

# Our Rights - issue 12, July 2009



## The International Disability and Human Rights Network

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## **Convention Sign-ups**

- 139 signatories to the Convention
- 82 signatories to the Optional Protocol
- 59 ratifications of the Convention
- 37 ratifications of the Optional Protocol

## **UK News**

### **Falconer amendment on assisted suicide defeated**

#### **Lord Falconer's amendment to the Criminal Justice Bill to protect those who assist in the suicide of disabled and terminally ill people was defeated by 194 to 141 votes**

The Coroners and Justice Bill in House of Lords to tighten up the Suicide Act to prevent the internet promotion of suicide had three amendments laid by Lords Falconer, Joffe and Alderdice. Lord Falconer's amendment specifically attempted to legalise support for those travelling abroad for assisted suicide.

### **Is the right to die becoming a duty to die?**

According to a Guardian article on June 22, many who have gone to die at the Swiss suicide organisation, Dignitas, were not terminally ill. Leading doctors expressed serious concerns. While most of the conditions could contribute to a patient's death, equally people with many of them - such as Aids, cancer, rheumatoid arthritis and tetraplegia - could, with the right treatment, lead fulfilling lives.

"NHS palliative care was too often "rather patchy", said Professor Steve Field, chairman of the Royal College of General Practitioners, who was "worried" that not all the 114 patients may have been aware of treatments that could have prolonged their lives.

Dr John Saunders, chair of the Royal College of Physicians' ethics committee, said: "The conditions are so varied that it suggests that Dignitas is not undertaking adequate medical assessment [of patients

seeking its help] that might be expected. The list does suggest that Dignitas is cavalier in arranging for people to end their lives."

Interestingly, the Swiss Government, alarmed about the activities of Dignitas, is considering banning it.

### **British Medical Association Annual Representative Meeting Care**

Doctors have reaffirmed their opposition to assisted suicide following a debate at the BMA's Annual Conference in Liverpool, on the first July. Doctors rejected calls from Thameside doctor, Kailash Chand to change legislation to allow the choice of an assisted death by patients who are terminally ill and who have mental capacity.

Doctors also rejected calls to ensure that those accompanying the patient at an assisted death, but not actively participating, will not be subject to criminal prosecution.

Dr Brian Keighley, Deputy Chairman of the BMA in Scotland, said:

"It is clear that doctors do not wish to play a role in assisting a patient's death. Assisting patients to die prematurely is not part of the moral ethos or the primary goal of medicine. If the legislation were to be changed, it would have serious negative consequences on the relationship between doctors and their patients.

"It remains vital that access to the best quality palliative care is available in order to ensure that terminal suffering is properly managed."

Source: **British Medical Association**

## **Job Seekers With Disabilities Face Discrimination At Application Stage**

In a snapshot survey published by Terrence Higgins Trust, two thirds of top organisations were found to ask irrelevant health related questions on job application forms. A coalition of charities wants these questions banned to reduce the discrimination faced by people with 'invisible' conditions such as mental illness or HIV.

HIV and sexual health charity Terrence Higgins Trust (THT), NAT (National AIDS Trust) and leading mental health charity Rethink are among the organisations that want an amendment to the Equality Bill to ban irrelevant health-related questions until after a job offer has been made. Employers could still ask in advance about conditions which would affect a candidate's ability to undertake that particular role.

THT surveyed the application forms of 50 organisations including charities, local councils, government departments, police forces, fire brigades, health services, law firms, colleges, and housing and construction companies.

66% asked medical questions on their application forms including questions asking whether candidates have specific disabilities. Some companies also expect candidates to undergo medical examinations and even blood tests, prior to being offered jobs.

Under the current system, employers are allowed to ask about disabilities, if the candidate is taking medication or has a medical condition – even if it has no relevance to the job. This can lead to discrimination and allows employers to make decisions based on prejudice, rather than ability. The coalition wants to see the Equality Bill amended to prevent this from happening.

In the United States and a significant number of EU member states, pre-interview disclosure is against the law, offering significant protection to people with disabilities and long-term medical conditions.

Sir Nick Partridge, Chief Executive at Terrence Higgins Trust said “Some companies use the answers to these health related questions as a way of cutting out potential candidates. Someone with HIV could be the best person for a job but could be turned down because of assumptions the employer makes about their health. This is unacceptable. All we want to see is a system which gives people with stigmatised conditions a fair chance.”

Paul Corry, Rethink Director of Public Affairs, says: “This survey shows what job seekers are up against – irrelevant questions about their health before they have even applied for a position. Such questions can create a very real fear of discrimination and discourage some good candidates from putting themselves forward. Others feel they have to lie to get an interview. Those who are up-front about their medical history tell us that it is almost impossible to find a job.

“The Government is committed to helping people with mental health problems back to work. Pre-employment questionnaires are a major barrier to this. The Equality Bill is the perfect opportunity to address this issue.”

THT is running an e-campaign against discrimination in recruitment. People can sign up by visiting [www.tht.org.uk/campaign](http://www.tht.org.uk/campaign).

