

Newsletter

OF THE EUROPEAN COALITION FOR COMMUNITY LIVING

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Word from the Editorial Team

Dear Readers,

Our first issue this year begins with an article by Camilla Parker on the UN Convention on the Rights of Persons with Disabilities ('the Convention'), which has in little over a year received the required 20 ratifications to become a legally binding treaty. While this shows that there is a lot of support among the international community for the treaty - and therefore the rights of disabled people - it is disappointing that only four European countries have ratified it so far (Hungary, Croatia, Spain and San Marino). Hopefully more will ratify the Convention over the coming year, but even then this is only the beginning. The real challenge is to ensure that the rights under the Convention are implemented in full.

Earlier this year ECCL took part in the European Parliament ('EP') debate on deinstitutionalisation of children with disabilities in the EU¹, which highlighted the many obstacles that still exist in the implementation of the Convention. Progress in developing alternatives to institutionalisation is still very slow in many European countries, largely due to the lack of political will on all levels. During the debate, both the European Commission and the European Parliament expressed their commitment to do 'more', and we must make sure to take them up on that. It is therefore important to lobby MEPs to support the EP Written Declaration on the discrimination and institutionalisation of children with disabilities in the EU, opened for signature on 9 April. **393 MEP signatures are needed by 15 July 2008 for the Declaration to be adopted. On page 12 of the Newsletter, you can find out how you can lobby your MEPs.**

Following the BBC documentary which exposed the continued use of cage beds in the Czech Republic, ECCL interviewed Milena Johnová, Director of the Czech association QUIP, to find out what has happened since then (page 5).

As in previous issues, we have taken a look outside Europe to present experiences of the process of deinstitutionalisation. Prof. Kelley Johnson from Australia has written about her involvement in the closing of an institution for women who were thought 'unsuitable' for life outside the closed walls (page 8).

Finally, we have included an update about ECCL, which is now based at the European Network on Independent Living, with the generous financial support of the Open Society Mental Health Initiative. We have also established an Advisory Council composed of individuals with long standing commitment and expertise in advancing the rights of disabled people. Among our main focus areas this year will be the ratification and implementation of the Convention. You can support our efforts by becoming a member - to do that, simply download the application form from our website www.community-living.info and send it to us by e-mail or fax.

We look forward to hearing from you!

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¹ Panel debate "Bringing an end to institutionalisation of children with disabilities in the EU", European Parliament, 4 March 2008. ECCL's Statement to the European Parliament is available at <http://www.community-living.info/?page=284>.

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The Right to Community Living and the UN Convention on the Rights of Persons with Disabilities

By Camilla Parker

On 3rd April 2008 Ecuador became the 20th country to ratify the United Nations Convention on the Rights of Persons with Disabilities ('the Disability Rights Convention'). This means that it will become a legally binding treaty on 3rd May 2008¹.

This article provides an overview of the Disability Rights Convention and considers its relevance to the work to promote community-based services as alternatives to institutionalisation.

The importance of the Disability Rights Convention

The Disability Rights Convention is not intended to create new rights, its purpose is to:

'...promote, protect and ensure the full enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity².'

The Disability Rights Convention includes a range of rights such as the promotion of equality and protection from discrimination, the right to privacy, freedom from torture or cruel or degrading treatment, access to justice; participation in political and public life; education and employment. Importantly, it is the first international human rights treaty to expressly recognise right of all disabled people³ to live in the community as equal citizens.

Article 19 (Living independently and being included in the community)

State Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

Disability Rights Convention and Community Living

Article 19 of the Disability Rights Convention requires governments to take action to facilitate disabled people's 'full enjoyment' of this right and their 'full inclusion and participation in the community'. (See box for the full text of Article 19.)

Although Article 19 focuses specifically on the promotion of 'living independently and being included in the community', the themes of living in the community, inclusion, participation and promoting autonomy run throughout the Disability Rights Convention. For example:

- ◆ Article 3 (General principles) includes 'the freedom to make one's own choices and independence of persons', 'full and effective participation of persons' and 'equality of opportunity';
- ◆ Article 9 (Accessibility) requires States to take action to make a range of areas accessible to disabled people (such as the physical environment, public services and information) so that disabled people can 'live independently and participate fully in all aspects of life';
- ◆ Article 26 (Habilitation and rehabilitation) seeks to enable disabled people 'to attain and maintain maximum independence, full physical, mental social and vocational ability, and full inclusion and participation in all aspects of life'.

Although the Disability Rights Convention refers to 'living independently' it makes clear that this is not about disabled people being left in 'splendid isolation'. On the contrary, the emphasis is on ensuring that disabled people receive the support that they need so that they can achieve their aspirations and engage in community life⁴. For example, Article 19(b) refers to disabled people having 'access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community'. This reflects the

goal of those advocating for 'community living' ('also referred to as independent living'). For example, the Open Society Mental Health Initiative's vision is of "A Community for All" and promotes

‘independent living’ which is defined as:

‘...ensuring that people with disabilities have the same freedom to choose as every other citizen, that they are supported in their choices, and that they have opportunities to participate in the everyday activities that people without disabilities take for granted.’⁵

Institutionalisation and the Disability Rights Convention

One area which represents a serious and persistent failure to respect the rights of disabled people is the segregation of disabled people in long stay institutions, often for life. The recent television documentary showing the appalling treatment and neglect of disabled children in a Bulgarian institution is just one example of the human rights abuses that too often occur in such settings⁶. This follows a series of reports over the last decade that highlight serious concerns about the situation of disabled people in long stay institutions in Central and Eastern Europe. Such reports identify a range of substantial human rights abuses such as the involuntary placements subject to no independent review, appalling living conditions, the lack of privacy and the absence of rehabilitative or therapeutic activities⁷.

