

Newsletter

OF THE EUROPEAN COALITION FOR COMMUNITY LIVING

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Word from the ECCL Coordinator

Dear Readers,

The European Coalition for Community Living was established in August 2005 to work on what is still one of the great challenges in the protection of human rights - ensuring that people with disabilities have access to comprehensive, quality community-based services, so that they no longer have to spend their lives segregated in long-stay institutions. We want to do this by bringing together organisations and individuals from all over Europe, who will promote the development of community-based alternatives to institutional care by carrying out advocacy, lobbying and awareness raising activities, as well as sharing experiences and developing new strategies.

In less than a year, we have grown into a network of members in twenty countries across Europe (including one in the United States), we have organised a very successful seminar on the Right to Live in the Community and launched a new website on www.community-living.info. The support that we continue to receive shows just how important and necessary our work is.

It is therefore my pleasure to present to you the first issue of our newsletter. In this and the future issues, we will bring you interesting articles on different aspects of community living, updates about our activities and information from our members. We hope that you will find the newsletter informative and would like to invite you to send us contributions from your organisations, related to community living, which you would like to share with the network. Also, please share this newsletter with anyone who you think could support our efforts. Thank you and I look forward to your contributions and your feedback.

Ines Bulić, ECCL Coordinator

Editorial By Gerard Quinn

Why is de-institutionalisation so important? What moral imperative does it speak to? And what guidance is available to help ensure that it is appropriately implemented?

These are not trivial questions. Over reliance on institutions is a legacy of a dark past that devalued the humanity of persons with disabilities. De-institutionalisation is now one of the greatest challenges confronting our collective conscience and it is not easily accomplished. Ultimately, it draws on a moral sense of what it means to be human. And it vitally depends on the development of a sophisticated social infrastructure to ensure that life after institutions and in the community is meaningful. De-institutionalisation, is above all else, a human rights issue.

It is, however, a profound mistake to simply reduce human rights to a series of legal instruments or treaties such as the European Convention on Human Rights. These treaties give legal expression to ideas - moral imperatives - that form a common standard of human accomplishment. It is these moral imperatives that explain the importance of de-institutionalisation. It is these moral imperatives that animate human rights and not the other way around. And it is these human rights that will increasingly be relied upon to ensure that de-institutionalisation happens.

About 50 years ago Eleanor Roosevelt - one of the key architects of the Universal Declaration of Human Rights - was asked a deceptively simple question: 'where do human rights begin'? Her answer was profound and speaks in its own way to the challenge of de-institutionalisation. She answered 'human rights begin in small places.' In truth, human rights begin everywhere people talk about right and wrong, about justice and about the right relationship between people. Human rights do not begin in law school. They do not belong to the professionals. And they are not some mysterious omni-presence in the sky. Importantly, human rights will be judged on whether they can reach into small places - places hidden from the mainstream - and help bring about real change.

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What moral values of human rights are at stake in the de-institutionalisation debate? Take the simple idea of human dignity - an idea that lies at the very root of modern thinking about humanity and the rights of individuals. Put simply, this idea rejects the view that a person's inherent self-worth is to be judged by his/her usefulness in society and in the economy. To the contrary, all persons have an inherent and inestimable self-worth which does not depend on utility. Society, however, often judges - and treats - persons on their use-value rather than their inherent value. Persons who were (often wrongly) judged to have a reduced use value were frequently marginalised and indeed warehoused in institutions in the past. In short, institutionalisation deeply offends the concept of human dignity.

Take the related idea of equality - the idea that all persons are of equal inherent self-worth and that all lives are worth living and celebrating. Yet the harsh reality is that disability was often heavily discounted almost to the point that humanity itself was denied. It often seems as if the well-intentioned Aristotelian idea of treating 'equals equally and unequals unequally' was abused in the past to justify segregation and isolation from the community. In short, de-institutionalisation requires us to decisively reject a theory of equality that sees nothing wrong with using the reality of human diversity as a justification for extreme marginalisation. To be equal means to belong.

Deinstitutionalisation challenges us to re-engineer social support to ensure that it does not become a gilded cage. In practical terms, this means a commitment to the ideal of community living and the provision of the means to make it happen.

