

# Newsletter

OF THE EUROPEAN COALITION FOR COMMUNITY LIVING

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## Word from the Editorial Team

Dear Readers,

We are pleased to issue this Newsletter in the week of the International Human Rights Day. Just last week, we celebrated the International Day of People with Disabilities and had the opportunity to attend a European conference organised by the European Commission and the European Disability Forum (EDF) in Brussels. The topic of this year's event was the active involvement of disabled people in EU's internal market. There was a general agreement among Europe's decision makers - represented by the European Commission, Parliament and the Portuguese Presidency - that disabled people must be able to work, study and travel across the Member States, on an equal footing with other citizens. At the same time, having listened to experiences that many disabled people face in realising these very rights, it was clear that there is a long way to go before Europe's freedoms become a reality for all. In her closing speech, the Vice President of EDF, Donata Vivanti, made an important point by calling for the debate on EU's internal market to include hundreds of thousands of disabled people still living in long-stay institutions. ECCL will continue in our work to highlight this issue and press for action to promote the development of community based services and end the unjustified institutionalisation of disabled people.

This issue provides an update on some recent developments that are of direct relevance to the debate on quality community-based services for disabled people. Our first article looks at the work of the UK's independent living movement, more specifically the drafting of the Independent Living Bill. This issue also includes a summary of a new report on community-based services in Europe '**Deinstitutionalisation and community living - outcomes and costs**'. This report, which was published in November 2007, offers strategies on how to manage the process of transition from institutional care to new, inclusive services for people with disabilities in the community.

Our colleagues from New Zealand have contributed an article describing the process of de-institutionalisation in their country, which resulted in the closing of the last institution for people with intellectual disabilities last year.

Finally, we provide you with an overview of the activities that took place during ENIL's Freedom Drive in Strasbourg, in September 2007. This biennial event brought together disabled activists from across Europe, who presented their demands to the European Parliament and representatives of the Council of Europe. ECCL supported the event and spoke at a session of the European Parliament Disability Intergroup. ECCL's speech and a summary of the discussion on independent living in the Parliament are also included in this issue.

The New Year is approaching fast and in ECCL we are revising our strategy and finalising our new activity plan. Some of our aims for 2008 are to strengthen the network by attracting more members and to place a stronger focus on the collection and promotion of good practices in community living. We hope you will continue to follow our work and, if you are not already a member, please do join ECCL. If you have any ideas for articles for future newsletters, or information that you would like to share with ECCL members, please let us know. You will find all the details on how to support ECCL, together with the updates about our work, on

[www.community-living.info](http://www.community-living.info).

*We wish you all the best for the holiday season and look forward to hearing from you!*

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

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## Independent Living in Britain: An adult care service crisis and approaches to reform

By Neil Coyle, *NCIL*

### General trend in Great Britain

The situation of disabled people in Great Britain may look rosy to some observers. Britain has witnessed a trend of declining institutionalisation, with about 267,000 disabled people now funded by their Local Authority in residential care (1). This decline matches Government rhetoric on seeking greater personalisation, choice and control for disabled people; but the trend has not been uniform for everyone.

People with learning disabilities and/or mental health problems are still over-represented in institutions. In response to this situation, the Government recently announced that 8,000 people with learning disabilities will specifically be supported to move out of institutions and to live more independently, which is very welcome.

The overall trend of de-institutionalisation has occurred alongside the delivery of stronger civil rights - in accessing 'goods and services' (shops and leisure for example) and greater participation for disabled people in employment than ever before (2).

However, despite many positive developments, one issue remains of very significant concern for disabled people and their families across Britain: the crisis in adult social care services. Disabled people, the Government and Local Authorities (who are responsible for delivering care services) are increasingly asking difficult questions such as: who should be able to access support, what services should be available, how should they be managed, and how should they be paid for. This is a result of rising demand and expectations from services and resource constrictions.

The National Centre for Independent Living (NCIL) is run and controlled by disabled people, with a membership of disability organisations and individuals. NCIL promotes independent living locally through providing support and information to empower disabled people to have choice and control. NCIL campaigns nationally to influence Government policy on independent living.

The concern that adult social care services are failing to provide adequate support for disabled people and their families is creeping up the political agenda. The Government has now finally opened discussions with stakeholders on developing plans to reform the adult social care system.

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### A debate on support services: the Independent Living Bill, 'Disability Agenda' and Social Care Reform

The Government entering debate on what reform of adult care services should achieve follows the opening of a more general discussion some time ago by other stakeholders. NCIL has been engaged for some time, attempting to make the case for a more positive, empowering vision of social care with reform and investment of services to support equality and human rights aims.

The lifelong disability equality activist Lord Ashley of Stoke has already successfully steered the Independent Living Bill through the House of Lords. The Bill is a private piece of legislation, which the Government prevented being debated in the House of Commons. Lord Ashley's Bill (3) would dramatically change the care and support system.

A further contribution to the discussion on social care reform came from the Disability Rights Commission's (DRC) 'Disability Agenda' (4), a set of public policy positions aimed at the Government and other policy-makers. The main thrust of the Disability Agenda was the need to mainstream disability equality in public policy-making in order for disabled people's citizenship to be seen as integral to creating sustainable policies and not as needing a separate, more costly and 'special' approach.

The Disability Agenda maintained that Britain's core public policy goals - economic prosperity, full employment, an end to child poverty, better health, less crime - will fail unless the experiences of disabled people are understood and addressed as part of mainstream policy and legislation. One of the Disability Agenda priority documents, entitled 'Developing a social care system fit for the future' (5), made a significant contribution to the debate on adult social care reform.