However, human rights abuses in institutional settings are not limited to Central and Eastern Europe. In 2006 an investigation into the care and treatment of people with learning disabilities in the UK found that the residents had been subject to years of abusive practice, with the report concluding that ‘institutional abuse was widespread’.⁸

The Disability Rights Convention’s emphasis on community living and social inclusion of disabled people shows why it is not enough to challenge the abuses that take place within institutional settings. The fundamental objection to institutionalisation is that the unjustified segregation of disabled people in institutions is in itself a human rights violation. However good the environment and quality of care, placement in an institution is likely to represent a grave interference with an individual’s human rights, in particular the right to private and family life. For example, a study of institutions in France, Hungary, Poland and Romania found that only a minority of the residents received weekly visits from their families or were able to go out to meet friends⁹.

The Disability Rights Convention articulates the principles of community living in the language of human rights. It makes clear that in order to ensure that disabled people can truly achieve full and equal enjoyment of their human rights and freedoms, States must take action to ensure that disabled people can live and participate in the community.

Moving from institutional care to community living

A European study published in 2007 found that across 25 of the European countries included in the study nearly 1.2 million disabled people were living in residential establishments¹⁰. This report, *‘Deinstitutionalisation and community living - outcomes and costs’* made a series of recommendations aimed at assisting governments shift the provision of care and support from institutional settings to the community, including that governments should ratify the Disability Rights Convention. The report also recommended that governments should:

‘Set out the goal that all disabled people should be included in society and that the help they receive should be based on the principles of respect for all individuals, choice and control over how they live their lives, full participation in society and support to maximise independence’.

Such a goal reflects the core values of the Disability Rights Convention.

The promotion of community living and participation are also policy objectives of both the European Union and the Council of Europe. For example, in 2006 the Council of Europe published its disability action plan which identified independent living as a key goal. The plan states:

‘People with disabilities should be able to live as independently as possible, including being able to choose where and how to live. Opportunities for independent living and social inclusion are first and foremost created by living in the community’¹¹.

The European Union was active in supporting the development of the Disability Rights Convention and is now a signatory. Article 13 of the Treaty of Amsterdam authorising the European Union (EU) to take action to combat discrimination based on a range of grounds, including disability, has led to the introduction of an EU Strategy on Disability and action plan, which aims to ‘develop concrete actions in crucial areas to enhance the integration of people with disabilities’.¹² Furthermore, Article 26 of the European Union’s Charter of Fundamental Rights (2000) provides:

The fundamental objection to institutionalisation is that the unjustified segregation of disabled people in institutions is in itself a human rights violation. However good the environment and quality of care, placement in an institution is likely to represent a grave interference with an individual’s human rights, in particular the right to private and family life.

'The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.'

Article 4 of the Disability Rights Convention requires governments *'to take measures to the maximum of their available resources ... with a view to achieving progressively the full realization of these rights'*. While this acknowledges that governments may not be able to achieve compliance with all Convention rights immediately, they should take concrete steps towards achieving the rights set out in the Disability Rights Convention¹³. Furthermore, some obligations take effect immediately, such as the guarantee that rights will be exercised without discrimination. Thus, governments should show what steps they are taking to eliminate discrimination against disabled people and promote the social inclusion of disabled people.

Conclusion

For the reasons outlined above, the institutionalisation of disabled people undermines the principles and purpose of the Disability Rights Convention.

The Disability Rights Convention reflects the vision and principles that organisations such as the European Coalition of Community Living (ECCL) and its network members seek to promote: a society in which disabled people can live as equal citizens. The development of services and support that are available to disabled people in their communities and are designed to be responsive to their individual needs is key to achieving social inclusion and ensuring respect for the human rights of disabled people.

¹ United Nations Enable www.un.org/disabilities/, accessed 3rd April 2008. The four European countries that have ratified the Convention so far are: Croatia, Hungary, Spain and San Marino.

² Article 1 Disability Rights Convention.

³ This paper refers to 'disabled people' rather than 'persons with disabilities'. The Disability Convention provides a broad definition of disability: *'...includes those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'*.

⁴ See also a discussion on 'independent living' in European Coalition for Community Living Newsletter Issue No. 2 Jim Elder-Woodward, 'From the Rolling Quads to Direct Payments', November 2006 p 3 http://www.community-living.info/documents/Newsletter_no_2_06.pdf

⁵ www.osmhi.org

⁶ More information about the BBC 4 documentary 'Bulgaria's Abandoned Children' is available at <http://www.bbc.co.uk/bbcfour/documentaries/features/bulgarias-children.shtml>

⁷ See for example, Amnesty International (2003) *Bulgaria, Far from the Eyes of Society: Systematic Discrimination against People with Mental Disabilities*, London, Amnesty International and Mental Disability Advocacy Center (MDAC) (2003) *Cage Beds, Inhuman and Degrading Treatment in Four Accession Countries*, Budapest, MDAC.

⁸ Commission for Social Care and Inspection and Healthcare Commission, *Joint Investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*, July 2006.

⁹ Freyhoff G, Parker C, Coue M, and Grieg N (2004) *Included in Society, Results and Recommendations of the European Research Initiative on Community-based Residential Alternatives for Disabled People*, Brussels 2004

¹⁰ 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, p 25. The study included all 27 European Union Members and Turkey. The relevant information was not available for Austria, Germany and Greece.

¹¹ Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015, Recommendation Rec(2006)5.