Take the notion of autonomy - the idea that every person has some latent capacity for self-direction. Too often our political and legal systems simply assumed the complete absence of a capacity for autonomy in persons with disabilities. Decisions were made for others by professionals who 'know best.' It is no accident that two of the most hotly debated articles in the draft UN Convention on the Rights of Persons with disabilities concern the issues of capacity and liberty. The ancient Greeks believed that all persons possessed innate ideas and an inherent capacity to be human. They indeed believed that the task of education was not primarily to equip individuals with marketable skills but to draw out what was innate in order to enhance self-comprehension. Deinstitutionalisation challenges us to take autonomy seriously and to put in place mechanisms that support it rather than undermine it.

And take the ethic of solidarity - the idea that we owe something to each other simply on account of our common humanity. We owe each other a meaningful chance of living as a human being should. Welfare is not an end in itself - it is an indispensable means to enabling all persons to live a life of freedom. Too often however social largesse has not been used to enhance autonomy but to purchase segregation. Untold amounts of money have been used to build and maintain institutions. Deinstitutionalisation challenges us to re-engineer social support to ensure that it does not become a gilded cage. In practical terms, this means a commitment to the ideal of community living and the provision of the means to make it happen.

Institutionalisation locks away the human spirit and can leave people vulnerable to violence and exploitation. Deinstitutionalisation offers hope of allowing people an opportunity to be part of their community. Diversity is not merely good for the persons affected but sensitises the community to the value of human difference. There is then, a social and democratic dividend to deinstitutionalisation that should not be underestimated.

One caveat. Courts will sometimes get it wrong. The recent decision of the European Court of Human Rights in *DH v Czech Republic* (7 February, 2006) would appear to leave States with a wide margin of appreciation when it comes to segregated education (at least on the ground of race with unstated but ominous implications for disability). This decision would seem to stand in stark contrast with the 1999 judgment of the US Supreme Court which effectively mandated a process of deinstitutionalisation (*Olmstead*). Courts are not infallible. It follows that the struggle for deinstitutionalisation will have to be fought as much with hearts and minds and through parliamentary law reform as much as through the courts.

Gerard Quinn is one of the leading human rights scholars. He is a professor of law at the National University of Ireland, Galway and the author of numerous articles and books on the rights of people with disabilities. ECCL is thankful to Mr. Quinn for his contribution to this issue.

Working Together for Community Living

Report from the Right to Live in the Community Seminar

ECCL's Right to Live in the Community Seminar took place on 17 May 2006 in Brussels and has brought together around eighty participants from across Europe, in addition to three participants from the United States and New Zealand. The participants came from a wide range of backgrounds - for example, there were representatives of disability organisations, user organisations, service providers, research institutes, governments and the European Commission.

Europe-wide commitment to community living

The seminar was opened by **Ingrid Körner**, President of Inclusion Europe, who reflected on the achievements of the European Year of People with Disabilities and emphasized that implementation of anti-discrimination legislation and policies will never become a reality, if there is neither political will nor public support. She pointed to the importance of listening to people with disabilities and warned against repeating the same mistakes by stating that "one-size-fits-all should no longer be the motto for any service provided". To this end, she called for exchange of good practice and better cooperation with the governments in providing community-based services for people with disabilities.

Ottmar Miles-Paul, the Coordinator of the German Campaign "March out of Institutions - Tear the Walls Down", discussed why it is so hard for societies to find ways to support people with disabilities in the community, rather than in institutions. He continued by asking the plenary: Which one of us wants to move into an institution? By making a parallel between people with disabilities and elderly people, he made it clear that each of us could one day find ourselves in a situation without a choice.

Mr. Miles-Paul emphasized that the closure of institutions needs to be accompanied by the development of alternatives for community living. He also added that it is important to avoid the so-called "independence trap", according to which people with disabilities must prove that they can do everything by themselves, with no support, if they want to live independently or find employment.