The publication of this document took place against a backdrop of disabled people's equality and human rights being undermined on a daily basis through a failure to provide care services that protect people's independence, dignity and privacy. Local Authorities have failed to acknowledge that cutting services or minimising access undermines disabled people's human rights or ability to participate in, or contribute to, society.

### **A smaller future for adult services?**

In October, the Government published its spending plans for adult care services for the next three years, announcing a 1% rise in expenditure available to Local Authorities for adult services. This figure fails to account for Britain's changing demographics; like many countries across Europe, the numbers of older and disabled people are increasing in Britain - providing a corresponding rise in support needs (6).

The 1% increase fails to account for inflation which has led to significant rises in the costs of services. Traditional services have seen the highest cost increases, with residential care prices for young people with learning disabilities across England and Wales rising 30-35% between 2002 and 2005.

According to the Association of Directors of Adult Social Services (ADASS) (7), a real terms increase in funding of around 20% would be needed in order to meet all local needs. The Government's 1% increase will mean a withdrawal of further services and an even heavier reliance on informal support from disabled people's relatives and friends (acting as informal carers).

Disabled people and carers therefore expect to experience further disadvantage and undermined life chances over the next three years as a direct result of the Government's low investment. This will have a massive impact on the equality and human rights of disabled people and their families. It is also likely to incur some costs to the overall public purse.

### **The full 'care equation' and impact of inadequate services**

NCIL does not believe that the Government fully values adult support services. It mostly sees expenditure as a 'loss' with little financial or social return, thus ignoring the potential of services to deliver returns, and to help avoid losses or expenditure elsewhere. The knock-on effects of failing to provide support to disabled people and their families are dramatic:

- ◆ Disabled people are not supported to maintain/seek work, become reliant on benefits and are more likely to live in poverty and less likely to save a pension. The state must then provide benefits and pensions.
- ◆ Carers have to leave work to provide support to disabled people (8). Carers not working means higher benefit dependency, inability to pension-build and an increased likelihood of poverty.
- ◆ Disabled people and carers develop more resource-intensive additional care and health needs as a result of no or minimal professional support. Failing to meet low-level needs leads to avoidable health and social care costs at a later date.
- ◆ Young carers have educational and other life chances undermined, which risks perpetuating intergenerational poverty and disadvantage. There are 175,000 young carers in the UK, including 5,500 children 5-7 years of age.

NCIL believes that, alongside the issues outlined above, if social care is reformed and invested in to secure Independent Living it would also assist the Government in meeting its objectives in several areas, where the connectivity with social care services is not always clear. These include tackling the 'pension time bomb' (9), eliminating poverty, promoting gender equality, strengthening the economy and reform of the National Health Service (10).

### **Independent Living for all?**

A lack of appropriate support services means carers are increasingly relied upon; carers are predominantly women. Providing substantial personal support means limited work opportunities for women and an inability to save for a pension, often resulting in poverty and ill health (11).

The impact of the current service crisis on so many people's lives has meant that disabled people, older people, carers and gender equality organisations have united in support of the Independent Living Bill. For too long, these groups have been pitted against each other for minimal state resources, which prevented agreement on services that meet everyone's needs.

The Disability Agenda maintained that Britain's core public policy goals - economic prosperity, full employment, an end to child poverty, better health, less crime - will fail unless the experiences of disabled people are understood and addressed as part of mainstream policy and legislation.

'Our Lives, Our Choices' is a coalition of organisations supporting the Independent Living Bill and includes groups affected by restricted support services. There is now greater agreement than ever before amongst disabled people, older people and carers' organisations in particular that all groups could benefit from the principles of independent living. Increasing choice and control maximises all citizens' independence and opportunities.

## Next steps

NCIL believes that independent living provides the sustainable direction for the Government in reforming adult social care services in Britain, especially when the full 'care equation' is estimated and when the full equality and human rights picture is examined. An independent living approach would deliver for the millions of families currently let down by existing services. It would better meet the needs of older and disabled people, their carers and children, the wider economy and Government policy. To this end, NCIL will be working closely with the Government as its plans are developed.

- 1 CSCI, State of Social Care, 2007. This represents a decline from 2004 of about 11,000.
- 2 People with mental health problems also experience higher incidence of unemployment however, representing 40% (and the single largest group) of UK Incapacity Benefit claimants.
- 3 The full title is the Disabled Persons (Independent Living) Bill. NCIL supported the DRC in drafting the Bill for Lord Ashley.
- 4 The Disability Agenda is available at: <http://www.equalityhumanrights.com/Documents/Disability/General%20advice%20and%20information/Disability%20agenda/Disability%20agenda%20Creating%20an%20alternative%20future.pdf>
- 5 Available at: [http://drc.uat.rroom.net/DisabilityDebate/docs/Developing\\_a\\_social\\_care\\_system\\_fit\\_for\\_the\\_future.doc](http://drc.uat.rroom.net/DisabilityDebate/docs/Developing_a_social_care_system_fit_for_the_future.doc)
- 6 A King's Fund report on the future of care for older people in England estimated that the proportion of the population aged 85 and over is set to increase by two-thirds in the next 20 years. Carers UK estimate that the growth in older people with associated needs will mean a fifty per cent increase in the number of informal carers to 9 million. There are 6 million carers currently according to Census data, 2001.
- 7 ADASS is an association which represents every Local Authority's Director of Adult Social Services.
- 8 One study suggested 2.2 million carers have given up full-time employment since 2004.
- 9 This refers to more people drawing pensions and a lower proportion of the population of working age.
- 10 Reform of the NHS towards early intervention, low-level support and better management of health conditions to avoid crisis-only interventions.
- 11 There are 6 million carers in the UK. The disadvantage which female carers experience led Jenny Watson, Chair of the Equal Opportunities Commission (EOC), to describe independent living as a gender equality issue at the launch of Our Lives, Our Choices. The EOC shut at the end of September 2007. Its remit is now represented by the Equality and Human Rights Commission (EHRC).

