

# Newsletter

OF THE EUROPEAN COALITION FOR COMMUNITY LIVING

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## Word from the ECCL Coordinator

Dear Readers,

As we approach the International Day of Disabled Persons on 3 December, we bring you the second issue of the ECCL Newsletter. Inside this issue, you will find information about the work of the European Coalition for Community Living since July, as well articles on independent living, the delivery of community-based services for people with disabilities and recent developments in Europe. They were selected and edited by Camilla Parker (Open Society Mental Health Initiative) and John Evans (European Network of Independent Living), who will continue working as editors on future issues of the Newsletter.

The work of ECCL in the past couple of months has been diverse. We have continued strengthening our network by inviting organisations to join ECCL, we have been preparing the **Break Down the Barriers - Community Living for All Campaign** and we have recently adopted a **Position on the Right of Children with Disabilities to Live in the Community**. This position paper will be a part of ECCL Focus Report, which will be launched at the beginning of December.

Recently, ECCL has intervened at the European Commission and the World Bank, protesting against Romania's intentions to build new institutions for people with disabilities, instead of investing into development of community-based services. On a more positive note, we have learnt that Serbia has announced plans to develop a range of community-based services in the country. This will enable many people with disabilities now living in institutions to start a new, better life. The work of the Down's Syndrome Aid Society Serbia, with the support of the Open Society Mental Health Initiative, played a crucial role in bringing about this policy change.

We hope that there will be more good news to report in the future and will continue with our efforts to see that this happens. For this, we need your support and would like to invite you to join ECCL. We also look forward to receiving your comments and contributions to the next issue of our Newsletter.

Ines Bulić, ECCL Coordinator



## The Cornwall Inquiry

By Jim Mansell, *Tizard Centre*

### Introduction: Publication of the report

The publication of a report, in July 2006, of an investigation into the care and treatment of a group of people with intellectual disabilities in the south west of England caused serious and widespread concern. It concluded:

*'...institutional abuse was widespread, preventing people from exercising their rights to independence, choice and inclusion.'*

This report is a stark reminder that it is not enough merely to shift the provision of care from long-term institutions to community-based services. Such changes must be accompanied by a shift in attitudes so that disabled people are respected as equal members of society rather than passive recipients of care. There must also be clear mechanisms for identifying and addressing poor practices before they lead to the unacceptable situation that this report highlighted and condemned. Jim Mansell, a Commissioner for Social Care Inspection, gives further details of this investigation in the article that follows.

# ECCL

European Coalition  
for Community Living

c/o Inclusion Europe  
29 Chaussée d'Ixelles 393/32  
B-1050 Brussels, Belgium  
T: + 36 1 235 6185  
F: + 36 1 235 6170  
coordinator@community-  
living.info  
www.community-living.info

The report has demonstrated a failure of monitoring... The Healthcare Commission's inspection régime relied on statistics and performance indicators and so missed the quality of care.

## A failure of monitoring

The government inspectorates of health and social care in England have heavily criticised services for people with intellectual disabilities in Cornwall. They found physical, emotional and environmental abuse of some people over many years, with widespread poor practice, preventing people from exercising their rights to independence, choice and inclusion. They instigated special investigations to protect individuals in 40 cases and have launched an investigation into possible fraud relating to people's monies.

The problems were discovered both in small institutions which were supposed to provide assessment and treatment for people with intellectual disabilities who presented challenging behaviour, and in homes in the community provided by the same organisation. The organisation was a hospital trust which had set up the pattern of services when closing the last large institution over ten years ago.

With one exception, the assessment and treatment centres did not accord with best practice. They primarily provided long term accommodation. The environments in which services are provided were unacceptable. In two of the three centres, no-one had an assessment and treatment plan. In the third centre, these plans were not based on a 'person-centred' approach. There was evidence of excessive use of medication and routine use of physical restraint. The community services were supposed to be people's own homes with visiting staff support. In fact, people were moved between houses, individual money was spent as staff decided and the quality of support was poor.