¹² Equal opportunities for people with disabilities: A European Action Plan COM (2003) 650 Final

¹³ This argument is based on the approach taken by the Committee on Economic, Social and Cultural Rights, see the Committee's General Comment 3, 14/12/90

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One Step Forward and Two Steps Back

Interview with Milena Johnová, Director of QUIP, Czech Republic



Through our Newsletter, we try to inform the readers about the situation of people with disabilities in different countries around Europe. This year, the Czech Republic was again in the spotlight after it was revealed that cage beds are still being used in institutions for people with disabilities, despite last year's legal ban on their use. We spoke to the Director of QUIP, Ms Milena Johnová, to find out more about the situation of people with disabilities in the Czech Republic, what are the main barriers to their social inclusion

and the work that is being done by her organisation to encourage the development of alternatives to long-stay institutions for people with disabilities.

Situation in institutions for people with disabilities

Q: In 2003, there was a high profile campaign against the use of cage beds in institutions for disabled people in the Czech Republic and other countries in Central and Eastern Europe. Has the campaign helped improve the situation of disabled people in the country, in relation to the type and quality of services provided?

The campaign certainly brought a lot of international attention to the issue and provoked a response from the Czech Government. It was the first time that serious attention was paid to what happens in institutions for people with disabilities. Unfortunately though, the attention was limited to the use of cage beds. The debate did not consider the appropriateness of institutions as such.

Q: How satisfied were you with the results of the campaign?

After the campaign, the Ministry of Labour and Social Affairs undertook the first mapping exercise of the use of cage beds in institutions. It was also the first time that institutions willing to stop using cage beds received support. Among those were institutions in Central Bohemia, where many - 24 of them - are located.

Q: Despite last year's legislation which prohibits the use of cage beds, a BBC documentary shown in January revealed that cage beds are still very much used in some institutions for people with disabilities. What was your Government's response this time?

The Government ordered an inspection into the institution shown in the documentary, which surprisingly enough concluded that the rights of service users are being respected. That was the end of their interest. If we compare our Government's response to the one issued by Bulgaria after 'Bulgaria's Abandoned Children', our authorities were much worse. The Bulgarian Government at least accepted that institutionalisation is a problem, which was not the case with our authorities.

Q: Can you tell us a bit about your organisation's response to the documentary and the actions you have taken since then?

At QUIP, we find it unacceptable that the Government's inquiry came out with such positive result. We do have quality standards in the Czech Republic, and they were not being upheld in this institution. As for our next steps, we will request the whole report of the inspection and depending on its content we will consider our next actions.

We also sent an Open Letter¹ to the Minister of Labour and Social Affairs on 31 January and will be meeting with the Deputy Minister in May. We will make sure he understands that what we have seen in the documentary, and the subsequent developments, are not acceptable.

¹Available at <http://www.community-living.info/index.php?page=233&news=249&pages=&archive=>

Availability of alternatives

Q: What community-based services are available in the Czech Republic? To what extent are they directed at helping people with disabilities participate in the community?

QUIP - Association for Change

Q: What is QUIP's mission?

QUIP was founded in 2003 with the aim of promoting high quality social services, raising awareness about the rights of people with learning disabilities and increasing the quality of supports and services available to them. Sadly, many people with learning disabilities in our country still live in long-stay institutions.

Q: What are your main activities?

One of the main pillars of our work is education. We train staff working in the social service sector, but also support processes that lead to implementing quality standards into social services for people with learning disabilities. We also provide legal support to social service users and providers, focusing on the protection of human rights and freedoms of people with learning disabilities, legal capacity issues and guardianship. Since 2006, we have been promoting examples of good practice in the provision of quality services in the community. A few months ago we launched a web portal www.kvalitavpraxi.cz (Quality in Practice), with resources for staff in social services and other sectors.

Q: QUIP has recently launched a project entitled Hope for the Change of Institutions. Can you tell us something about it?

The competition 'Hope for the Change of Institutions' is a part of an European Social Fund (ESF) project named For Change, and is supported by the Ministry of Labour and Social Affairs. This is the second time we have run this project. Last year it covered only Central Bohemia but this year it is open to institutions all over the country.

Institutions for people with learning disabilities are asked to decide upon some basic principles for transforming their services, and to describe their experiences with person centred planning and supporting people in leaving institutional care. They are then asked to consider their residents' situation and to come up with the initial steps they would need to take in order to transform themselves into a community provider. The three best projects will receive staff training, will be taken on a study trip to a community-based provider abroad and will receive financial support to take the first steps in the process of closure. As a separate project, we are planning to meet with the management of institutions which are planning to close down, to see how we can support them.

² Self-advocates are people with intellectual disabilities campaigning for their rights.

³ Launch of the Deinstitutionalisation and Community Living - Outcomes and Costs study, which took place in November 2007.

We have a whole spectrum of social services available in the Czech Republic. Community-based services are generally of good quality and some are very innovative, such as the early intervention programme and the personal assistance scheme. The problem is that there are not enough of them, which means that they are not available to many disabled people.

Q: Have there been any developments recently that could support the development of additional services in the community?

Regrettably, since our new Social Services Act came into force, the situation has got much worse. The problem is that there are no funds earmarked for the development of community-based services. The Act provides for cash benefits for people with disabilities, but they are not administered very well. In reality, cash benefits are too often used to cover household expenses rather than buy services. Also they sometimes go to people who do not need them. People with learning disabilities are in an especially difficult position, since it is their guardians who decide how the money is used.