*Neil Coyle is Head of Policy at the National Centre for Independent Living and formerly Policy Manager for Health and Independent Living at the Disability Rights Commission.*

## Newsflash

On 10 December, the UK's Health Secretary Alan Johnson announced that an extra £520 million of ring fenced funding will be used to transform the social care system over the next three years through the introduction of Personal Care budgets. The agreement, entitled "Putting People First" was signed by the central government, local government, the leadership of adult social care and the National Health Service (NHS). The key elements of the reform are substantially increasing the number of people who receive personal budgets so they can choose the support services they want for themselves or a family member, and increasing the number of people who use direct payments. Another key element is rewarding high quality care homes, home care and day services and making sure that those that do not respect people's dignity are no longer used by local councils and the NHS. Furthermore, the reform aims to make initiatives such as first-stop shops (where people can access advice and advocacy about community services) commonplace, so that they are available to everyone, including people who do not receive support from social services. Finally, investments will be made into support for older people to prevent their isolation and ensure better health, and collaboration between the NHS and local government will be improved so that people receive more coordinated and efficient support in the community.

# A Blueprint for Community Living



A new report aims to help European governments modernise services for disabled people by replacing institutional care with community-based services that are focused on improving disabled people's quality of life and promoting their equal participation in society.

The report, entitled 'Deinstitutionalisation and Community Living - Outcomes and Costs'

was launched at a recent conference in Prague. It is the result of a project funded by the European Commission and implemented by a European consortium led by the Tizard Centre at the University of Kent, the Personal Social Services Research Unit at the University of Kent and the London School of Economics. The Consortium included experts from Universities in Germany, Belgium, Spain and the Czech Republic, supported by the main European non-governmental organisations and professional networks and associations.

The aim of the project was to collect available information on the number of disabled people living in residential institutions in 28 European countries, and to provide Member States with recommendations and strategies for replacing institutions with community-based services.

According to the report, in Europe, well over 1 million disabled people still live in some form of institutional care. The report confirms that institutional care is often of an unacceptably poor quality and represents a serious breach of internationally accepted human rights standards. Community-based services, when properly established and managed, deliver better outcomes in terms of quality of life and ensure that disabled people can live as full citizens.

## The report concludes that

- ◆ **Current information systems are inadequate to help Member States plan and monitor the transformation of their disability services from institutional care to services in the community.** It points out that Article 31 of the UN Convention on the Rights of Persons with Disabilities requires States to collect data to enable them to give effect to the Convention and to disseminate these statistics. It says that it is clear that the countries taking part in this study have some way to go to meet this requirement. At present, comprehensive information is not available for all types of residential services provided nor for all the client groups involved, nor is there clarity about the definition of kinds and characteristics of services provided or people served. Where such information exists, it is not always collated at national level. The report recommends the creation of a harmonised data set at European level that will enable the review of Member States' progress in the closure of institutions and of the growth of independent living and services in the community.
- ◆ **There is a need for national and regional governments to take a strong leadership role in this transformation, working closely with disabled people and their families.** Study of transformation of services in other countries shows clearly that this cannot be left to residential institutions or to local authorities acting on their own because of the range of new services needed, the need to transform services for the whole population and the complexities of funding and administrative arrangements. The report recommends that Member States take action to:
  - ◇ strengthen the vision of new possibilities in the community (through legislation, policy, a stronger voice for disabled people and their advocates and learning from good practice on other countries);
  - ◇ sustain public dissatisfaction with current arrangements (through independent inspection and scrutiny and publication of comparative studies of institutions and community services);
  - ◇ create some practical demonstrations of how things can be better (by creating innovative services, especially for people with severe disabilities); and
  - ◇ reduce resistance to change by managing incentives for the different actors in the process (through removing obstacles to change, creating new funding opportunities and making funding contingent on quality).

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- ◆ *Services in the community need not be more expensive than institutional care once proper account has been taken of the needs of residents and the quality of care.* The report points out that the current lower cost of many institutions is achieved because they offer poor quality care. Member States will have to improve quality and therefore costs will rise over time. The choice facing Member States is not therefore between inexpensive institutions and more expensive community services but between institutions that cost as much as community services to run but achieve poorer results, or services in the community that cost the same but do a better job.

The report was enthusiastically received at the launch conference, attended by people from all over Europe as well as visitors from as far afield as Israel, the United Arab Emirates and Australia. The European Commission has welcomed the report and is considering what its next steps should be to promote the transformation of services for disabled people.

