

# Newsletter

OF THE EUROPEAN COALITION FOR COMMUNITY LIVING

## Issue No.9

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## Word from the Editorial Team

Dear Readers,

The first 2009 issue of ECCL's Newsletter focuses on two main topics - **the quality of services for people with disabilities** and **activities promoting the UN Convention on the Rights of Persons with Disabilities**.

We start this issue with an interview with the Pentru Voi Foundation from Timișoara, Romania. Pentru Voi is one of the few organisations in Romania that provides community-based services for people with intellectual disabilities. They have received numerous awards in Romania (the 2008 Civil Society Gala Award) and abroad (the 2008 Hadinnov Europe award) that recognise Pentru Voi's outstanding contribution to social inclusion of people with disabilities in Romania. The Director of Pentru Voi, Laila Onu, spoke to Ines Bulić about the services provided by her organisation, including how they involve service users in quality evaluation, and also gave her views on the barriers to de-institutionalisation in Romania and the importance of the Convention on the Rights of Persons with Disabilities.

This issue's main article is by Mr. Istvan Haller, a Board Member of the Romanian equality body, the National Council for Combating Discrimination. Mr. Haller explains how this body works and how organisations in Romania can file complaints about discrimination. Similar equality bodies exist in all EU Member States and we hope you will feel encouraged to seek out more information about their work and ways of bringing complaints. Links to the websites of all the national equality bodies in the EU are available at: [www.ec.europa.eu/social/main.jsp?catId=616&langId=en](http://www.ec.europa.eu/social/main.jsp?catId=616&langId=en).

Moving on to the second main topic of this issue, Christian Bundgaard describes the work of Disabled People's Organisations Denmark (DPOD), the Danish umbrella organisation of people with disabilities, in raising awareness about the Convention on the Rights of Persons with Disabilities. DPOD has started a project in which they train their representatives, who are working with the Danish local authorities, to use the Convention when developing local policies and monitoring practices in local communities.

Such information will be helpful to organisations developing community-based services for people with disabilities and anyone working towards implementation of the Convention on the Rights of Persons with Disabilities.

*If you would like to tell the ECCL network about the work of your organisation, whether you are providing community-based services, are involved in advocacy activities promoting community living or are seeking to raise awareness about the Convention, please let us know. We look forward to hearing from you!*

Finally, we would like to encourage you to join the European Coalition for Community Living and look forward to hearing from you at [coordinator@community-living.info](mailto:coordinator@community-living.info).

With best wishes,

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

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## Community-based services: A Question of Political Will, not Money

### Interview with Laila Onu, Pentru Voi Foundation

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The Pentru Voi Foundation provides community-based services for adults with intellectual disabilities and their families. Founded in 1996, at the initiative of parents of people with intellectual disabilities, the Pentru Voi Foundation has become a well recognised and well respected organisation in Timișoara, and in Romania. It has done so in large part because of the great support received from the local community, the partnership with the Town Council of Timișoara, international cooperation, governmental collaboration and various income generating activities.

Pentru Voi was the first organisation in Romania to develop and offer programs such as supported employment, independent living, self-advocacy, and an activity centre for adults with profound intellectual disabilities. At this moment, Pentru Voi provides community-based services to 160 individuals with intellectual disabilities and their families. It also organises training events, advocates for the rights of people with intellectual disabilities in Romania and functions as a resource centre.

We have spoken to the Director of Pentru Voi Foundation Ms. Laila Onu to learn more about the services provided by her organisation, the process of de-institutionalisation in Romania and the potential impact of the UN Convention on the Rights of Persons with Disabilities on the lives of disabled people in Romania.

The first set of questions deals with the quality of services for people with disabilities - the theme which we will continue exploring this year in the next two issues of the Newsletter.

#### Quality of services

**Q: How does Pentru Voi define good quality community-based services for people with intellectual disabilities? What criteria do such services have to satisfy?**

In Romania, there is an official system of quality standards. These are defined by nine principles of excellence:

1. Leadership
2. Rights
3. Ethics
4. Comprehensiveness
5. Person-centred care
6. Participation
7. Partnership
8. Result-orientated
9. Continuous Improvement

All service providers have to be accredited before starting to deliver specific services. This implies that the service provider has met the minimum general quality standards.