As a result of the new Act there is also a danger that many of the small service providers, providing quality services in the community will be forced to close down, since they will no longer receive financial support from the public authorities. This is especially worrying if one considers that, at the moment, community-based services are mostly provided by NGOs. The State - more precisely, the regional and local authorities - provides almost exclusively institutional care for people with disabilities and the elderly, and domiciliary care for the elderly.

Q: What do you consider to be the main barriers to the process of de-institutionalisation in the Czech Republic?

The main barrier is the lack of political will. Then there is the general public, who still think that people with learning disabilities belong in institutions because that this is where they are best taken care of. Many professionals share the same view.

One of the problems is also that the biggest disability lobby pays no attention to the issue. This could be because it consists mainly of people with physical disabilities, who have other concerns. On the other hand, the self-advocates' lobby² is very weak. This is why at QUIP we are planning to support the creation of an alliance, so that we can help put the problem of institutionalisation on the political agenda.

Q: The two major European studies on de-institutionalisation - Included in Society and Deinstitutionalisation and Community Living - Outcomes and Costs were both presented in Prague. Have the recommendations of these studies been taken on board by the relevant stakeholders?

There was someone from the Ministry at the last conference³, but those who should be paying attention are not doing so. As an example, the Ministry is now planning a nationwide project, during which they are planning to close down a minimum of 13 institutions (one in each County, with the exception of Prague), and provide the residents with alternative services. However, some of these alternative services will also include "homes" with up to 40 beds.

Q: Could quality services in the community be developed as a part of the project?

While theoretically quality services could be developed, there is only money for buildings - like group homes - and staff training, but there is no budget to finance the hump costs⁴. I can give you an example from Central Bohemia, where an institution for 30 people with complex dependency needs is planning to close down. Alternative housing in the community was recently found for three residents, but there was no funding to make up for the income the institution will lose when these three residents leave (because the existing institution must provide services with almost the same expenses). This means that the institution must admit another three residents and deinstitutionalisation will have stopped just as soon as it started.

Impact of EU membership

Q: Did joining the European Union have any impact on the lives of disabled people in the country?

The Czech Republic managed to reach the minimum level of social inclusion of people with disabilities set by the EU. Many Government papers and policies now mention social inclusion and there is a lot of talk about it. However, social inclusion remains something that is talked about, but not done in practice.

Q: Is the Czech Republic getting enough support from the European Union to reform its social care system - both in terms of funds and know-how?

When it comes to funds and know how, we have enough support from the EU. But I am not sure that all of it is used as much as it could be. For example, the first call for ESF projects for 2007-13 was only published last week (Editor's note: beginning of April 2008).

One of the positive aspects I wish to highlight has been the financial support that NGOs have been able to access through the European Social Fund (ESF) in the past. The same fund could be used to transform institutions into community-based service providers, but institutional management does not know how to write ESF projects. At the same time, there are no strict instructions on how EU money should be used, so there are chances that some of it is going into supporting institutional care instead.

Q: The Czech Presidency of the EU (which will begin in January 2009) has identified accessibility of the physical environment and the quality of social services as one of its priorities. Are you aware of any specific Government plans?

According to the information we have at the moment, our Government is planning to develop a European framework for the quality in social services. The Presidency is still quite far, so more should be known later.

Q: Is the Czech Republic planning to ratify the UN Disability Convention?

We have written to the Ministry of Justice to ask about the UN Disability Convention, but haven't received an answer. There is no discussion, to our knowledge, at the Ministry of Labour and Social Affairs about the ratification.

Looking ahead

Q: What would be some of the ways ECCL can support the reform process in the Czech Republic?

There are several areas where we could use help. One of the major problems is the absence of a strong self-advocacy movement. Some support in this respect would be very welcome, to make sure that people with learning disabilities get a place on the national platform of people with disabilities. It is also important to continue putting pressure on our Government to change the situation, and we need support in that.

⁴Refers to double costs of running residential institutions and services in the community during the transition period.

Deinstitutionalization: Half Open Doors¹

By Prof. Kelley Johnson, University of Bristol

For many people with disabilities, deinstitutionalization led to the closure of the doors of the institutions in which they had lived. It was then anticipated that new doors in the community would open to citizenship and equal rights with other community members. However, more than 30 years after what has been called “one of the most significant human service events of the 20th century” (Chenoweth, 2000 p. 80) many doors in the community remain only half open and those in institutions remain only partly closed. While whole generations of people in some countries have now not been exposed to institutional life, the achievement of their rights and inclusion in the wider community often remains problematic. (Tideman, 2005; Tossebro, 2005). Further, in some countries the doors of institutions are still firmly open and institutions remain important parts of the service system (Bulic, 2007). In spite of the strong emphasis on community living in both the UN Convention on the Rights of People with Disabilities and Council of Europe Action Plan the questions remain about the nature of deinstitutionalization and how we can make it work better. This article explores three questions in the context of one case study of the closure of a large institution for people with intellectual disabilities in Australia.

What does deinstitutionalization mean? What factors influence what happens in deinstitutionalization? What role does legislation play in deinstitutionalization?

A case study of institutional closure

The 1990s saw an increasing movement to close large institutions for people with disabilities in Australia. As a PhD student I was interested in exploring what deinstitutionalization meant to people who were living in large institutions (Johnson, 1998). My research involved twenty months as a participant observer with a group of twenty one women who lived in a locked ward in a large institution for people with intellectual disabilities. The women had been labeled as having challenging behaviour and intellectual disabilities. They were regarded by the management of the institution as either being a danger to others or to themselves. They were seen as a group of people least likely to benefit from institutional closure.