The inquiry found systemic flaws in local procedures. Complaints were investigated by the managers responsible for the practices complained about, complaints had to be made twice because of the lack of action taken after the first referral and there was a failure to recognise that particular instances of abuse required the trust to review its practices to ensure that such abuse was not occurring elsewhere in its services.

The local social services department, as leading agency for intellectual disability, failed to carry out assessments of the appropriateness of care for people receiving these services and failed to investigate abuse properly.

The report has demonstrated a failure of monitoring. It shows that the health service trust responsible for intellectual disability services was not paying enough attention to them and the social services department regarded them as the trust's responsibility. The Healthcare Commission's inspection régime relied on statistics and performance indicators and so missed the quality of care. Many of the community services were actually operating illegally as unregistered care homes and so were not inspected by the Commission for Social Care Inspection.

The inquiry has sent shockwaves through Government. A national survey of all services provided by health bodies is being carried out by the inspectorates. Every health trust in England has been told it must cooperate and it must ensure that it has expertise in intellectual disability. Every social services department has been told that it cannot ignore people in health service care, and that it has a legal responsibility to assess and meet their needs. In Cornwall, a special team has been brought in to reorganise services, the trust has a new chief executive and one of the hospital units is being closed. As yet, though, no-one has been prosecuted for any wrong-doing.

# From the Rolling Quads to Direct Payments

By Jim Elder-Woodward, *ENIL*

This article considers the concept of 'independent living', what it really means and why it is of fundamental importance to achieving equal rights for all.

## What is 'independent living'?

Independent Living (IL) is a philosophy, which underpins the work of disabled people, like me, in our campaign for self - determination, equal opportunities and full participation in society as equal citizens. The philosophy has come from our own experience of discrimination and being subjected to segregated substandard services over which, historically, we have had little or no choice and control.

IL does not mean that we want to do everything by ourselves and do not need anybody's help. Neither does it mean we should be left to make decisions and choices in splendid isolation. Rather, independent living means that we have the support, advice and guidance to make the same choices and take control in our lives that non-disabled people take for granted.

We want to grow up in our families, go to the local school, use the same bus as our fellow traveller, work in jobs that are in line with our education and abilities and start families of our own.



Jim Elder-Woodward

## The development of the Independent Living movement

The Independent Living movement began in California in the mid - 1960's. Ed Roberts, a university student with severe poliomyelitis who was campaigning for the human rights of Puerto Ricans suddenly realised that, as a disabled person, his own human rights were being denied.

Along with a few other disabled students, he formed a new radical group called the "Rolling Quads". Together, they persuaded the state to give them money to pay for support and accommodation, which would allow them to participate in the full life of the university.

Later, this money was extended to disabled people outside the university and Roberts opened the first Centre for Independent Living. The Centre provided support to disabled people and assisted them in managing their money and the people they employed as helpers, whom they called "personal assistants". Now Ed's idea is a worldwide phenomenon.

## Independent Living and Community Living

In European countries independent living is also referred to as 'community living' but both concepts have the same goals - these are set out in Box 1 (page 4).

In the United Kingdom, the major agency in the advocacy of community living for people with complex multiple physical and learning difficulties is "Values into Action" - VIA.

Their research worker, Andrew Holman<sup>1</sup>, writes:

*"All people with learning difficulties have preferences, no matter what their level of disability. Questions about an individual's capacity to consent to a course of action should not be confused with their capacity to make choices about their life, who supports them, the people they like to be with and the things they like to do."*

*"Many people with learning difficulties have shown that, given the correct support, they can exercise control over their service, enabling them to achieve better quality of support and life. VIA argues that the user's consequent satisfaction itself constitutes consent to the method used to achieve it."*

<sup>1</sup> Holman A (1999) "Funding Freedom 2000: People with Learning Difficulties Using Direct Payments", published by Values Into Action

### Four principles of IL:

- That all human life is of equal value;
- That anyone, whatever their impairment, is capable of making a choice;
- That people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives;
- That disabled people have the right to participate fully in society.