The general conditions for management and delivery of social services apply to all social service providers. They include being in line with the local government strategies, carrying out evaluations of the services provided, using individualised care plans, having qualified personnel, using tools to assess client satisfaction, etc. In addition, service providers must use a 'service delivery' contract, which needs to be signed by the client. In this contract, the client's rights and obligations are stipulated, together with the main steps necessary to achieve the objectives of the individualised care plan.

There are also specific quality standards defined and set out in ministerial orders, for different types of specialised services: day centres, "protected homes", respite centres, residential care, in-home services. Since 2008, the Social Inspection Service has the specific role of verifying if service providers are complying with the quality standards.

Pentru Voi must comply with these regulations and standards. However, some of the Romanian quality standards are, in our view, contrary to our philosophy. I will give you two examples, both for “protected homes”. We have several apartments and a house where people with intellectual disabilities live. One of the official quality standards requires that we have a so-called “guest book”, which everybody who comes to visit individuals living in the apartment has to sign. In our opinion, this is an absurd regulation, because at home, we don’t ask our friends and people who visit us to sign in. Why should people with disabilities do it? So, when the social inspection visited our services, they noted in the report that we fail to respect this rule and recommended that we start a guest book.

Another example of an absurd rule imposed by the quality standards is that each “protected home” should have a fence. Our protected homes are apartments in regular blocks of flats and of course they don’t have a fence.

The problem is that people in charge of writing these quality standards do not understand the concept of social inclusion and they do not consult service providers like us before they approve such standards.

**Q: How do you evaluate and monitor the quality of services you are providing?**

Apart from evaluation required by the government, we have our own evaluation and monitor the quality of our services. This year, we have introduced a questionnaire for families and service users asking for their opinions on the quality of our services.

**Q: Do you involve service users in the evaluation of services? If yes, how does this work and what have been the results so far?**

Yes, for us, this is an important part of our internal evaluation process. It is done through interviews and focus groups with the service users. Another internal procedure is that representatives of service users take part in the weekly and monthly staff meetings, where they can express their concerns and make suggestions. We are very satisfied with the way this works. In a radio interview, one of our service users was asked: “What is the difference between Pentru Voi and the institutions in which you used to live?” and she answered: “I finally found a place where I am valued”.

**Q: You have received a number of awards for the services you are providing. Has this encouraged other service providers to develop similar services or local authorities to support projects similar to the ones you are implementing?**

I don’t know whether the awards motivate other organisations to develop similar services. I think that the best motivation is the need for services, and there are several groups of parents from different parts of the country who come to visit our services and try to develop something similar in their own community.

## Examples of services provided by Pentru Voi

### Supported Employment

Thirty three of Pentru Voi’s service users are employed full-time in companies throughout Timișoara and benefit from supported employment. Two specialised job coaches support the users by providing vocational profile, job searching, vocational and social abilities training, work placement and by accompanying them to work.

The service users have various jobs, depending on their skills, such as cleaner, tailor, computer operator etc. Last year, 22 service users participated in computer training, organised through a PHARE project and adapted for people with intellectual disabilities. Those who participated in this training now teach their colleagues to use a computer and participate in different projects, where they have the opportunity to practice what they have learned.

### Protected unit

In Romania, companies with 50 or more employees must ensure that at least 4% of their workforce are people with disabilities. If they fail to do so, they must pay a monthly tax equal to 50% of the gross minimum national salary for each position that is not filled by a person with disabilities. Instead of paying this tax, however, companies can choose to purchase products or services from “authorised protected units” in the amount equal to the monthly tax. This provision (Article 78 of Law 448/2006) was added to the legislation at the initiative of Pentru Voi.

Based on this law, in 2007 Pentru Voi created a protected unit with the goal of employing as many people with disabilities as possible. The unit provides a number of services, including:

- mobile teams that provide gardening/landscape maintenance and offer cleaning services;
- a business/copy centre that produces brochures, posters, business cards, etc.
- an assembling group which make plastic parts for a German company;
- a bakery that manufactures and delivers delicious rolls;
- a unique “working group” at the Pentru Voi day centre for persons with severe disabilities where 20 people perform various tasks.