Life in the locked unit was difficult for both the women living there and the staff who were all women. There was no privacy, although each woman had a partitioned off cubicle in a large room or in rare cases a small room of their own. The women spent most of their time in a large day room where there were no activities or programmes. Two women went to occupational therapy for morning sessions twice a week. There were eight locked doors between the front door and the back of the ward. To move from one space to another required permission from staff. Excursions outside the ward were limited to a group walk with staff once or twice a week. The ward was noisy with women screaming and shouting and both the women living in the ward and the staff lived with an ever present risk of violence.

During the time I spent in the locked ward, the Government decided to close the institution. This was to be done over a twelve month period. For financial reasons half of the four hundred and fifty three people living in the institution were to move to homes in the community with the other half going to other institutions. A consultation with families and the residents of the institution was undertaken to provide advice on where people might live, however the final decisions were made by a professional relocation team.

There was resistance to the closure of the institution by the trade union branch representing staff (although the national trade union supported institutional closure) and by some parent groups attached to the institution. For the women in the locked ward, the closure was difficult. They were moved from their ward to others around the campus and then either to other institutions or to houses in the community. No counseling was offered to them during this experience. In spite of the reservations expressed by management at the institution, fourteen of the twenty one women went to live in houses in the community with seven moving to other institutions. Those denied a place in the community included women who had high support needs, those whose families preferred institutional to community living and those who were regarded as too ‘dangerous’ by those around them, to live in the community. None of the fourteen women going to the community returned to institutional life.

¹ This article is based on a paper given at a deinstitutionalization workshop at the EASPD conference in Rome February 2008.

Learning from the Case Study

There have now been thousands of cases of institutional closure in many different countries. Each one is both the same and different to others. In this second part of this article I will explore what lessons we can draw from the case study briefly described above.

What is deinstitutionalization?

The process of institutional closure described above fits a definition of deinstitutionalization as:

The reduction in the numbers of admissions to public institutions, the development of alternative methods of community care, the return to the community of those individuals capable of functioning in a less restrictive environment and the reform of public institutions to improve the quality of care provided. (Willer and Intagliata, 1980)

This perspective to deinstitutionalization focuses on the closure of large congregate care settings, the establishment of new services in the community and also suggests that not all people will be able to live in the community.

However, deinstitutionalization can also be seen as recognising:

...the variety of needs among people with learning difficulties, their rights to individual treatment, their value as individuals and the importance of integration as a guiding principle in the development of services. (Booth and Booth, 1990, p.70)

Research evidence suggests that unless we adopt the second approach to deinstitutionalization we run the risk of replacing large institutions with small ones (Johnson and Traustadottir, 2005) and of failing to explore the ways in which people may be included in the communities in which they are living. In the case study I have described, while there was an effort to take the individuals' needs into account through consultation, final decisions about future living arrangements owed more to issues of cost and of ease of management than they did to a focus on valuing the individual or integration or inclusion. However, visits to the women with whom I worked, after they left the institution, revealed that while they were not fully included within the community, their physical living conditions were vastly improved. In houses they had privacy, freedom to move around their home, and increased flexibility in daily living.

There is (and there should be) continued debate about what makes an institution. While traditionally an institution has been defined as 'a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life' (Goffman, 1961, p.11) it can be argued that sometimes many of institutional practices have been transferred into smaller community institutions and group homes (Clement, Bigby and Johnson, 2006). We need to continue to question the nature of institutions and to acknowledge that this label is not restricted to large scale services. The challenge now is to make community living better. We know many of the ways of doing this. Placing people at the centre of planning, ensuring that staff have education about how community inclusion can be developed with the individuals they work with and that they are reflective about their work, ensuring that people have opportunities to develop meaningful occupations and loving relationships are not 'rocket science'. Yet it does seem that it remains difficult for many people with intellectual disabilities to be more than a presence in the community.

What factors influence deinstitutionalization?

Underpinning the example of deinstitutionalization outlined in this article was a strong view that people with disabilities would lead better lives in the community and that their rights as citizens could be better protected outside of the institution. Concerns about rights were increased by media stories of the poor quality of life led by people within the institution and a number of reports to Parliament documenting concerns about institutional life.

However, there were also other factors influencing institutional closure. Like many other large congregate care settings, the institution was old and in need of extensive renovation to make it fit for people to live there. The land on



which it was sited was valuable and could be sold to partly pay for the closure and for the community houses which would replace the institution. At that time too, there was a belief that it would be cheaper for people to live in the community. These factors influenced both the timing for institutional closure and also how it occurred.

Limited resources led to half of the residents of the institution moving to other congregate care settings. They also led to the provision of limited choices in type of housing and location for those leaving the institution.

Politically it was important for the institution to close quickly as the Government believed rightly that it would lose the next election and it wanted to complete the closure process before a party less sympathetic to deinstitutionalization took over. It was also politically important to ensure that staff at the institution were given continuing employment. This led to many of the institutional staff transferring to community houses as support workers. There were some advantages in this, as staff sometimes knew the people moving in the house. However, they often also transferred institutional ways of working to their new positions.

There was a continual interplay and series of compromises between the need to assert and protect the rights of people leaving the institution and the issues of management and finances.

We need to continue to question the nature of institutions and to acknowledge that this label is not restricted to large scale services. The challenge now is to make community living better.

How important is legislation in deinstitutionalization?

It is timely with the new Convention on the Rights of Persons with Disabilities which in Article 19 enjoins States to facilitate full inclusion and participation in the community by people with disabilities, to consider the importance of legislation and legislative frameworks in deinstitutionalization. Certainly at a state level in Australia, legislation was extremely important in leading to the deinstitutionalization described in this article.