Professor Jim Mansell, who led the project, said *"Everyone has seen pictures of the appalling conditions in institutions for disabled people in some European countries. By drawing together the available research we have tried to provide governments with a framework they can use to replace these institutions with good services in the community. There has been huge demand for the report - another 1000 copies are being printed already - and a great deal of interest in how to move forward."*

*The three-volume report, consisting of the Executive Summary, the Main Report and the Country Reports, can be downloaded from the Tizard Centre website, at [www.kent.ac.uk/tizard/research/DECL\\_network/Project\\_reports.html](http://www.kent.ac.uk/tizard/research/DECL_network/Project_reports.html).*

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# An End to Institutions for New Zealand

By IHC New Zealand Incorporated

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## Introduction

In November 2006, New Zealand celebrated the end of an era, the end of institutionalisation, with the closing of its last large institution for people with intellectual disabilities - the Kimberley Centre, Levin. Spurred by national and international advocacy from the growing disabled people's rights movement and the 1975 UN Declaration on the Rights of Disabled Persons, successive governments progressed with deinstitutionalisation, relocating thousands of people with intellectual disability to community residential settings in various locations throughout New Zealand. Today's New Zealand offers a very different landscape for children and adults with intellectual disabilities and their families.

## Background

At the height of institutionalisation, in 1964, over 10,000 people with intellectual disabilities and/or mental health issues were housed in 13 institutions across New Zealand. Most were located on the outskirts of towns reinforcing the "out of sight out of mind" philosophy of the time.

At the same time that institutions were viewed as the favoured option, there were also parents who did not support the status quo and did not take the medical profession's advice to put their child in the closest institution. It was from this group of parents, parents wanting education and support for their children that IHC (1) formed in 1949 and went on to develop nationwide services for adults and children with intellectual disabilities (Millen, 1999).

Before the era of deinstitutionalisation, IHC was the only community based residential provider. By 2001, many providers both large and small had developed from the closure of the institutions, with IHC still being the largest and the only nationwide service.

## Indecisions

What to do about the Kimberley Centre, New Zealand's last large institution had been the subject of discussion over many years. By 2001, there had been 12 years of uncertainty for the people residing there and their families, with many people having left over the years and the entry of new residents being restricted. Many New Zealanders, particularly family members, expressed grave doubts about the suitability of community living for the group of 400 people remaining in the institution.

Two specific consultations had already occurred, firstly in 1994 and then again in 1996. The 1994 consultation, which involved the provider, Midcentral Health, the funder, the Ministry of Health, and representation from the Kimberley Parents and Friends Association (KPFA) concluded with an agreement about an approach to the deinstitutionalisation process. A protocol was drafted which formalised the principles and process for deinstitutionalisation (Ministry of Health, 2001). However, by 1996, no progress had occurred. Thus a further round of consultation was held following the release of a report, *Options for the Future*. The report outlined the principles underlying deinstitutionalisation, the process of change and the preferred location of the residents. Nationally and internationally recognised principles of deinstitutionalisation were referred to: normalisation, least restrictive environment, the right to live in the community, inclusion, the right to choose, and support and security (Ministry of Health, 2001).

In 1999, under a Labour led government, New Zealand had its first ever Minister for Disability Issues and it was under her direction that further planning began about the future of the Kimberley Centre. The planning had three stages:

**Stage 1:** new needs assessment (a process of identifying support needs and allocating appropriate services) and consultation with families;

**Stage 2:** the development of an options paper (status quo, partial deinstitutionalisation or deinstitutionalisation);

**Stage 3:** the development of a plan for each of the three identified possibilities (Ministry of Health, 2001).

As part of the first two stages, a Project Working Group was formed with members from KPFA, Maori and representation of major stakeholders, including the Director of IHC Advocacy and the wider disability sector. Their role was to develop an options paper and give a provisional recommendation to the Minister. The options

<sup>1</sup> IHC New Zealand Incorporated was first established in 1949 and has had several name changes over the last 50 years. 1949-62, Intellectually Handicapped Children's Parents' Association (IHCPA), 1962-75, Intellectually Handicapped Children's Society Incorporated, 1975-94, NZ Society for the Intellectually Handicapped Incorporated and from 1975, IHC New Zealand Incorporated, (Millen, 1999).



Ray Rose (left) and Ross Clarke, who used to live at Kimberley Centre, cut the cake at a party to celebrate the closure of Kimberley. The cake said "Kimberley has closed". © IHC

paper, including the provisional recommendation, was to be used as the basis of discussions with family and legal guardians of the residents (Ministry of Health, 2001).

Consultation with family, *whanau* (2) and legal guardians began and an independent analysis was completed in November 2000. The analysis outlined the results of 14 meetings (attended by 173 people) and 152 written submissions (Ministry of Health, 2001). While views of the meetings and submissions by family, *whanau* and legal guardians expressed a desire for the status quo, there were also expressions of cautious interest for deinstitutionalisation, with issues of safety and security identified as the foremost concerns. Many felt that a range of community settings should be offered, including a cluster housing model which had been an option for two of the previous deinstitutionalisation projects.

Additionally, the project working group identified that it would be beneficial to ask people with intellectual disabilities who had previously experienced deinstitutionalisation what they thought. History was made when the government working group commissioned this consultation, as it was the first time in any deinstitutionalisation process that the people themselves were asked to give their views. IHC undertook this work from within its Advocacy service and the report of the consumer forums, titled *A Journey of a Thousand Miles Starts with One Short Step* (Nathan quoting Chairman Mao), was produced. Overwhelmingly, people who had left institutions and now resided in community residential settings felt the people in Kimberley should have the same opportunity they had had and the centre should close. As part of this consultation exercise, two consumer forums were also held inside the Kimberley Centre. The residents found the topic of living in any place other than the Kimberley Centre too difficult a concept to express any views about, however it was clear that the uncertainty of their future was causing them great anxiety.