### Box 1: Goals of Independent and Community Living

- People live in their own homes, not institutions;
- People choose where to live; they are not told where they must live;
- All means all; no-one is excluded from living independently because they are considered to need too much support;
- People take up and maintain valued roles as tenants and community members rather than clients or residents;
- The provision of housing and support is separate, i.e. provided by different agencies so that people may be able to take their support with them when they move from place to place;
- Support is organised around the person, rather than the person being made to fit in with whatever support is available;
- People, their families and the professionals involved take more risks because participating actively in the 'normal' life of the community is, ipso facto, riskier than living in an institution;
- There is a shift in the locus of control from staff to service user; staff people see themselves and are seen as standing beside people who use services, not standing over them;
- Personal relationships and informal supports are highly valued. Care involves caring about someone;
- There is a change in the relationship between staff and the community. Staff are working in the community, building and maintaining connections not just with the person, but assisting that person in making connections with other members of the community, as well as general support systems within the community at large, e.g. local commercial and public services as well as shops, neighbours etc.

### Supporting Independent Living

In the United Kingdom legislation has been introduced which supports independent living, via 'direct payments'. These are cash payments that are made to disabled people, instead of providing them with the social care services that they have been assessed as needing. This allows disabled people to make their own arrangements for getting the support that they need, for example, employing a personal assistant. The legislation recognises that people may require assistance in managing their direct payments and the support systems they want to establish.

This assistance may not be needed by some people, or like myself, they may wish to employ an accountant to run their pay-roll system, just like any other small scale employer.

Others may like to have the day-to-day support of an Independent Living Adviser, employed by a user-controlled Centre for Independent Living. These advisers help disabled people assess their own needs, recruit and manage staff, and generally encourage people to use their resources productively, so that they can engage with their interests and community at large.

**Advocacy services** - where the person is supported on a one to one basis by a trained and skilled individual to make and execute a decision.

**Circles of support** - here, networks of supporters and friends who know the person well can make decisions to which the person freely consents.

**User controlled independent living trusts** - which is very much like a circle of friends but with a legal structure that sets up the necessary framework of decision-making around the individual. Here, someone is legally authorised to make decisions on a person's behalf regarding how the money is used and what quality of support is provided. However, like circles of support a trust can only be set up at the bequest of the person and with their involvement in the actual decision-making being maximised as much as possible. In the case of people with mental health issues, independent living trusts may only be temporary and cover those periods when the person lacks capacity to make decisions about their finances. Once that time has lapsed, the trust ceases to be in effect.

**Service brokerage** - where a skilled supporter enables someone to look at what they want and need. They may offer advocacy in the assessment process and support in implementing assistance packages. A brokerage agency can act as the named employer of support for an individual if required.

In all of these options the severely multiply-impaired person, or the person temporarily incapacitated by a mental health problem, has, if they wish it, or require it, constant contact with others more able to deal with the intricacies of decision-making and interpersonal relationships, both of which are necessary for good personnel management. Nevertheless, these 'options' show that independent or community living do provide opportunities for independence for all.

### Independent Living: a crucial factor for an inclusive society

It is often said that placing someone "in care" is good for them and that they will be protected and looked after. It's like a millionaire locking up his prized art collection in a vault - safe and sound.

Well, I'm no oil painting, but it is true that as humans we all have intrinsic or potential value. But people have, or should have, more than potential value. People's full value is displayed in the roles they play within the family, within their immediate community and society at large.

Disabled people's full value - as individuals, as family members, as socio-economic participants and as citizens can, however, only be achieved if we operate within a socio-political system that is inclusive and supportive.

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So, disabled people must be enabled, by an inclusive and supportive society to exhibit our full value. We must exhibit this total value by having the support and resources to exercise our own choice and control over our lives and support systems. We need such resources and support to exercise our rights and responsibilities as equal members of our family, community and society at large.

As part of this process, the concept of “co-production” of support services has been advocated by the British think-tank Demos. There are three facets to co-production:

1. Recognition of the value of the contribution disabled people can make from their experience to a problem-solving or policy issue, or even the development and delivery of a service;
2. Putting disabled people in the driving seat of any service development or service delivery;
3. Lastly, providing non-disabled people with the role of a supportive ally.