In 1987, the Intellectually Disabled Person's Services Act was passed in Victoria (a state in Australia). It was drafted after extensive consultation and established the need for people with intellectual disabilities to live in the community rather than in institutions as a key principle. It set a framework for policy and was also a guide to successive governments, to service providers and to advocacy organizations.

Other legislation was passed concurrently which established an Office of the Public Advocate (ombudsman) with a specific remit to protect the rights of people with disabilities and other citizens unable to make their own decisions. The Office also had a brief to report to Parliament annually on issues which were of concern to it. Over a period of more than 10 years it repeatedly reported the poor quality of life offered to people in institutions and documented instances of abuse which were then reported in the media. This systemic advocacy played an important role in leading to institutional closures.

Later legislation at a national level such as the Disability Discrimination Act (DDA) has also been important in raising issues and forcing open doors in community which had previously been closed to people with disabilities. Legislation provided a framework within which community organizations and government organizations had to work. For example, neighbourhood learning centres in my home state by law became places which had to become accessible to people with disabilities (Johnson, 1996) and advocacy organizations used the DDA to argue for better provision of work opportunities. Further, some individuals used the legislation to force change to happen. For example, Amanda Miller, a self advocate, used the DDA to counter discrimination by the Australian Scouts (Miller with Johnson, 2000). Legislation is essential for change. The ratification of the UN Convention by individual countries provides a framework within which national legislation, policy and practice can occur. However, legislation is not sufficient for change to happen. For the Convention to be more than words on paper it does need a commitment by Governments and skilled organizations and groups who can advocate strongly to ensure that people are not disabled by the societies in which they live.

Professor Kelley Johnson is the Director of the Norah Fry Research Centre at the University of Bristol. She has researched and written extensively about deinstitutionalisation and community inclusion in Australia and internationally.

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Act Now!

Lobby your MEPs to support the Written Declaration on the Discrimination and Institutionalisation of Children with Disabilities in the EU

The Written Declaration 0024/2008 on the Discrimination and Institutionalisation of Children with Disabilities in the EU was opened for signature at the European Parliament on 9 April.

The Declaration, submitted by MEPs Kathy Sinnott, Bastiaan Belder, Els de Groen, Marie Panayotopoulos-Cassiotou and Richard Howitt, calls for the allocation and monitoring of EU funds to ensure that all Member States can provide appropriate and inclusive care for children. Furthermore, it asks the Commission and the Member States to support deinstitutionalisation through alternatives like community based services, including education and recreational facilities, and to prevent future violations of fundamental rights of children in state care.

A minimum of 393 MEP signatures are required before 15 July 2008 for the Declaration to be officially adopted by the European Parliament.

You can lobby your country's Members of the European Parliament (MEPs) to sign the Written Declaration by sending them an e-mail or a letter. The names of your country's MEPs and their full contact details are available on the website of the European Parliament www.europarl.europa.eu (under Your MEPs). Many MEPs also have their own websites, with contact details in their home countries. A short e-mail or a letter to your MEPs saying that it is important they sign the Declaration might be enough to get their support. The full text of the Declaration can be downloaded from ECCL's website www.community-living.info.

Background to EP Written Declarations

The European Parliament Rules of Procedure (Rule 116) provide for a procedure of written declarations. According to the procedure, up to five MEPs may submit a written declaration on a matter falling within the EU sphere of activities. Any member may add their signature to a declaration within three months after its publication. Where a declaration is signed by the majority of MEPs, it shall be forwarded to the institutions concerned together with the names of the signatories.

Act Now!

New European Legislation Prohibiting Discrimination on the Ground of Disability

Commissioner for Employment, Equal Opportunities and Social Affairs Vladimír Špidla officially stated at the European Parliament Employment and Social Affairs Committee meeting on 2 April that the European Commission would propose non discrimination legislation on the ground of disability (also known as 'Disability Specific Directive'). The new legislation would extend the prohibition of discrimination against people with disabilities outside employment, into other spheres of life.

The proposal will be submitted to the College of Commissioners at the end of June as part of a comprehensive 'social package'. Once adopted by the College of Commissioners, the proposal will go through to the European Parliament and Council of Ministers.

The European Disability Forum (EDF) and the European Parliament (EP) Disability Intergroup are holding a hearing on the proposed legislation on 14 May 2008 in Brussels (at the EP).

To support the adoption of the Disability Specific Directive, please write to the relevant Ministers in your country, to the Commissioners from your country, as well as to Members of the European Parliament from your country, which you can encourage to attend the EP hearing. More information about the Directive and how you can support it is available on the EDF website, at www.edf-feph.org.

Source: Articles adapted from the EDF Weekly Mailing.

Living Independently and Being Included: Understanding the UN Convention on the Rights of Persons with Disabilities

ECCL Seminar
2008

12–13 September 2008, Oslo, Norway

The objective of ECCL's Annual Seminars is to promote good practice in the development and provision of quality community-based services for people with disabilities. Representatives of disability organisations, service providers and policy makers - national and European - are invited to discuss recent developments, share good practice and identify solutions to barriers to social inclusion of people with disabilities.

The highlights of the 2008 Annual Seminar:

- ◆ Understanding the UN Convention on the Rights of Persons with Disabilities
- ◆ Implementing the recommendations of the European study De-institutionalisation and Community Living - Outcomes and costs
- ◆ Overcoming challenges in the transition from institutional to community-based models of services
- ◆ Delivering quality community-based services: presentation of good practice

The Seminar Programme and registration form will be available at www.community-living.info in May 2008.