The recommendations of the consumer forums included: the importance of listening to the people who have experienced deinstitutionalisation, the need to have a well planned transition from institutional care to community based services, the need to ensure good communication with everyone involved and to involve self advocacy and advocacy groups. The report also stressed the need to make a decision as soon as possible, due to the stress the uncertainty was creating for people still living in the Kimberley centre (Johns, 2000).

Frustrated at the lack of decision-making, People First, which was a part of IHC at the time, discussed and voted to call for an end to institutionalisation and for the closure of the Kimberley Centre. They decided to circulate a petition and to hold a march on Parliament to present the petition. Meetings were held around New Zealand to discuss the issue and signatures to the petition were gathered. IHC supported People First and assisted with the work involved to stage a march.

### A way forward

In the 11th hour before the march, Minister Dyson, Minister for Disability Issues announced that the Kimberley Centre would close. People First had previously advised the Minister that, should a decision be made before the date of the march, then the protest could turn into a celebration. Over 500 people with intellectual disabilities and their allies from all over New Zealand took to the streets of New Zealand's capital Wellington with chants and banners, and handed a petition with over 2000 signatures to the Minister for Disability Issues (IHC, 2001). It was a great day for self advocacy and the end of uncertainty for the people in Kimberley.

The Ministry of Health established the Kimberley Project Steering Group with members representing KPFA, staff of the Kimberley Centre, local *iwi* (3), union representatives and two consumer representatives. The two consumers were people with an intellectual disability.

Consumers were also involved with the contracting of services as part of the Ministry of Health panels which undertook a process of interviewing and deciding what services to contract. Consumers were supported at all project steering group meetings and at contracting panels by IHC staff from the advocacy or self advocacy teams.

### No quick process

Initially it had been estimated that the deinstitutionalisation process would take up to three years. However, the process of planning, contracting, and establishing services, including the building and/or purchasing of suitable housing, and finally moving people into their new homes, took over 5 years. Throughout this time, the Ministry of Health Project Manager led the change and the Project Steering Group met monthly to discuss progress and work through issues. Substantial delays occurred, firstly with undoing the legal processes (4) that had been put in place and then with the purchasing and building of suitable housing.

2 Maori is one of New Zealand's three official languages. *Whanau* is a Maori word meaning extended family, family group, a familiar term of address to a number of people.

3 Maori is one of New Zealand's three official languages. *Iwi* is a Maori word meaning tribe, nation, people, race.

4 Most people living at the Kimberley Centre had become the subject of personal orders under the Protection of Personal and Property Rights Act 1988. This legislation deals with the care and welfare of people who are deemed incapacitated. All applications and amendments are required to be heard by Judges in the Family Court judicial system. Therefore delays occurred due to the Family Court's capacity to respond to the volume of amendments to personal orders that were required.



Even though the majority of people with intellectual disabilities were already living in regular houses in regular streets in all communities throughout New Zealand, either with family members or with residential providers, the “not in my backyard syndrome” still proved to be alive and well. Potential neighbours, when hearing of the possibility of people from the Kimberley Centre moving into their neighbourhood, fuelled by their own prejudices, outdated stereotypes and myths, sparked fear into others and demanded public meetings and attracted negative media attention.

Despite the issues along the way, October 20, 2006 saw the last residents leave and the Kimberley Centre close after over 60 years; its reputation of being at one time the largest institution in the southern hemisphere and the memories it held were forever filed in New Zealand’s history. A celebration to mark the end of institutional residential services was held in the Parliament in November 2006, marking four decades of deinstitutionalisation for New Zealand (Dyson, 2006).

## Looking to the future

Today, in 2007, New Zealand has had a Minister for Disability Issues for seven years and the first review of the New Zealand Disability Strategy (2001) is occurring. An Office for Disability Issues has been established and the New Zealand delegation played an integral role in the recent drafting of the UN Convention on the Rights of Persons with Disabilities. However, there is still much to be done.

While there are no large institutions, people with intellectual disabilities can still be institutionalised - just as they can be in their community but not part of their community. Deinstitutionalisation is not just about the buildings, it is about putting the principles of deinstitutionalisation into practice. These include choice and self determination, opportunities and possibilities, inclusion and meaningful participation, and the way support is contracted and delivered. New Zealand needs to keep moving forward to ensure people with intellectual disabilities do get to experience an ‘ordinary’ life (NHC, 2003). IHC, through its advocacy, continues to challenge discrimination and advocate for people with intellectual disabilities to truly experience deinstitutionalisation and have their rights as citizens of New Zealand.

## Conclusion

Any deinstitutionalisation process will have its issues, from the conception of the idea through to its completion. Competing voices will want to have their say and the Kimberley project offers an example of this. However, with well researched theories, practices and agreed principles, a way forward is possible.

While the closure of the Kimberley Centre was reason to celebrate, a symbolic end to institutionalised care, New Zealand recognises this is just one step in the right direction. There is still much to do and for this reason disability advocacy groups worldwide, including IHC, welcomed the recent development and signing of the United Nations Convention on the Rights of Persons with Disabilities. This Convention gives hope and encouragement for further progress both in New Zealand and internationally, that people with intellectual disabilities will achieve their rights as true citizens of the world.

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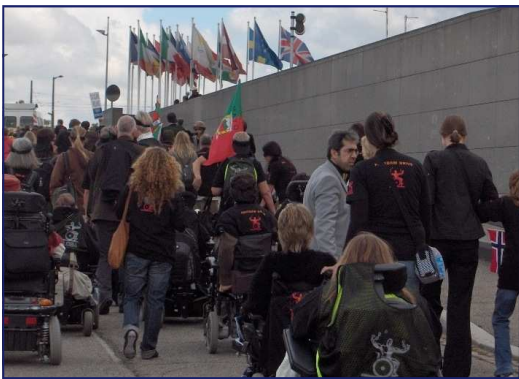
Deinstitutionalisation is not just about the buildings, it is about putting the principles of deinstitutionalisation into practice. These include choice and self determination, opportunities and possibilities, inclusion and meaningful participation, and the way support is contracted and delivered.