The inspiring presentation by Ottmar Miles-Paul was followed by **Steven Eidelman** from the University of Delaware's Disabilities Centre, who presented lessons learnt during the long and still ongoing process of de-institutionalisation in the United States. He pointed to the fact that the aim of de-institutionalisation is not the closing of the institution itself, adding that closure is only the vehicle to community inclusion and a better quality of life. For this reason, he recommended that the term de-institutionalisation be replaced with "developing community capacity for all people".

Mr. Eidelman highlighted that closing an institution is primarily a political decision and that, to be successful, people with disabilities and their families need to market the agenda of community living. He also pointed to the need to work with the legislators, develop infrastructure, raise awareness and fight disinformation.

Changing paradigms

In the three parallel focus groups, participants pointed to the need for quality monitoring, not just of conditions in institutions, but also community-based settings. They stressed the fact that there is a difference between community-living and community-based services, highlighting that just living in the community does not guarantee inclusion. They also called for better cooperation between different stakeholders and for the evaluation of services to be carried out jointly, by parents, service providers, governments, staff and most importantly, people with disabilities.

There was a general agreement on the need to change the paradigm and relate as people to people, rather than as professionals to patients. In this sense, the importance of peer training of fellow users of services and professionals was highlighted, as well as the need to replicate good practices. The system of direct payments was presented as an important method to give more control and choice to people with disabilities and ultimately improve their quality of life.

Finally, participants stressed the need to strengthen self-advocacy organisations and carry out public education and information activities when a strategy for community living is being promoted.



Ottmar Miles-Paul

Towards a European strategy on de-institutionalisation

The final plenary session started with a presentation by **Wallis Goelen**, the Head of the Disability Unit in the European Commission, who acknowledged the importance of ECCL, as a good follow up to the In-cluded in Society project (which was supported by the European Commission). She pointed to the importance of having a rights-based approach to disability issues and stated that instead of speaking about de-institutionalisation, we need to speak about independent living and community-based, person centered services. By invoking the motto of the European Network of Independent Living “nothing about people with disabilities without people with disabilities”, she also stressed the importance of involving people with disabilities in the shaping of EU disability strategies.



John Evans, Paul Trehin and Wallis Goelen

Ms. Goelen pointed to the broad consensus within the EU on the need to tackle disability issues at all the levels of governance - the national, European, regional and local - particularly in relation to social services, and noted the growing correlation between aging and disability.

Following overview of EU’s approach towards disability issues and community living, **Kent Ericsson** presented his rich experience with the development of community-based alternatives to institutionalisation in Sweden. As one of the biggest obstacles to de-institutionalisation, Mr. Ericsson pointed to the challenge of conquering the “citizen perspective”. Once people with disabilities are recognized as citizens, the closing of an institution becomes a matter of rights.

By stating “Every person must move!”, Mr. Ericsson pointed to the importance of developing community-based alternatives, as the key to the closing of institutions. Asked what has led to the de-institutionalisation in Sweden, he replied - “committed people”.

Looking to the future

The first closing speech of the seminar was delivered by **Jan Jařab**, member of the Cabinet of Commissioner Špidla, who reiterated Commission’s support for the flexible, sensitive and individualized services, and the promotion of community living. Reflecting on the questions *Who are we?*, *Where are we coming from?* and *Where are we going?*, he stated that the promotion of community living “aims at transforming public responsibility and creating new communities, which are essentially modern rather than traditional in their perspective of ethics, human rights and human needs”. Mr. Jařab then pointed to the Open Method of Coordination on long term care, as a way to spread good practices in community living across the European Union.

On behalf of ECCL’s Management Committee, the seminar was closed by **John Evans**, who pointed to the challenging task of ECCL in following up on the conclusions and recommendations of the seminar. He emphasized that ECCL is about creating conditions for independent living and living in the community and called the participants to continue feeding in their ideas to ECCL after the seminar. He stressed the importance of partnerships with other stakeholders and looked ahead at the work that needs to be done, not only in the Central and Eastern Europe, but also other European countries.