The 2008 Seminar is hosted by ULOBA - Cooperative on Personal Assistance. ULOBA was founded in 1991 and is based on the principles of empowerment, full citizenship and human rights. The cooperative is owned and run by disabled people according to the philosophy of Independent Living.

Advocacy Manual: Developing a Strategy for Community Living

Upcoming
publications

The European Coalition for Community Living is in the process of writing an advocacy manual, which aims to assist organisations in their work to improve the situation for people with disabilities. In countries where community-based services for people with disabilities are scarce or non-existent and many disabled people still live in long-term residential institutions, the manual will help organisations think about what they can do to change the situation and provide them with a variety of tools and ideas.

The manual will present examples of good practice in different areas of advocacy in the form of case studies. It will explain how advocacy tools, such as lobbying, campaigning, awareness raising and media work can be used to support the development of quality community-based services for people with disabilities.

The manual is aimed at organisations that want to change the situation in their communities (on the local level) or in their country (on the national level). These could be organisations providing services in the community for people with disabilities, organisations representing the interests of disabled people, user led groups and self advocacy organisations. The main target region of the manual is Central and Eastern Europe, but it will also be accessible to those in other parts of Europe.

The manual will be launched at the ECCL Seminar in Oslo, Norway on 12 - 13 September. A workshop will be organised for a smaller group of participants on the 13th September.

Members of the Reference Group: John Evans (UK), Camilla Parker (UK), Kapka Panayotova (Bulgaria), Tina Coldham (UK), Eric Bloemkolk (Netherlands), Gengoux Gomez (Belgium), Julie Beadle-Brown (UK) and David Towell (UK). The publication is funded by Socires, Netherlands.

ECCL is collecting examples of advocacy activities from local or national organisations to include in the manual as case studies. These can be examples of lobbying activities, campaigns, awareness raising activities, partnerships with the local authorities, media work, coalition building and others. If you would like to contribute, please include a short description of your activity (one paragraph) and send it to coordinator@community-living.info. Thank you!

ECCL

European Coalition
for Community Living



New Leadership of ECCL

The European Coalition for Community Living (ECCL) was established in 2005 by a group of organisations involved in the first European study on the situation of people with disabilities in long-stay institutions, *Included in Society*. Among them were Autism Europe, the Center for Policy Studies of the Central European University, the European Disability Forum, the European Network on Independent Living, Inclusion Europe, Mental Health Europe and the Open Society Mental Health Initiative. During the first two years, ECCL has been led by a committee composed of representatives of each organisation, who put together ECCL's strategy for the first three years (2006 - 2008) and agreed on the main activity areas of the Coalition - advocacy, monitoring, promotion and exchange of good practice. During this time, a number of organisations and some individual members also joined ECCL to support its activities in their own countries.

At the last meeting of ECCL's Management Committee in 2007, a decision was made that the European Network on Independent Living (ENIL) should take over the leadership of ECCL from January 2008 onwards. The founding organisations felt that this would allow ECCL to better react to developments in Europe, improve its visibility and have a closer relationship with the disabled people's movement. One of the important considerations was also ECCL's financial sustainability and efforts that have to be made to ensure that ECCL can implement its long-term work programme. ECCL is currently funded by the Open Society Mental Health Initiative, based in Budapest, Hungary.

ENIL was formed in Strasbourg at the European Parliament in 1989 when over 80 severely disabled people from 15 European countries met and demanded the right to personal assistants for the first time in Europe. Its mission from the beginning has always been the promotion and development of Independent Living as an alternative to institutionalisation. Independent Living in Europe has its roots in disabled people moving out of institutions. ENIL campaigns for the right of all disabled people to live in the community, and social inclusion and self determination are at the heart of its activities. The wealth of its expertise in developing community support links well with the vision of ECCL and its future work. Every two years since 2003—the European Year of Disabled People—ENIL has been demanding to the European Parliament that resources should be moved from institutions into Independent Living.

ENIL has its Secretariat in Valencia but operates as a network throughout Europe with its Board members coming from many different European countries both East and West. It is currently funded by the European Commission as part of the PROGRESS Initiative 2008-2010.

Even before taking over ECCL, ENIL has played an important role in its work, mainly through its previous Chair, John Evans. At the 2007 Freedom Drive, together with ENIL, ECCL has been able to address the European Parliament Disability Intergroup and highlight the continuing abuses against disabled people in long-stay residential institutions and the lack of quality alternative services in the community. This recent cooperation laid out a good basis for the future efforts of ECCL and ENIL to lobby at the European Parliament, the European Commission, the Council of Europe and other fora, for social inclusion of disabled people.

In addition to ENIL's Board, which is responsible for ECCL as an initiative of ENIL, the Advisory Council helps ECCL maintain its cross-disability perspective by advising on its strategy, particular issues related to community living and various activities. The Council meets once per year, but also provides regular guidance to the Coordinator, based in London, and the ENIL Board. ECCL is lucky to have been able to put together a group of very knowledgeable and committed individuals, most of whom have been supporting ECCL since the very beginning.

Another innovation ECCL introduced from January this year is making the membership of the Coalition free of charge. This move was motivated by the wish to get as many organisations and individuals as possible on board, and increase the number of our supporters in the old EU Member States. This is important if we want to mount enough pressure for a faster development of quality community based services and the implementation of Article 19 of the UN Disability Convention, which enters into force in a couple of days.

To join ECCL and support our activities, please visit regularly our website www.community-living.info or contact us by e-mail.

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!