In 2008, 33 adults with intellectual disabilities were employed on the open labour market, while 56 worked in Pentru Voi’s social enterprise. Pentru Voi has contracts with a number of companies from the local community and its protected unit had a turnover of 294,403 EUR in 2008 (all of which will be reinvested in the protected unit). In the time of world-wide financial crisis, Pentru Voi’s main goal for 2009 is to ensure that all the employed service users are able to retain their contracts and to develop the social enterprise through new partnerships, in order to increase the number of people with intellectual disabilities employed.

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**Q: There is a fear that the current financial crisis will further slow down the development of community-based services in Central and Eastern Europe. Do you think this will be the case in Romania and if yes, what do you think needs to be done to minimise the impact?**

I don't think that the development of community based services is a question of money - it is more a question of political will to make real changes and to have the courage to confront the existing "establishment" from the old institutions. Huge amounts of money went into the reform of the system, and very little has changed in the lives of people with disabilities. In fact, it is a disgrace that major donors like the European Union and UNICEF are not interested in evaluating the results of the programmes they have financed.

Romania now has the possibility to use Structural Funds and that should be a source of funding during the economic crisis. Unfortunately, the terms of reference for the European Regional Development Fund, which is supposed to finance the reform of the system in terms of infrastructure, are composed in such way that organisations cannot develop new services, they can only renovate old ones.

## **De-institutionalisation in Romania**

**Q: The Romanian authorities are often keen to point out how successful the process of de-institutionalisation in Romania has been in the last 10 years, especially in relation to children with disabilities. How do you see this process, in relation to both children and adults with disabilities?**

There was a major reform in the child care system. The number of children in institutions has decreased substantially - there are family type homes for children with severe disabilities and a foster care system. However, the problem is still the quality of services, especially in relation to children with severe disabilities and those with challenging behaviour. Also, for disabled children in general, the problem is that most of them still have no access to education.

In relation to the reform of services for adults with disabilities, there are still around 20,000 people living in institutions. So far the focus has been on renovating old buildings rather than creating services in the community. In the whole of Romania, there are only 270 people with intellectual disabilities who benefit from day care centres. There are 12 such centres in the country, 2 of which are run by Pentru Voi in Timisoara. There are 140 people who use our day care centres, which means that we alone have more than 50% of people in our services. That gives you a picture about the situation in the country.

There is an urgent need for community-based services in Romania. The institutions have been renovated and no, you will not come across the same shocking images as in the 1990s. However, there is still a very long way to go before we achieve the social inclusion of people with disabilities in Romania.

**Q: Has joining the European Union (and the process of accession) been helpful in encouraging the development of community-based services for people with disabilities?**

The process of accession to the EU has been very helpful. Both the financial help and the pressure exerted by the EU during that time helped to launch reforms in the social care system. Now that we have joined the EU that pressure has disappeared. We need to make things better because it is in our interest and not because somebody else is asking us to do so.

**Q: What do you see as the main barriers to the process of de-institutionalisation in Romania?**

There are different types of barriers. Firstly, there is a lack of qualified staff to work in community-based services. Such services require a different type of staff than those employed in institutions if they are to be of good quality. Then there is the strong opposition coming from the institutional care sector. The institutional staff are well organised and have a strong union, and are very much against change and in fear of losing their positions. It is also about trying to keep control over the resources currently going into institutions.

Among other barriers are the regulations, which are the same for institutions and services in the community. Because they were designed for institutional care, the regulations are completely inappropriate for community-based services. Attention is paid to sanitary conditions, for example, rather than the quality of life of service users.

One of the main barriers, in my view, is the fact that the medical approach still very much predominates among professionals in the social care field. The whole gate-keeping system is based on the medical classification. What is missing is a person-centred approach in developing services. Institutions are therefore still the preferred option, because they are meant to fit all the residents, regardless of their individual needs.

## **Q: And the main opportunities?**

As one of the main opportunities I would single out the EU Structural Funds and their potential use for the development of community-based services in Romania. For this to happen, however, the Structural Funds regulations need to change. We know there are delays with the spending of Structural Funds, and so far, I am not aware of these funds being used to develop community-based services.

## **Q: What can initiatives such as ECCL do to help?**

Initiatives such as ECCL can support our work by lobbying at the European level, for example around the issue of Structural Funds spending. We would also benefit from better exchange of knowledge.