Source: Terence Higgins Trust

### **IMPORTANT NOTE : The Cheltenham Borough Council case**

Cheltenham Borough Council lost an attempt to sue its Chief Executive for £1m for not revealing her history of depression before taking the job.

Mrs Laird, 52, took the job in 2002, but left in 2005 on an ill-health pension after taking sick leave on full pay. The council said her actions caused it to lose more than £1m.

At the centre of the case was a medical questionnaire Laird filled in when she applied for the job. To the question: "Do you normally enjoy

good health?" she replied "Yes". To: "Do you have a mental impairment?" she replied "No".

The court was told Laird suffered "three episodes of depression with associated anxiety" between 1997 and 2001. But she saw it as "stress-related illness and not depression" linked to "non-specific, non-recurrent events".

Mr Justice Hamblen dismissed the High Court action, finding the representations she made were not false nor, "given the terms of the questions asked, were they misleading."

Paul Farmer, chief executive of mental health charity Mind, welcomed the ruling.

He told the BBC: "I think this is a pretty important verdict. It makes very clear that an employer cannot sue somebody because they have simply answered the questions on the application form."

Source: BBC news

## International News

### **Freedom Drive. Strasbourg 2009: rally for independent living**

This year's Freedom Drive, 14 - 17 September, will be the 4<sup>th</sup> event organised by the European Network on Independent Living (ENIL) where disabled people from many European countries join together and converge on the European Parliament in Strasbourg.

At the last Freedom Drive in 2007, more than 125 disabled citizens and their personal assistants from Germany, Norway, Ireland, Sweden, UK, Bulgaria, Belgium, Italy, France and Spain. They demanded UN Convention ratification both by the European Commission and Member States; a continuation of prior goals of deinstitutionalisation and the establishment of a personal assistance system; encourage co-operation between the Commission and the Member States; mainstreaming Disability in Policy Formulation; and full Participation of People with Disabilities. They emphasized that Independent Living should remain central in the disability policies of

the EU and that 5% of EU development funding goes to disabled people in developing countries.

This year the Freedom Drivers will be marching through the streets of Strasbourg towards the European Parliament. The theme is on Implementing §19 of the UN Convention on the Rights of Persons with Disabilities.

A good reason to go to Strasbourg for the Freedom Drive is to experience the solidarity for the demand for independent living in Europe by demonstrating in the streets of Strasbourg in a rousing rally and ending with addressing the European Parliament.

You will be able to meet a wide range of European disabled people living independently – from the well-established organisations to the newly formed advocacy services. As well as networking, this is an opportunity to explore and question the relevance of EU legislation to disabled people to MEPs and other fellow Europeans.

Strasbourg, itself, is a lovely city with its accessible tram system and Alsatian architecture. It hosts the Council of Europe as well as the Court of Human Rights.



Freedom Drivers with Hans-Gert Pottering outside the European Parliament

For a fuller report on the 2007 Freedom Drive – read ENIL's report (<http://tinyurl.com/nnas37>)



Videos of the previous rallies can be found on youtube (from Dublin CIL) (<http://tinyurl.com/mu4tfq>)

Photos of the 2007 rally can be found on Flickr (<http://tinyurl.com/luh96b>)

For Freedom Drive 09, disabled people interested in participating should contact their country contacts which can be found at the ENIL website (<http://tinyurl.com/l5zy89>)

Information is available for accessible hotels, transport in Strasbourg and travel to Strasbourg via Paris TGV, and the ENIL Conference Program, 14 Sep 09 on the ENIL website (<http://tinyurl.com/mxg7sl>)

### **Bangladesh: The story of Sumi: DPOs working with individuals**

**Sumi Akter is a disabled girl who was sent by her poor family to beg in Dhaka.** Spotted by a Centre for Services and Information on Disability (CSID) staff member, she was persuaded to attend a children's group meeting with her parents when the project paid her compensation for her day's lost income. While she does not like begging, she has to be able to help her family to survive.

Sumi wanted to be able to attend school. With help from the CSID project, she was enrolled in a school and is able to participate with the other children, disabled and non-disabled.

The project also invited her parents to attend the meeting to see and observe what other children do in the meeting and what activities they are involved in. Sumi has also been included in a theatre group with other disabled children. It has given her more self confidence.

Hopefully, her family can be supported in other ways so that it will not be necessary for her to beg anymore.

Sumi's story is not unique. Many disabled children are in similar poverty stricken situations

Source: Resource Center on Disabilities (RCD)

## **Sri Lanka: Access Rights - not charity**

Sri Lanka has had legislation with physical access standards with specific measures designed to remove access barriers.

However, there is little evidence to show that people with mobility problems have the opportunity to physically access places in their communities.

“The problem is that legislation is not being enforced,” says Dr Ajith Perera, a former Test cricket umpire with a PhD in Chemistry and an disability activist.

“You know, if the police catch a person drink-driving or speeding, he is immediately fined. But if a person puts up a building that violates the laws of this country, adherence to which will bring a wide range of benefits to the people and the country, there is no punishment. But it certainly punishes us!” exclaims Dr Perera.