The Right to Live in the Community Seminar was organised with the support of Inclusion Europe and the Open Society Mental Health Initiative. Speeches, presentations and a summary of the seminar conclusions are available on www.community-living.info



Speakers in the Focus group on Quality in Service Delivery

Introducing ECCL's Management Committee

In each issue of the newsletter, we will bring you a summary of decisions made by ECCL's Management Committee in the previous period. As this is our first issue, we will also introduce you to the members of the Committee and tell you what role they play in ECCL.

The seven founding organisations of ECCL - **Autism Europe, the Center for Policy Studies of the Central European University, the European Disability Forum, the European Network of Independent Living, Inclusion Europe, Mental Health Europe and the Open Society Mental Health Initiative** - are referred to as ECCL's Management Partners. Each of the organisations has elected one representative and one deputy to serve on ECCL's Management Committee. Members of the Committee meet at least three times per year to make decisions about ECCL's activity plan and budget, ECCL's policies and positions, and questions related to membership in ECCL. They also act as spokespersons and publicly represent ECCL's positions.

Since the end of 2005, ECCL also employs a full time Coordinator, who works closely with the Management Committee, implements the decisions made at the Management Meetings and serves as ECCL's contact person. The Coordinator is currently based at the Center for Policy Studies in Budapest, Hungary.

Since the establishment of ECCL, the Management Committee has met four times - in August and November 2005 and March and June 2006. The most important decisions made during this time were the adoption of ECCL's Mission Statement, Partnership Agreement and Membership Rules. After this work was finalised, ECCL was able to start inviting other organisations, institutions and individuals to join the Coalition as members. The first invitations were sent in February 2006 and since then, the number of members has been continually growing.

A lot of work has gone into the organisation of the Right to Live in the Community Seminar, which took place in Brussels on 17 May 2006. The Management Committee has also been planning the publication of ECCL's Annual Report. The launch date of the report will be announced on ECCL's website in the coming months.

In April, ECCL submitted a response to the Green Paper on Mental Health (Green Paper *Improving the Mental Health of the Population: Towards a strategy on mental health for the European Union*), as a part of the European Commission's consultation process, which will result in a proposal for the EU strategy on mental health. ECCL's response can be downloaded from www.community-living.info.

During the last meeting in June, the Committee has adopted ECCL's Strategic Plan 2006 - 2008, which will be sent to ECCL's members in the coming weeks for comments. While working on the Strategic Plan, the Committee has relied a great deal on the conclusions and recommendations from the Right to Live in the Community Seminar.

Also in June, the number of Management Partners grew to seven, as the European Disability Forum joined the Management Committee as one of the founding organisations.



Representatives of ECCL's Management Committee at the Right to Live in the Community Seminar

Members of ECCL's Management Committee: Paul Trehin (Donata Vivanti) - Autism Europe, Zsuzsanna Gábor (Andrea Krizsan) - CPS, Yannis Vardakastanis (Ingemar Färm) - EDF, John Evans (James Elder-Woodward) - ENIL, Ingrid Körner (François Jan/Geert Freyhoff) - Inclusion Europe, Josée Van Remoortel (John Henderson) - MHE, Camilla Parker (Judith Klein) - the Open Society Mental Health Initiative.

Note: The names of deputies are written in brackets.

ECCL's Calendar of activities

From now until the end of 2006:

- ▶ Strengthening the Coalition by working with the current members and inviting new organisations to join ECCL.
- ▶ Following of developments in de-institutionalisation and the provision of community-based services in Europe.
- ▶ Collection of practices, tools and instruments from organisations providing community-based services.
- ▶ Signature collection campaign to promote the Commitment to Stop the Building of New Institutions.

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

European Year of Equal Opportunities 2007

The European Commission has designated the next year as the European Year of Equal Opportunities. If your organisation is planning any activities on the national level related to community living, please let us know. We can support you in disseminating the information and help you identify potential partners within our network. More information about the Year is available on http://ec.europa.eu/employment_social/equality2007/index_en.htm.

Join ECCL!

ECCL is a cross-disability initiative and our membership is open to all organisations, institutions and individuals committed to the promotion, development or provision of community-based services as an alternative to the institutions.

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

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 on the website. Please send all contributions to Ines Bulić, coordinator@community-living.info

Our 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 • Association with non-economic aims for realising public-useful work for children with mental difficulties 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

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