As an illustration, we have launched a campaign *Autism Doesn't Disappear at 18*, funded by the EU. In Romania, once a child with autism turns 18, s/he loses this diagnosis and becomes 'psychotic' or 'schizophrenic'. There are no services for adults with autism in the country, since so to speak, adults with autism do not exist. As part of the project, we have taken a group of 30 people who are being assessed and for whom an individualised support plan will be developed. The problem is that there are no existing tools and no professionals in the country who are able to do this type of assessment. We therefore had to look outside for help. It would be good if tools like this were shared through ECCL.

## **UN Convention on the Rights of Persons with Disabilities**

### **Q: Will the UN Disability Convention be helpful to organisations - such as Pentru Voi - advocating for the social inclusion of people with intellectual disabilities in Romania?**

The Convention will be of great help. It is the first time we have a binding treaty on the rights of people with disabilities and we can use it to persuade our Government to change the relevant legislation and practices.

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

I believe Romania will ratify the Convention. During last year's elections we have spoken to different candidates and there was general agreement that Romania should ratify. The first step, in my view, should be to change the Law on Disability.

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

It is very important that non-governmental organisations monitor whether the Convention is being implemented. In my view, the focus should be on three areas. Firstly, we need to monitor what progress the Government is making in developing sustainable community-based services. Secondly, we need to keep a close eye on developments in the social care sector. The development of services in the community is clearly not a question of resources. A lot of money has already been invested in the sector by donors such as the EU and the World Bank, yet none of the funders have thought of evaluating after 5 or 10 years whether their investments contributed to social inclusion of disabled people. Romanian citizens have a right to know where public money goes, but this is simply not happening.

Most importantly, it is crucial that we all work towards the paradigm shift that the Convention promotes, and that is the move from viewing disabled people as objects (of care, charity, pity) to rights holders. Without this paradigm shift, it is hard to expect that there will be any real progress towards social inclusion of people with disabilities in Romania. And we need to work not only with the Government, but also amongst ourselves in the NGO sector, in order to ensure that we make better use of our resources and better share the expertise we have. If we can get mainstream human rights organisations on our side, that will also be very helpful.

### **Q: Having in mind the situation in Romania, what role should the EU institutions play in implementing the UN Disability Convention?**

The EU should play a more direct role in implementing the Convention. At the moment, we only have one piece of legislation to prevent discrimination against people with disabilities, and that is the Employment Directive. We need the EU to adopt additional pieces of legislation in disability field, in order to have a stronger influence in the Member States, and contribute more to implementation of the Convention.

*Laila Onu is the Director of the Pentru Voi Foundation in Timișoara, Romania. For more information about Pentru Voi, please visit: [www.pentruvoi.ro](http://www.pentruvoi.ro)*

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## Using the EU Anti-Discrimination Legislation

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This article provides a brief overview of the existing European Union anti-discrimination legislation, followed by an article by Istvan Haller, a Member of the Board of Directors of the National Council for Combating Discrimination in Romania.

### Overview

In 1997, the European Union Member States unanimously adopted the Treaty of Amsterdam, which granted the EU new powers to combat discrimination on the grounds of sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation. Since the Treaty of Amsterdam came into force in 1999, the following anti-discrimination laws have been adopted:

- Council Directive 2000/43/EC implementing the principle of equal treatment between persons irrespective of racial or ethnic origin
- Council Directive, 2000/78/EC establishing a general framework for equal treatment in employment and occupation
- Council Directive 2004/113/EC implementing the principle of equal treatment between men and women in the access to and supply of goods and services.

All Member States were required to transpose the Directives into their national legal systems and to establish “national equality bodies” for the promotion of equal treatment. Romania’s National Council for Combating Discrimination is an example of such body. The Council can consider individuals’ complaints about unfair discrimination. This includes complaints from disabled people who have been discriminated against on the basis of their disability in contravention of anti-discrimination legislation.

More information about protection against discrimination in the EU is available on the website [www.ec.europa.eu/employment\\_social/fundamental\\_rights/legis/legln\\_en.htm](http://www.ec.europa.eu/employment_social/fundamental_rights/legis/legln_en.htm). The website also provides contact details of national equality bodies in all EU Member States.