## Disabled Activists Descend on Strasbourg to Demand Their Rights

ENIL Strasbourg Freedom Drive 2007, by John Evans

The third biennial Freedom Drive of the European Network on Independent Living (ENIL) took place on the 4th - 6th September in Strasbourg at the European Parliament and Council of Europe. ENIL launched its Freedom Drive in 2003, the European Year for Disabled People. It was started to bring to the attention of the European Parliament the importance of Independent Living, Personal Assistance, deinstitutionalisation and Community Living, and the violation of the Human Rights of disabled people.



Freedom Drivers on their way to the European Parliament. © ECCL

The third year significantly took place in the European Year of Equal Opportunities, and was by far the most successful and largest one yet to be held. There were over 150 disabled people, most of whom were personal assistance users and their supporters who assembled in Strasbourg for the three days. They came from Italy, Spain, Bulgaria, UK, Ireland, Germany, Belgium, Norway, Sweden, Hungary, France and Croatia. Many of the Freedom Drivers travelled long distances to get there, sometimes even at their own cost. This in itself showed the kind of commitment and dedication of these people. There was even a group of 25 disabled people and supporters who had travelled over two days from Bulgaria to get to Strasbourg, thanks to the sponsorship raised by the Norwegian Independent Living Organisation "Uloba".

It seems like the enthusiasm grows with each Freedom Drive. This event has now become "a must do" in the diaries of many European Independent Living Activists, well at least those who can manage the funding to get there! It gives us the opportunity to express our views about the principles of Independent Living by lobbying the European Parliament, but at the same time it provides us all with the unique chance to network and exchange our ideas and experiences with our fellow disabled people striving to achieve Independent Living in their own countries.

The Freedom Drive activities started on the Tuesday morning, 4th September, at the Youth Centre, which became our headquarters and meeting place for the three days. It started with a briefing which outlined the programme, and explained the purpose of the Freedom Drive, together with our demands in the context of the European legislation.

In the afternoon, all the representatives of the different countries organised meetings with their National MEPs in different parts of the Parliament building. There was also a special meeting arranged with the Portuguese MEPs, as Portugal was holding the EU Presidency. Many of these meetings instigated lively discussions between MEPs and activists covering issues ranging from the new UN Convention and its ratification, the EU structural funds and how these could be used for capacity building and empowerment of Independent Living organisations, to other issues related to the European legislation and Directives, and the importance of Independent Living and Personal Assistance for disabled people.



ENIL hands a petition to the European Parliament President Hans-Gert Pöttering. © Corina Zolle

The following day, Wednesday, was the highlight of the Freedom Drive, where everybody met up in a park to get into the mood of the rally. Then we marched through the streets chanting slogans all the way to the European Parliament building. The mood was very inspiring and empowering. At the European Parliament, we were met outside by the President of the Parliament Hans-Gert Pöttering, President of the European Disability Intergroup Richard Howitt and the Deputy President of the Intergroup Jan Andersson.

Later that afternoon, most of the Freedom Drivers congregated in one of the larger Parliament rooms, together with many European MEPs, for a special session organised by the Disability Intergroup. After Richard Howitt, the Intergroup's President, welcomed everybody, there were two presentations. The first one was

from John Evans (ENIL) who took this opportunity to review the changes that have happened since the original 2003 Freedom Drive, and remind everybody that we still had some way to go to meet all ENIL's demands. He also encouraged everybody to do what they can to try to ratify the new UN Convention and sign the European Disability Forum's 1million4disability campaign. The second speech was by Ines Bulić from ECCL, who explained the objectives and work of the Coalition, and outlined how there were still countries who seem more interested in building institutions than creating community based solutions, and that there were still many violations of disabled people's human rights in such institutions.

In the evening, everybody relaxed and partied, thanks to the Irish and Norwegian delegations who arranged the entertainment, food and drink at the Youth Centre. It gave everybody the chance to make the most of the last evening together before returning to their different home countries. It was a very uplifting evening that had a strong sense of achievement about it after the work of the previous few days.

On Thursday morning, a small ENIL delegation had a meeting at the Council of Europe with its Disability Unit led by Thorsten Afflerbach, which was exploratory and helpful. It was hoped that both would be able to work closer together in the future on the implementation of Council of Europe's Disability Action Plan 2006 - 2015.



## ECCL's Presentation at the European Parliament Disability Intergroup meeting, 5 September 2007 ENIL Strasbourg Freedom Drive 2007, by Ines Bulić

### European Coalition for Community Living

During the last Freedom Drive in 2005, ENIL has spoken to you about the fact that thousands of people with disabilities still live segregated and excluded in long-term residential institutions, without any choice of living in the community and with no, or very little, control over their lives and the decisions that affect them. The same year, Included in Society, the report of a study supported by the European Commission, estimated that more than 180,000 disabled EU citizens, including children and young people, still live in long-term residential institutions. [Note: The number of people with disabilities living in long-term residential institutions is much higher than as estimated by the Included in Society project. A new study from November 2007, which was launched as a follow up to the Included in Society project, revealed that the number of disabled people living in long-term residential institutions in 28 European countries is close to 1,2 million.]

