice’ was also highlighted as the problem, especially in case of Central and Eastern European countries. In many cases, institutional settings in Western Europe are presented as examples of good practice in setting up community-based services.

Day 2: Implementing the Convention



The second day of the Seminar focused on the role each of us has in implementing the UN Convention on the Rights of Persons with Disabilities. It began with a presentation by the Head of the Integration of People with Disabilities Unit at the European Commission, **Johann Ten-Geuzendam**, who shed some light on the role of the European Commission in implementation of the Convention in the EU Member States. The European Community has signed the Convention and is expected to ratify in the near future. Mr. Ten Geuzendam also announced that the Commission is finalising the Toolkit for Managing Bodies and Beneficiaries of the EU Structural Funds and the Cohesion Fund, which he elaborated on in more detail in the discussion that followed. *Mr. Ten Geuzendam’s presentation, and the Question & Answer session that followed, can be found on pages 2 - 5 of the Newsletter.*

Continuing on the same topic of facilitating implementation of the Convention, **Prof. Steven Eidelman**, from the University of Delaware in the United States drew on his long term experience in closing institutions and developing community-based services in the US to suggest strategies to implement Article 19 of the Convention (*Living independently and being included in the community*). One of the points he emphasised is that just the physical presence of a person in the community does not equal inclusion or choice. He suggested, however, ways in which we can use the Convention to move from a mere physical presence to real community living, and the implications this entails for Governments, service providers, advocacy organisations and people with disabilities. For example, Governments will have to develop financing mechanisms that recognise individual difference and support needs, while service providers might have to develop new or modified accountability mechanisms for managers.



Seminar participants

Mr. Eidelman furthermore provided a number of arguments why inclusion is not possible while individuals are living in institutions, and presented a number

of steps that should be taken at the national level. These include: closing institutions, building community capacity for all, supporting families, enhancing communities, preventing institutionalisation, providing all children with education, education of policy makers and finally, “second order” de-institutionalisation. This refers to closing those residential programs that were once considered a good alternative to large institutions. Mr. Eidelman ended with a message that de-institutionalisation is not about closing down buildings, but developing community capacity for all. *Steven Eidelman’s presentation can be downloaded from the ECCL web-site.*

Discussion

The discussion that followed resulted in additional ideas about moving the change forward:

- One of the participants suggested that it would be important to look at what ‘independent living’ means in different European countries and promote a uniform concept based on the aspirations and needs of people with disabilities.
- Considering that many important points were raised in the discussions during the Seminar, it was suggested to compile these in the format of Frequently Asked Questions, which could be used when approaching policy makers, service providers, organisations of disabled people and others.
- In the US, a ‘Community For All’ toolkit was developed, and could also be a useful resource for organisations in Europe⁵.

Seminar conclusions and moving forward

David Towell, Conference Rapporteur, summarised the main points raised by the speakers and participants during one and a half days of the Seminar and invited everyone to reflect on what they are going to do to take this agenda forward when they return to their countries.