## Preventing and Fighting Discrimination in Romania

*By Istvan Haller, National Council for Combating Discrimination*

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### Short history

Around the mid-’90s, a number of Romanian human rights organisations became engaged in intense lobbying at national and international level to promote legislation for preventing and combating discrimination. An expert group was formed as a result of agreement by the Government, which drafted a piece of legislation modeled after the International Convention for Combating Racial Discrimination, that was adopted in the form of a Government Ordinance<sup>1</sup>. The law suit brought by non-governmental organisations against the Romanian Government for the “failure” to create an institution to implement anti-discrimination legislation finally triggered the process and the National Council for Combating Discrimination (NCCD) was established in the summer of 2002.

In the following years, the Government Ordinance 137/2000 went through numerous amendments, reaching its current format in October 2006. Currently, Romanian legislation for preventing and combating discrimination implements both Protocol 12 to the European Convention on Human Rights and Council Directives 2000/43/EC<sup>2</sup> and 2000/78/EC<sup>3</sup>.

### Legal provisions

The Government Ordinance 137/2000 defines direct and indirect discrimination, harassment, multiple discrimination, victimisation, and does not require positive measures<sup>4</sup> in the field of discrimination. As grounds of discrimination it includes race, nationality, ethnicity, language, religion, social background, belief, sex, sexual orientation, age, disability<sup>5</sup>, chronic non-contagious conditions, HIV status and belonging to a disadvantaged group, keeping in mind that any other criteria can be invoked.

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The Ordinance prohibits discrimination in five major areas:

- Equality in the field of economic activity, employment and occupation;
- Access to public, administrative and legal services, health services and other services, goods and facilities;
- Access to education;
- Freedom of movement, the right to free establishment of residence and access to public places;
- The right to personal dignity.

NCCD can establish the presence of discrimination in other areas as well, but in these cases it cannot apply sanctions.

If NCCD finds that discrimination, harassment or victimisation have taken place in one of the five areas mentioned above, it imposes an administrative fine on the individual or organisation that has perpetrated the discriminatory act. The fine can be as high as 4000 RON (about 1000 EUR) if the discriminatory act targets an individual, or up to 8000 RON (about 2000 EUR) if a group of people or a community were subject to discrimination. If discrimination occurs in an area not covered by the anti-discrimination legislation, NCCD can take note of the discriminatory act without imposing a fine. NCCD is not entitled to provide legal remedies. However, the victim of discrimination can apply to a court (either right away or after the case is dealt with by NCCD) if they wish to get the consequences of the discriminatory act removed (for example, if not granted a job) or to restore the situation that existed before the discrimination occurred (for example, if fired due to having a disability).

All kinds of evidence can be brought both before NCCD and the court (including audio and video tapes, statistical data etc.) and the principle of sharing of the burden of proof applies. Burden of proof means that the claimant has the obligation to prove the existence of facts that allow for the presumption of discrimination, and the defendant must prove that the facts do not constitute discrimination.

**Non-governmental organisations involved in human rights protection or combating discrimination (including organisations of persons with disabilities) can petition NCCD or can bring an action in the court of law in cases where discrimination concerns a group of persons or a community. If the victim of discrimination is an individual, that person can authorise an organisation to act on their behalf.**

## The National Council for Combating Discrimination

Set up in 2002, NCCD was initially a body under the subordination of the Romanian Government. In 2007, it became an independent state entity, under the control of the Parliament.

According to the law, the Council has the following responsibilities:

- to prevent acts of discrimination,
- to mediate in acts of discrimination,
- to investigate, establish the existence of, and sanction, acts of discrimination,
- to monitor instances of discrimination,
- to offer specialised assistance to victims of discrimination.

These responsibilities can be summed up under two headings: **prevention** and **sanctioning**.

The preventive function is exercised through campaigns, publishing of leaflets, brochures, reports, organising debates, conferences, training programmes, summer schools, etc. Some activities are organised only by NCCD, but most are organised in partnership with non-governmental organisations.