We use the term 'institution' to mean:

*"Any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size."*

One of the main problems the report has identified, and this supports what ENIL has stated two years ago, is that community-based services for people with disabilities are still not available, or are very scarce, in many European countries.

Following the conclusion of the Included in Society project, a group of disability organisations - among them ENIL, Inclusion Europe, the European Disability Forum, the Open Society Mental Health Initiative, Mental Health Europe, Autism Europe and the Center for Policy Studies at the Central European University - established the European Coalition for Community Living. Our main objective is to make sure that quality community-based services for all people with disabilities are developed as a matter of priority in all the European countries. This is the only way people with disabilities who now live in institutions or at home, but without the support they need, will be able to live in the community, with the same opportunities as other citizens.



Meeting of the European Parliament Disability Intergroup. © Corina Zolle

## UN Convention on the Rights of Persons with Disabilities

In order to illustrate the seriousness and urgency of the situation, I would briefly like to go over the developments since the last Freedom Drive in 2005, in relation to provision of community-based services for people with disabilities.

To start on a positive note, I would like to mention the adoption of the UN Convention on the Rights of Persons with Disabilities. Article 19 of the Convention, which recognises the equal right of all disabled people to live in the community, with choices equal to others, requires States to:

*"...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."*

This means that, once they ratify the Convention, countries will have the obligation to make community-based services available and accessible to all people with disabilities. This, in turn, will avoid the need for people to be admitted to institutions and lead to their closure. It is therefore crucial that the Convention enters into force as soon as possible - for which at least 20 ratifications are needed - so that its provisions can be implemented in practice as a matter of priority.



Freedom Drivers in the streets of Strasbourg. © ECCL

So far the Convention has been signed by the European Commission and a large number of European countries. It has been ratified by only two European countries - Hungary and Croatia.

In addition to the Disability Convention, we also have action plans on the European level which call for de-institutionalisation of services for people with disabilities and full inclusion of disabled people in society. These action plans, and I am referring to the European Commission Disability Action Plan 2006 - 2007 and the Council of Europe Action Plan 2006 - 2015 are very much in line with the UN Convention and both stress the need to develop community-based alternatives to institutions as a way to facilitate social inclusion of people with disabilities. It is important to note that many EU Member States have adopted their own disability policies which are in line with the two European action plans and support the development of community-based services.

### No end to human rights abuses in institutions

At the same time - despite existing social inclusion policies - reports of human rights violations in institutions continue to pour in. Just two weeks ago, the Mental Disability Advocacy Center from Hungary filed an application against Bulgaria at the European Court of Human Rights.

The case involves a disabled elderly woman who died after she was placed in a social care institution. While there, she suffered broken bones, extensive severe bruising and her head and eyebrows were shaved. Although an administrative enquiry at the institution uncovered serious violations, no one was held accountable for her death. Why was she placed in the institution in the first place? This was because in the absence of appropriate services in the community, she had no other option.

In February this year, a fire broke out in a social care home for adults with disabilities in Latvia. Almost one third of the 90 residents died in the fire. Latvia has a total of 33 institutions - the so-called social care homes - for people with mental disabilities. There is a long list of people waiting to be admitted. But it is not that people want to live in a social care home, where abuses and tragedies like the one in February are just waiting to happen - they simply have no other option.

These are just two of the recent reports about the situation in institutions, which I have chosen in order to explain why there is an urgent need to develop community-based alternatives. During the last Freedom Drive, mention was made of cage beds, which were used to restrain disabled people in institutions across the Czech Republic, Hungary, Slovakia and Slovenia. There have been many, many similar reports in the previous years and they will continue until institutions like these are closed down.

I would like to add that, despite the fact that we most often hear of human rights abuses in countries like Romania and Bulgaria, the two most recently joined EU Member States, it is wrong to think that large institutions for people with disabilities do not exist elsewhere in Europe. In Germany, for example, more than 170.000 disabled people still live in institutions. The situation is no better in countries such as France, Belgium, the Netherlands, Greece and others.

### No rights without community-based services

It is recognised that every person has the right to an adequate standard of living, the right to private and family

life, the right to education, the right to work, the right to live included in the community and so on. However, the only way that these rights can be enjoyed by disabled people is by developing comprehensive, quality community-based services, which will be available to all people with disabilities, including people with complex dependency needs. Only then can institutions, which deny disabled people their human rights and make them vulnerable to abuse, be closed down.

We know that the process of de-institutionalisation is a long one and that it must be done properly, so that poor services are not replaced by something even worse. However, if we want to stop hearing reports about deaths, ill-treatment, exclusion and segregation, this process needs to begin NOW.

At the same time, it is clear that policies for community living are necessary, but not enough. What we need are clear action plans, with a timeframe and a budget for the development of community-based services and the closing down of existing institutions. Furthermore, it is important that no new institutions for people with disabilities are built and that any improvements are limited to targeted interventions to health and life safety, in the framework of a plan to close the institution within an agreed time frame.

Most importantly, the development of quality community-based services needs to start without delay. Otherwise, at the next Freedom Drive and the one after that, we will again be speaking about thousands of disabled people still segregated and excluded in institutions.

What we hope is that some of the disabled people now living in institutions will be able to join one of the next Freedom Drives and come to speak to you, just like we are today. For now, support services like personal assistance and direct payments are still a far cry from reality in those European countries where disabled children and adults have no choice but to spend their lives in an institution.