- The Convention, which was the main theme of the Seminar, is a big opportunity and a new foundation for civil society advocacy. The starting point for any action should be that we are all human beings with the same rights. The golden thread which runs through the Convention is personal autonomy and controlling our own destinies. This means being active participants in the political process and not being perceived as the object of charity. Language easily gets distorted and a part of our role is making sure that our definition of community living does not get diluted by others.
- As the DECLOC study shows, there are nearly 1,2 million people living in institutions and even more people have no control over their lives because of barriers in education, housing, employment, health and so on. We have a moral duty to push the community living agenda forward and support each other. At the same time, we all have to make our own solutions in different countries, and sustain the efforts that are already out there.
- Some of the barriers we can expect to implementation of the Convention are reservations and interpretative declarations. There will also be a lot of paper ratification without the real implementation. What is important is to challenge the lack of action. The EU can support this process, in the Member States and accession countries.
- In the process of moving towards community living, it is important not to repeat the same mistakes. This includes ensuring that no more resources go into building of institutions, regardless of their size.
- **What did we learn about being successful?** Critical to this are three building blocks: self-determination, inclusion and personal support. An important part of self-determination is strengthening our own awareness of our rights, which might be difficult for those disabled people who have never had an opportunity to exercise choice.
- Personal support is about being in control of the support you need to lead the life you want to live. There are good demonstrations of this being done, so it is important that these are shared and promoted, by the EU and other stakeholders.
- Positive stories are very important. We need to make use of real life stories, in order to strengthen our vision of autonomy and community living, and translate it into a language which makes sense to other members of the public across Europe.
- We need to get better at designing support for individuals and work together with service providers. We also need to get better at civil society advocacy, and make sure that our coalitions are broad coalitions, not just limited to the disability sector.
- Critical to our work is that we link action at local, national, European and international level. It is also important that we make a connection between the actual lives of people and different documents, strategies and toolkits. **Strategy, in particular, must mean action, not just words on paper.**

The Seminar was closed by Tina Coldham, from Mind UK, who presented ECCL’s upcoming publication ‘Creating Successful Campaigns for Community Living: An advocacy manual for disability organisations and service providers’. The manual, which will be available from ECCL’s website by the end of the year, should help take some of the excellent ideas presented at the Seminar forward.



Disability Convention wall chart

⁵ Community for All Toolkit is available at: <http://thechp.syr.edu/toolkit/>

ECCL Workshop Report: Strengthening Local and National Campaigns for Community Living

11 September 2008, Drammen, Norway

The European Coalition for Community Living is about to publish an advocacy manual which will support the efforts of disability organisations and service providers lobbying for the development of quality community-based services for people with disabilities in their countries. The manual, entitled *'Creating successful campaigns for community living: An advocacy manual for disability organisations and service providers'* will be published by the end of the year and will be available free of charge from ECCL's website www.community-living.info.

Workshop objectives

1. To help participants understand community living as a policy objective and explore the ways through which policies can be influenced;
2. To help participants plan how they and their organisations can strengthen their advocacy strategies for community living;
3. To explore ways of sharing ideas and experience after the workshop.

Before publishing the manual, ECCL organised a one day workshop on 11 September 2008, in conjunction with ECCL's Annual Seminar. The workshop was aimed at current and potential advocacy leaders, and provided an opportunity to explore effective ways of presenting and using ideas in the manual to strengthen advocacy efforts in Europe. Like the ECCL Seminar, the workshop took place at the headquarters of ULOBA, a co-operative on personal assistance in Drammen, Norway.

The workshop attracted 37 participants, including personal assistants and supporters for disabled participants. Participants represented mainly non-governmental and disabled people's organisations, with half of them coming from Central and Eastern Europe and the other half from Norway and other countries. An experienced group of three facilitators - Gengoux Gomez (Inclusion Europe, Belgium), Kapka Panayotova (Center for Independent Living Sofia, Bulgaria) and David Towell (Center for Inclusive Futures, UK) designed and delivered the Programme. They were joined by one of the authors of the manual Agnes Kozma and Prof. Julie Beadle Brown, both from the Tizard Centre at the University of Kent, UK.

The workshop loosely followed the structure of the manual and took participants through elements of successful campaigns, ways of formulating clear messages and the seven key action planning steps, as presented in the manual. Two main sets of concepts - concerned with the nature of advocacy and community living as a policy issue - formed the basis for the programme. Following the logic of the manual, which features a number of examples of good practice in advocating for community living, ULOBA's experience of lobbying for the right to personal assistance in Norway was used as a basis for discussion and sharing of experience.

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Group work

There was considerable interest among participants in finding ways of sustaining the networking and exchange of experiences which the workshop had set in motion. In addition to making the manual available for downloading from its website, ECCL will provide e-space for providing updates and reporting national and local experience in campaigning for community living. This will include further examples of local workshop programmes, as they become available. There was general agreement among the workshop facilitators that organising local and national workshops should be the next step, in order to give those interested or already involved in advocacy work an opportunity to construct concrete and practical advocacy strategies that can be implemented either locally or nationally.