Sanctions can be applied after consideration of petitions submitted by organisations or victims of discrimination. By monitoring specific situations, NCCD can also act on its own initiative. NCCD considers each petition and invites the parties to present their case, after which NCCD makes its decision. More complex cases can be investigated by field teams who gather the information necessary to consider the petition. The defendants must place all documents at the disposal of the investigation team, otherwise they can receive an administrative fine. At this stage, victims of discrimination can receive specialised assistance, such as information about the law and the relevant legal provisions, as well as information about the procedure and the opportunities for presenting evidence<sup>6</sup>. The dispute can also be mediated if the parties request it. When the necessary information has been obtained, the case is considered by the Board of Directors of NCCD (the decision making body of NCCD). This Board decides, by a majority vote, on whether discrimination exists or not, and, in cases

where discrimination is found, on the sanction. NCCD can also decide whether to issue recommendations or to continue monitoring the situation.

The Board's decision is communicated to the parties through a reasoned decision (similar to a court ruling) which can be challenged by the parties before the administrative courts.

NCCD Board of Directors has up to 9 members who have the same status as state secretaries<sup>7</sup>. Between 2002 and 2006, members of the Board were appointed by the Government for a 7-year mandate. Following a change in legislation, starting in 2007, the Parliament appoints (by vote) members of the Board, for a 5-year mandate. In practice, members of the Board of Directors cannot be dismissed during their mandate.

## Analysing instances of discrimination

In dealing with petitions, the Board of Directors looks at the following aspects:

- The presence of unequal treatment, based on comparison with other persons, groups or communities; unequal treatment is deemed to exist if persons in similar situations are treated differently, or if persons in different situations are treated identically;
- The presence of the recognised ground of discrimination, and whether a relationship of causality exists between the alleged act(s) and the ground of discrimination invoked;
- The violation of a right stipulated by the Romanian legislation or the international treaties that Romania is party to;
- The presence of an objective justification, consisting of a legitimate goal, reached through adequate and necessary means.

### Examples of cases dealt with by the Board of Directors:

1. The absence of a translation into sign language of news on the public television channel: people with a hearing impairment should not be discriminated in accessing information, and this right must be ensured through taking of positive measures (translation into sign language); the lack of funding of the public television is not an objective justification.
2. Roma pupils constitute 90% of the student body in a special school for children with mental disabilities: considering that in the respective city only 10% of the population is Roma, this percentage (90%) points to the presence of unequal treatment of Roma children, which affects their right to education; there is no objective justification for this practice, because the legitimate purpose (to provide education to Roma children) is not reached through appropriate means.
3. The absence of audio signals on traffic lights: not ensuring access for people with disabilities amounts to unequal treatment, because it violates the right to access public places; in cases when legislation imposes an obligation to equip traffic lights with audio signals, the lack of resources is not an objective justification.

## By way of conclusion

Romania has made important steps in preventing and fighting discrimination in a relatively short period of time, given all the shortcomings that still exist. In order to strengthen the efficiency of NCCD, local offices should be established, which would partially take over the prevention, and would at the same time carry out investigations and represent the institution before local courts.

Since the importance and visibility of NCCD has increased significantly, there is also the danger that the institution becomes politicised. The mandate of five of the members of the Board of Directors is due to expire in 2009. If these candidatures are politically motivated, they will hold an absolute majority needed to adopt decisions. Even though the Government Ordinance 137/2000 requires that members have a recognised track record in protecting human rights and combating discrimination, this aspect is not thoroughly taken into account by parliamentarians; during the last appointment (in 2007) they considered that participation in a conference on human rights satisfied this legal requirement.

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## Endnotes

<sup>1</sup> With the same status as a law.

<sup>2</sup> COUNCIL DIRECTIVE 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin



<sup>3</sup> COUNCIL DIRECTIVE 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation

<sup>4</sup> Ed. note: Positive action refers to the right to positively discriminate in favour of a group to make up for past or current inequalities suffered. Examples of positive measures are quotas in favour of people with disabilities, wage subsidies or preferential treatment in training. In the Employment Directive, the positive action provisions are contained in Article 7(1) and Article 7(2). Recitals 26 and 27 also make reference to positive action. Article 7(1) states: “With a view to ensuring full equality in practice, the principle of equal treatment shall not prevent any Member State from maintaining or adopting specific measures to prevent or compensate for disadvantages linked to [disability].”

<sup>5</sup> Romanian legislation still uses the term “handicap”.