Historically, there have been two camps in the development and delivery of services - the “for” variety of organisations, where services have been designed and delivered by non-disabled for disabled people, and the “of” organisations, where services have been designed by and for disabled people.

A co-produced service model brings together these approaches but gives the lead role to disabled people. The advantage of co-produced service organisations is that, with a common objective and combined resources, all working together, there should be a stronger force to tackle the barriers of disablism and build a future of equality and interdependence.

## Conclusion

Independence to participate as an equal citizen is a right we all share, but none of us can exercise that right without the co-production of an inclusive and supportive society

## The European Network of Independent Living

By John Evans, *ENIL*

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The European Network of Independent Living (ENIL) is an organisation mainly consisting of people who are personal assistant users. This means an organisation that represents the interests of disabled people who require assistance and support in their everyday lives. We promote Independent Living and the human rights approach for disabled people, and strongly believe that disabled people should have control over their lives, choices, opportunities and be empowered.

ENIL was founded in 1989 when over 80 disabled people, the majority of whom were personal assistant users from 15 European countries converged on the European Parliament demanding the right to Independent Living and personal assistance services. We felt it was time that disabled people affirmed their presence at the European Parliament in order to make European MEPs more aware of the importance of Independent Living issues.

### Why ECCL is important to ENIL

ENIL believes that all disabled people should have the choice to live in their own home at their desired location and not to live at an institution through the lack of choice. In many European countries Independent Living was started to enable disabled people to move out of institutions. This is one of it’s primary aims. Independent Living is about creating community based alternatives and solutions, in order to achieve a fully inclusive society.

ENIL has been pioneering and developing these alternatives and opportunities since its formation. Some of its original founders have been promoting Independent Living initiatives for over 25 years. As a result of this long and established practice we feel we have much to contribute and offer in the work of ECCL in working towards community based policies at a European level. We are fully aware of the challenges facing us, but strongly believe that working together with other key European disability organisations and stakeholders, a European Society affirming the rights of disabled people and freeing disabled people from institutions is achievable in the future.



## Break Down the Barriers

### C a m p a i g n

## Community Living for All

**Break Down the Barriers Campaign** calls on governments, service providers and funding organisations to shift the funds from long stay residential institutions to quality community-based services for people with disabilities and to stop new admissions into long stay institutions by providing services in the community. Moreover, it gives disability organisations

and the public a chance to support the right of all disabled people to live included in society.

### Why this campaign now?

Despite increased international recognition of the right of all disabled people to community inclusion, now also proclaimed in Article 19 of the Draft UN Disability Convention, long-stay residential institutions for people with disabilities are still a reality in many European countries. Quality, comprehensive community-based services for disabled people are often very scarce, if they exist at all.

With governments lacking policies and action plans that would promote community inclusion and the development of community support systems, funding is often directed at the building of new long stay residential institutions, rather than the development of community-based alternatives. This practice perpetuates the long term exclusion and segregation of people with disabilities from the society.

To break down the barriers between people with disabilities and the rest of society, it is not enough to make the physical environment accessible for people with disabilities. All disabled people must be able to choose and decide for themselves where, how and with whom they want to live. They must have access to quality, comprehensive services in their community, based on their rights and requirements, developed in close cooperation with organisations of disabled people.

For this, we need all the stakeholders to take action. Governments, service providers, funding organisations, disability organisations, the European Union, the Council of Europe and others must commit to developing or supporting community-based alternatives to long stay residential institutions for people with disabilities.

On 3 December, the International Day of People with Disabilities, the European Coalition for Community Living is launching the Break Down the Barriers Campaign - *Community Living for All*. This campaign is part of ECCL's overall effort to promote the development and provision of quality community-based services for people with disabilities as an alternative to long stay residential institutions.

### Breaking Barriers

As from December 2006, the European Coalition for Community Living will:

- Collect signatures from all the relevant stakeholders at the local, national and regional level.
- Raise awareness about the situation in long stay institutions for people with disabilities and the need to develop quality community-based services.
- Raise support for the right of all disabled people to live included in society.
- Involve its members and other interested organisations and individuals in campaign activities.
- Link up with Tear Down the Walls Campaign with Germany and other de-institutionalisation initiatives.