The workshop and the manual are funded by Socires Foundation, the Netherlands.

Workshop Programme (cont. on page 13)

Campaigning for Community Living: What are we learning from our experiences in different parts of Europe? Groups share experiences of campaigning and identify what is contributing to success and what is getting in the way.

Formulating a clear message about Community Living as a policy objective *Participants share ideas on the meaning of community living and are introduced to the basic concepts important for advocacy for community living.*

Advocating for Community Living in practice *Presentation of ULOBA's campaign for personal assistance.*

Developing effective campaigning strategies *Participants share ideas about the different steps that need to be taken in order to arrive at effective campaigning strategies. They are then introduced to the seven key planning steps for developing effective campaigning strategies. In groups, they work on one of the steps (for example, Understanding the policy environment, Producing a problem statement, Planning a course of action etc.)*

Developing our own local and national advocacy strategies *Participants draw on the day's work to identify key points they are taking home to strengthen the advocacy work of their own organisation and its allies.*

Building on this workshop *Participants discuss how they can use the manual in their countries and identify how they might support each other in the future.*

ENIL European Seminar Towards De-institutionalisation of Disabled Men and Women in Europe

12–13 December 2008, Madrid, Spain

The goal of the Seminar is to obtain, through expert contributions, a comprehensive and purposeful vision of the circumstances that affect policies aimed at deinstitutionalisation in Europe in the light of the new UN Convention on the Rights of Persons with Disabilities. The Seminar is organised by the European Network on Independent Living in cooperation with Spanish partners.

Specific objectives:

1. To set up strategies for the progressive extension of deinstitutionalisation policies at all levels of public administration according to the principles of the Independent Living Movement and the UN Convention.
2. To demonstrate to disabled people the real possibility to intervene and modify policies which affect their lives by using the Convention as a civic tool.
3. To determine targets for required action by the political community.
4. To demonstrate models of good practice and experiences which try to avoid institutionalisation.

Target audience:

Disabled people, Independent Living Centers, political representatives, civil servants and other stakeholders.

For additional information and to register for the conference, please visit the website of the European Network on Independent Living www.enil.eu.

Upcoming
events

Members

Autism Europe, Belgium (founding member) • European Disability Forum, Belgium (founding member) • Inclusion Europe, Belgium (founding member) • Mental Health Europe, Belgium (founding member) • Open Society Mental Health Initiative, Hungary (founding member) • European Network on Independent Living, Spain (founding member) • 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 • Heart of a Child Foundation, Romania • The Latvian Umbrella Body for Disability Organisations SUSTENTO, Latvia • Resource Centre for People with Mental Disability ZELDA, Latvia • Frank Mulcahy, Ireland • Serbian Association for Promoting Inclusion, Serbia • ProAssistenz e.V., Germany • Keith Gordon Sansom and Karen Victoria Beecher, Spain • Kevin Caulfield, UK • Janet Cobb, UK

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

Join ECCL

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.

If you would like to join ECCL, please visit our website 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!

Advisory Council

Tina Coldham, Mind UK • James Elder-Woodward, Inclusion Scotland • Ingrid Körner, Inclusion Europe • Prof. Jim Mansell, Tizard Centre • Camilla Parker, Open Society Mental Health Initiative • Judith Klein, Open Society Mental Health Initiative (alternate member) • John Patrick Clarke, European Disability Forum • Janina Arsenjeva, European Disability Forum (alternate member) • Prof. Gerard Quinn, National University of Ireland, Galway • Bojana Rozman, Association for Promoting Inclusion Croatia • Prof. Michael Stein, Harvard Project on Disability • Josee Van Remoortel, Mental Health Europe • John Henderson, Mental Health Europe (alternate member) • Donata Vivanti, Autism Europe • John Evans, European Network on Independent Living

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.