<sup>6</sup> Specialised assistance does not include representing the victim of discrimination in court. If the victim does go to court, the court will inform NCCD of proceedings and NCCD will submit a brief expressing their point of view on the matter. After deliberating, the court has the obligation to send the decision to NCCD, enabling NCCD to analyse how courts deal with cases of discrimination. There is therefore a permanent exchange of information regarding the interpretation and implementation of Government Ordinance 137/2000: from NCCD to the courts, through the brief (to which relevant decisions of NCCD can be annexed), and from the court to NCCD, through decisions.

<sup>7</sup> This status is meant to give greater independence to members of the Board of Directors and, implicitly, greater “courage” in solving petitions. So far, NCCD has had to deal with petitions against the President of Romania (who was also sanctioned with a warning), against the Prime Minister, against other ministers, or, on the contrary, it had to deal with petitions filed by high level officials; in certain instances the decisions taken resulted in the changing of laws (e.g. regarding the payment of the child allowance) or have seriously affected the budgets of public institutions (decisions regarding the obligation to pay benefits to certain categories of persons).

*Mr. Istvan Haller is a Member of the Board of Directors of the National Council for Combating Discrimination in Romania. ECCL is thankful to Ms. Alexandra Nerisanu for translating this article into English. The original version in Romanian can be downloaded from the ECCL website. For more information about Romania's National Council for Combating Discrimination, please visit: [www.cncd.org.ro](http://www.cncd.org.ro)*

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## Disability Convention Pilots

### *Using the Convention to improve the living conditions of people with disabilities in local communities in Denmark*

*By Christian Bundgaard, DPOD*

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As Denmark is about to ratify the UN Convention on the Rights of Persons with Disabilities (the Convention), it is very important that the Convention is seen not only as a document with a lot of good intentions and recommendations, but that it is implemented and has an impact. The question is: *Who is going to make this happen?* Obviously, the Danish authorities have the main responsibility for the effective implementation of the Convention. However, in line with the slogan of the disability movement worldwide "nothing about us, without us", Danish NGOs are doing their part to make sure that the Convention works in practice.

All of the 32 disability organisations in Denmark are members of the umbrella group, Disabled People's Organisations Denmark (DPOD), which represents more than 320,000 individual members with different disabilities. DPOD has a local branch in each of the 98 municipalities and has more than 3,000 designated volunteer representatives who represent DPOD in different boards and committees. DPOD is represented on the Advisory Board, which is a required body in each municipality. The Advisory Board is a body dedicated to disability issues and has to be consulted whenever the municipality deals with matters concerning people with disabilities.

With the consent of its member organisations, DPOD decided to offer those individuals representing DPOD on the municipality Advisory Boards a chance to learn more about human rights and especially the Convention. By training its representatives, DPOD wants to ensure that future local policies and practices promote social inclusion of people with disabilities and the right to equal opportunities, as the main principles of the Convention.

Because of limited resources, the project has to be run partly by a small group of about 10 people who have volunteered to help DPOD in training the local representatives. These individuals, known as "Disability Convention Pilots" will visit all the local DPOD branches in Denmark. To prepare for this task, last year the Pilots participated in three seminars where they were trained in human rights advocacy, based on human rights standards (including the Convention), as well as in inclusive teaching methods. Obviously, one cannot become an expert on human rights after three seminars. However, the ambition is not to produce human rights experts, but to enable the Pilots to teach the local volunteers how to use arguments based on the Convention in their daily work to improve the living conditions of people with disabilities. It means, for example, that whenever DPOD representatives on the Advisory Boards are informed of a new administrative initiative or plans for new buildings or other facilities, they will be able to put on their "human rights glasses" and point out potential barriers, give suggestions on how to prevent discrimination on the grounds of disability and how to ensure equal opportunities.



*ENIL's Freedom Drive 2007 - A march for the rights of people with disabilities*

The Disability Convention Pilots have already begun their 'tour' of Denmark and are in the process of visiting DPOD's local branches. Pilots work in pairs and hold an evening session which lasts about 3 hours. The program is a mixture of presentations and various interactive exercises used in workshops, such as asking the DPOD representatives questions which they have to answer by placing themselves in one of the four corners of the room or somewhere on an imaginary scale (to indicate level of agreement with a statement, for example). While the key element of the project is the Convention on the Rights of Persons with Disabilities and discussions are based on the Convention, there is also a focus on inclusive teaching methods.