*Freedom Drivers address MEPs in the lobby of the European Parliament. © ECCL*

## Working together

I would like to conclude my presentation by suggesting the two key areas in which we, as ECCL, and the Disability Intergroup, can work together in order to make community living a reality for disabled people.

First of all, we hope that the Disability Intergroup will support us in ensuring that development of community-based services for people with disabilities is taken forward as a priority by all the Member States.

We would also value the support of the European Parliament in calling for the ratification of the UN Disability Convention, by the European Commission and the individual Member States. We believe that once it takes effect, the Convention will accelerate the process of de-institutionalisation and the development of community-based alternatives.

Finally, we would appreciate your suggestions about how the European Parliament, more specifically the Disability Intergroup can further support the objectives of the European Coalition for Community Living.

Thank you very much for your time and attention.



## MEPs Discuss Community Living with Commissioner Špidla ENIL Strasbourg Freedom Drive 2007

At the European Parliament Session on 4 September, a number of MEPs (1) used the Question Time with the Commission to ask Commissioner Špidla about specific actions the Commission has taken in order to promote the principles of Independent Living.

MEPs used the occasion of ENIL's Freedom Drive to ask questions in relation to: progress made in promoting the concept of Independent Living for disabled people and the movability of funding for personal assistance between the Member States; the representation of disabled people and their organisations in the EU's social inclusion strategies, in line with the principle 'nothing about us without us'; mainstreaming of disability within different parts of the Commission; enactment of an enforceable disability-specific directive; overseas assistance for community development projects for disabled people and de-institutionalisation; human rights

abuses of disabled people in the EU and the rest of the world. With respect to the last two points, the Commission was also asked to respond to concerns about the increasing number of people with disabilities in institutions across Europe and to specify what actions have been taken to implement the recommendations of the Included in Society report (2).

Commissioner for Employment, Social Affairs and Equal Opportunities Vladimír Špidla began his response by referring to the Commission's Disability Action Plan, which promotes active inclusion of people with disabilities in society, based on their right to independent living. He stated that, as part of its overall deinstitutionalisation strategy, the Commission is actively looking into alternatives to institutional care for people with disabilities by commissioning research to support the Member States in their transition to community-based models of care. The Commissioner could not confirm that the number of disabled people living in institutions in Europe is on the rise, stressing that the data that would support this is not available. Despite this, the Commissioner assured Parliamentarians that the Commission will continue working in the same direction.

The Commissioner went on to say that countries which have completely dismantled institutional care in the interest of disabled people prove that community living can become a reality. He warned, however, against the closing of institutions without putting proper community-based services in place.

On the issue of movability of funding for personal assistance between the Member States (as one of the ways to ensure that disabled people can live independently), the Commissioner pointed out that there are still no comparable data on Member States' practices in this area. He assured the Parliamentarians that the Commission does plan to obtain better data and has been dealing with the issue within the debate on services of general interest.

Finally, the Commissioner acknowledged the importance of the UN Convention on the Rights of Persons with Disabilities, adding that the Commission plans to encourage Member States to ratify the Convention as a matter of priority and to take concrete actions to implement it. The Commission's Inter-Service Group on Disability and the High Level Group on Disability were identified by the Commissioner as venues where issues affecting disabled people are being discussed at the European level. When it comes to European legislation, the Commissioner acknowledged that Europe still has a long way to go and needs to complete its current legislation to better protect the rights of disabled people (4).

1 Questions were asked by the following MEPs: Richard Howitt, Evangelia Tzampazi, Proinsias De Rossa, Grazyna Staniszewska and Kathy Sinnott. The full transcript of the discussion at the EP is available at [www.europarl.europa.eu](http://www.europarl.europa.eu).

2 A copy of the Included in Society report (2004) can be downloaded from the website [www.community-living.info](http://www.community-living.info).

3 Results of the Commission funded project Deinstitutionalisation and Community Living - outcomes and costs (2007) can be downloaded from ECCL's website.

4 The Commissioner stated that a separate answer to each question would be provided in writing following the Session.

## Publications

### Deinstitutionalisation and community living - outcomes and costs: report of a European study

Authors: Mansell J, Knapp M, Beadle-Brown J, Beecham J

Publisher: Tizard Centre, University of Kent, 2007

Further information: [www.kent.ac.uk/tizard/research/DECL\\_network/index.html](http://www.kent.ac.uk/tizard/research/DECL_network/index.html)

### Community Living: Bausteine für eine Bürgergesellschaft

Authors: Maas T et al.

Publisher: alsterdorf verlag, 2007

Further information: [www.community-living.de](http://www.community-living.de)

Includes papers from the national Congress on Community Living, held in October 2006 in Hamburg, Germany. The Congress was organised by the Evangelische Stiftung Alsterdorf and members of the German Society for Social Psychiatry, with experts both from the theoretical and practical field. Academic presentations on Community Living were accompanied by practical examples. Language of the publication: German.

### The Amman Projects: Experiences from the community based approach to disability services

Author: Ericsson K

Publisher: Uppsala University, 2006

Further information: [www.skinfaxe.se/ebok/ammanprojects.pdf](http://www.skinfaxe.se/ebok/ammanprojects.pdf)

Documents the process of the reform of disability services in Amman, Jordan, carried out by the Swedish Organisation for Individual Relief, SOIR. Language of the publication: English

## 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. The annual contribution fee for membership in ECCL is between 50 and 200 EUR.

The Management Partners of ECCL are Autism Europe, the Centre 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.

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!

### 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

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

For more news and information about ECCL's activities, visit [www.community-living.info](http://www.community-living.info) and download the next issue of ECCL's newsletter.

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