### What you can do...

- Sign the commitment to actively develop quality, comprehensive community-based services and stop financing the establishment of new long stay institutions for any group of disabled people.
- Get involved by organising campaign activities in your community or your country.
- Distribute campaign leaflets in your country.
- Join the European Coalition for Community Living.

Updates about the launch and progress of Break Down the Barriers - *Community Living for All* Campaign will be available on [www.community-living.info](http://www.community-living.info). To get involved in the campaign, please contact ECCL Coordinator at [coordinator@community-living.info](mailto:coordinator@community-living.info).

# Update from ECCL's Management Committee

As a regular feature in ECCL's Newsletter, this article brings you the main decisions made by ECCL's Management Committee since the first issue in July 2006.

## ECCL's Strategic and Operational Plans

As reported in the July issue, the Management Committee has adopted a Strategic Plan for 2006 - 2008. The document has now been distributed to ECCL's membership and any feedback received will be considered during the first revision of the strategy in 2007. At the meeting in October, the Committee also formally adopted ECCL's Operational Plan 2006 - 2007.

ECCL's Operational Plan outlines the network's priorities in the upcoming year. These include the following activities:

- Strengthening the network by increasing the number of members;
- Implementation of Break Down the Barriers - *Community Living for All* signature collection campaign (see page 6 for more information);
- Starting the collection of country-by-country information;
- Collection of good practices in the provision of community-based services;
- Holding the annual seminar in 2007, as a follow up to the Right to Live in the Community seminar in May 2006.

In all of these activities, the Management Committee would welcome and encourage active involvement and support of membership to ensure their successful implementation.

## Cooperation with the Disability Unit

In October, representatives of the Management Committee met with the Head of the Disability Unit at the European Commission, Ms Wallis Goelen, and discussed areas of cooperation between ECCL and the Disability Unit. For example, it was agreed that ECCL will forward to the Commission information about good practices in relation to the development of community based services that exist in EU Member States, accession and candidate countries. Ms Goelen acknowledged the importance of ECCL's work and has expressed interest in continuing to participate in network's activities, such as next year's seminar.

## ECCL Seminar 2007

ECCL's first seminar on The Right to Live in the Community was held in Brussels in May 2006. In response to the seminar conclusions and the participants' feedback, the Management Committee is planning a follow-up seminar on **20 - 21 April 2007**. The seminar is to be held in Zagreb, Croatia and will be co-hosted by the Association for Promoting Inclusion. It will focus on the involvement of users of services in their planning, design and delivery by pointing to the existing challenges and highlighting examples of good practice. The draft program of the 2007 seminar will be available by the end of the year.

## Upcoming publications

In preparation for the International Day of People with Disabilities on 3 December, the Management Committee has adopted a Position Paper on the Right of Disabled Children to Live in the Community. The Position Paper will be a part of ECCL's Focus Report on the Right of Children with Disabilities to Live in the Community, and will be launched at the European Commission conference in Brussels on 4 - 5 December. The report will be distributed widely and will be available upon request from ECCL's Coordinator.

**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.*

## Newsflash: Last Institution in New Zealand Closed



IHC, a New Zealand disability organisation, announced on 13 November the closure of Kimberley Center, the last institution for people with intellectual disabilities in the country.

*"This will be the first New Zealand Christmas that no one will be in an institution just because they have an intellectual disability,"* said the IHC chief executive Ralph Jones.

*"Today, we do everything we can to ensure families are strong and are supported to care for and encourage their child with an intellectual disability in their home, within their networks and in our community."*

Since IHC was established in 1949, it has lobbied for institutions to close and for people with disabilities to live supported in the community. Self-advocates also played a great role in bringing about the closure of institutions. Their strong voice gave the New Zealand government the needed push to make the final decision.

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.

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

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

### New 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 • ADO Icarus vzw, Belgium • The Association for Helping Persons with Developmental Disabilities Gradačac - "Kutak radosti", Bosnia and Herzegovina

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