This approach has been chosen because people learn in different ways and DPOD wants to make sure it is "walking the talk". If the disability movement wants a society which is characterised by inclusion, non-discrimination and equal opportunities, it is important that among ourselves and the projects we develop, we also become highly aware of these principles. Anyone, regardless of disability, should be able to become a Disability Convention Pilot, and likewise, any of DPOD's representatives should be able to attend a session

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with the Pilots. The exercises developed for each session are based on challenges which the local branch is facing at the moment or has faced in the past. The idea behind the interactive part of the evening session is to help the representatives identify the barriers in a certain case, decide what they want to achieve and then, on the basis of the Convention, formulate arguments to support their views.

The sessions have so far been received with positive feedback, which highlights the interest among DPOD volunteers to use the Convention in the process of improving the living conditions of people with disabilities in Denmark. One of the challenges of projects like this is the fact that representatives come from different starting points, and have various levels of previous knowledge and expertise. However, as already mentioned, the aim of the project is not to create human rights experts. Those representatives who want to know more about human rights and the Convention than what is offered during the session, are provided with information about resources they can study after the session.

It is still too early to evaluate the outcomes of this project, and it may be difficult to decide how best to measure its impact. It is worth mentioning, however, that 66 out of 98 Danish municipalities have a disability policy already and 19 are in the process of formulating it. A vast majority have based their policy on the Convention, which tells DPOD and everyone concerned with improving the living conditions of persons with disabilities in Denmark that the Convention is on the municipalities' agenda. Through this project and other activities, Disabled People's Organisations Denmark will continue working tirelessly in order to keep the Convention on the agenda and make it the foundation for further improvements in the quality of life of people with disabilities.

*Mr. Christian Bundgaard is a Policy Advisor at Disabled People's Organisations Denmark. For more information about DPOD, please visit: [www.handicap.dk](http://www.handicap.dk)*

## News from ECCL

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The European Coalition for Community Living is participating in two European de-institutionalisation initiatives. We will keep you informed about developments with both initiatives via our website [www.community-living.info](http://www.community-living.info).

### **Ad Hoc Expert Group on Institutional Care (Long-Term Care) Reform**

The Group was created by Commissioner Vladimír Špidla (Commissioner for Employment, Social Affairs and Equal Opportunities) and is Chaired by Jan Pfeiffer (High Level Group on Children, the Czech Republic). Its aim is to identify priorities for action by the European Commission, in order to improve the situation of children and adults with disabilities (including people with mental health problems) and the elderly. The Group's main focus is on the residents of long-term residential institutions in the European Union. Other members of the Group, in addition to ECCL, are Inclusion Europe, Mental Health Europe, the European Disability Forum, the European Association of Service Providers for People with Disabilities and Age. Commission Departments such as DG Employment, DG Sanco and DG Justice, Freedom and Security are also represented. The Group will work until October 2009, when Commissioner Špidla will present the final report to the Commission.

### **WHO Europe Initiative on improving the health and opportunities of children with intellectual disabilities and their families in Europe**

The initiative was launched by WHO Europe in response to the high number of children with disabilities across Europe who live in institutional care. Its aim is to draft a Declaration (a policy statement) and an Action Plan to be adopted by WHO Europe Member States at the end of 2009/beginning of 2010. It is hoped that countries will use the Action Plan in order to create community-based services for children with disabilities, that will enable them to grow up in a family environment, together and with the same opportunities as their non-disabled peers. To that end, the initiative will also identify and create opportunities for exchange of good practice between countries. It is expected that a High Level Conference will take place in Romania at the end of 2009/beginning of 2010. ECCL is a member of the Drafting Group which works on the Declaration and the Action Plan. The initiative is chaired by Prof. Sheila Hollins from St. George's University of London.

## 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 • Ukrainian organisation for the protection of rights of persons with disabilities and users of psychiatry, Ukraine • ACASA - Association for Charity and Social Assistance, Republic of Moldova • Tamas Barnabas, Hungary • Action for Advocacy, UK • Helmut Budroni, Germany • Down Syndrome Kosovo, Kosovo • Andrew Ashbridge, UK

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

## 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](mailto:coordinator@community-living.info).

**For more news and information about ECCL's activities, visit [www.community-living.info](http://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.*

## 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!



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