Meet ECCL's Advisory Council

to advise their work. Tina is also on the Management Committee of the National Survivor User Network (NSUN).

James Elder-Woodward (United Kingdom) Born with cerebral palsy, James Elder-Woodward has had life-long experience of disability, not only as a health and social service user, but also as a service provider, planner and researcher. He is now the Vice Convenor of the Glasgow Centre for Inclusive Living; the Convenor of the Scottish Personal Assistant Employers Network; a board member of Inclusion Scotland; a board member of the National Centre for Independent Living; a member of Scope's Ezone and Chair of Scope's IL zone; and a member of the European Disability Forum's Independent Living Task Force.

John Evans OBE (United Kingdom) John Evans is a Disability Rights and Equalities consultant, trainer and researcher in the UK. He specialises in Independent Living, Direct Payments, User Empowerment, Disability Equality, Disability Rights and Human Rights. He is on the Board of the European Network on Independent Living (ENIL), and has been a Board Member of the European Disability Forum (EDF) since 1998.

Ingrid Körner (Germany) Ingrid Körner is the mother of four children, her second child - a 29 years old daughter - having Down Syndrome. Since 1977 she has been a member of the German Parents Association Lebenshilfe für Menschen mit geistiger Behinderung of which she became a Board member in 1989 and Vice-President in 1996 (national association). Since 1998, Ingrid Körner is a Board member of the national umbrella organisation Bundesarbeitsgemeinschaft Hilfe für Behinderte and one of the four speakers in the National Disability Council of Germany. She is currently the President of Inclusion Europe.

Jim Mansell (United Kingdom) Jim Mansell is Professor of Learning Disability in the Tizard Centre at the University of Kent, England and Adjunct Professor in the School of Social Work and Social Policy at La Trobe University, Melbourne. He is a Fellow of the British Psychological Society, a Chartered Psychologist and an Academician of the Social Sciences.

Donata Pagetti Vivanti (Italy) Mother of autistic twins born in 1986, graduate in medicine and specialized in haematology, Donata is a full time advocate for the rights of persons with ASD or other disabilities. At national level, she is the president of the Italian association Autismo-Italia and member of the Board of the National Council on Disability (CND) and of the Italian Federation for Overcoming Disability (FISH). At European level, she was the president of Autism-Europe AISBL (2000 - 2007), and she is currently vice-president of the European Disability Forum (since 2005).

Camilla Parker (United Kingdom) Camilla Parker is a legal and policy consultant specialising in mental health, disability and human rights. She is a consultant for the Open Society Mental Health Initiative (MHI) and is a board member of the Peter Bedford Housing Association - an organisation based in north London that provides supported housing, work, training and employment and community services to, and works with, people who have faced long term exclusion from society through homelessness, mental health problems, learning difficulties, or multiple needs.

John Patrick Clarke (Ireland) An accountant by profession, Patrick has a son aged 27 who has Down Syndrome. Pat serves on the executive of the EDF Board, is President elect of Down Syndrome International, Treasurer of Institute for Design and Disability, Ireland. Pat is past President of Down Syndrome Ireland and Treasurer of the European Down Syndrome Association.

Gerard Quinn (Ireland) Gerard Quinn is a leading expert on international and comparative disability law and policy. He is a member of the Irish Human Rights Commission and helps coordinate the work of human rights commissions worldwide on disability. He is a scientific Director of a new European Commission academic network on disability. A graduate of Harvard Law School who has a child with a disability, he is in the process of establishing a fully dedicated International Centre for Disability Law and Policy at the National University of Ireland (Galway).

Bojana Rozman (Croatia) For the past six years, Bojana has worked as a staff member of the Association for Promoting Inclusion (API) in Zagreb, Croatia. API is a non governmental advocacy and service provider, developing community-based alternatives to institutionalisation in Croatia and the region. Bojana is a Senior Program Manager for various training and development programs operated by her

The Advisory Council provides expertise to the Board of the European Network on Independent Living when it comes to strategy and policy of the European Coalition for Community Living.

organisation and also writes funding applications to various international donors. Bojana is currently working on her PhD at the Faculty for Education and Rehabilitation, University of Zagreb, Croatia with the focus on quality service provision.

Michael Stein (United States) Michael Stein is a Professor at William & Mary School of Law (Virginia, U.S.A.). He received a J.D. from Harvard Law School, and a Ph.D. from Cambridge University. Michael has established the Harvard Project on Disability.

Joseé Van Remoortel (Belgium) Joseé Van Remoortel is the founding member of Mental Health Europe, the founding member of EDF and a Board member until now. She is an active member of different European organisations such as the Social Platform, CEDEP, the WHO Task Force on Mental Health of Women and Mental Health in Prisons.

Alternate members: John Henderson (Mental Health Europe, United Kingdom), Judith Klein (Open Society Mental Health Initiative, Hungary), Maria Nyman (EDF, Belgium).

Members

Tizard Centre, University of Kent, United Kingdom • Rehabilitation Foundation "Speranta", Romania • "Woman and children - Protection and Support", Republic of Moldova • Center for Innovations in Education, Azerbaijan • Association for Social Inclusion of Persons with Mental Retardation Canton of Tuzla, Bosnia and Herzegovina • Brothers of Charity Services, Ireland • MDAC (Mental Disability Advocacy Center), Hungary • "Pentru Voi" Foundation, Romania • Association for Self Advocacy, Croatia • Association for Promoting Inclusion, Croatia • Steven M. Eidelman, United States • Klubi "Deshira" Clubhouse, Kosova • 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

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

CALL FOR CONTRIBUTIONS

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

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

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