Dr Perera calls this inaction a national crime, pointing out that it has discriminated against or marginalised millions of people, making them virtual prisoners in their homes.

“People cannot find jobs, if they cannot get into the offices or use a toilet. They cannot deposit money in banks, if they cannot get in. They cannot even spend their money, if shops or restaurants put obstacles in their way,” says Dr Perera.

Dr Perera estimates there is a minimum of three million other disabled people in the country, who are prevented from accessing or suffer loss of dignity or danger to their safety, when trying to use public facilities, in the hope that justice will be served. This three million includes thousands, nobody knows for sure how many, of soldiers injured in battle.

### **Insult to soldiers**

Major Anil Seneviratne is one such soldier. He lost a limb serving his country, and now acts as the CEO of a community based disability organisation in Tangalle, Navajeevena.

In an interview with The Nation, Major Seneviratne spoke of the 'insult' to a soldier's pride, at having to face the indignity of being helped or being denied access to public facilities, after fighting for the protection of their country and its people.

"It is an insult that the environment that we build to live in does not include the disabled. It is a dishonour to those proud citizens," says Major Seneviratne.

"It is true that disability changes your whole lifestyle, behaviour, and hopes; but it does not and should not erase ones beliefs – especially, core beliefs of a sense of self-pride. Therefore, it is much needed to enforce laws and create an attitude that considers their pride and dignity, if you really want to respect them as heroes."

The period after a major war, has been a time for positive changes for people with disabilities worldwide, as injured and disabled soldiers return home to re-integrate into society.

In Sri Lanka, these disabled war heroes are likely to face hardship, if these laws do not get enforced without further delay. While most of them will still be 'fighting fit', they may encounter more difficulty attending their sister's wedding, than crawling across the battlefield.

Dr Perera has had opportunities to talk with some of these Ranaviru soldiers, facing the new battle for their Rights for a dignified and productive integration into society.

"But what some of them have been telling me is that they are really afraid that people will just take pity on them and see them as charity cases, especially, if they have to be helped into a buildings in day-to-day life," says Dr Perera.

"Why should they continue to be physically helped or be dependent on others to access our country's buildings? They, like other people with mobility impairments, are productive members of our society, and if we just stop constructing these obstacles, then they could integrate like everybody else."

Source: Resource Center on Disabilities (RCD)

## **USA : Teacher who abused disabled child reinstated**

Alex Barton, age 5, is in the process of being diagnosed with Asperger's Syndrome. He has often been sent to the principal's office for various disciplinary issues, which his family feels are connected to his impairment.

In May, 2008, his kindergarden teacher, Wendy Portillo, led his classmates to vote him out of class. The 5-year-old boy was made to stand in front of the class as classmates were invited to tell him what they didn't like about him. The other children called Alex "disgusting" and "annoying."

Alex's mother, Melissa Barton filed a complaint but the state attorney's office concluded the matter did not meet the criteria for emotional child abuse, so no criminal charges were filed. Instead of disciplinary action, the teacher was reinstated and her tenure was restored.

Meanwhile, Alex Barton still struggles with anger and fear after the events he experienced. Alex has continued his education with the help of an in-home tutor, he has not been permitted to return to school.

"How far is too far?" asks Ms. Barton, who has filed state and federal lawsuits in connection with the mistreatment of her son. "Will it be enough when the wheelchair bound [sic] child is deemed a "distraction" for the teacher? Maybe next they will choose to take the deaf child and abuse him too. What will it be? When will we stand up and say enough is enough? If Alex were different in any other way-- any at all-- and he were expelled for that, what would the reaction be?"

Of Wendy Portillo in particular, Melissa Barton says simply, "[Alex] paid the price for her ignorance with his innocence."

Source: Disaboom.com

## **The Disability Rights Fund (DRF)**

DRF, a groundbreaking grant supporting the human rights of people with disabilities announced the second round of its 2009 grantmaking, “Raising Our Voice.” **The application deadline is September 15, 2009.** This round opens another year of possible funding to disabled persons’ organizations (DPOs) in: Ecuador, Nicaragua, Peru; Ghana, Namibia, Uganda; and Bangladesh and adds an additional region to the Fund’s reach – the Pacific. In the Pacific, 14 island countries are targeted: Cook Islands, Federated States of Micronesia, Fiji, Kiribati, Nauru, Niue, Palau, Papua New Guinea, Republic of the Marshall Islands, Samoa, Solomon Islands, Tonga, Tuvalu, and Vanuatu.

The broad objective of the Fund—which was officially launched in March 2008—is to empower DPOs in the developing world and Eastern Europe/former Soviet Union to participate in ratification, implementation and monitoring of the United Nations Convention on the Rights of Persons with Disabilities (CPRD).

In 2008, the Fund made one-year grants to 33 organizations in 7 countries (Ecuador, Nicaragua, Peru; Ghana, Namibia, Uganda; Bangladesh), totaling USD 800,000. Grants ranged from USD 5000 – 50,000 and supported CRPD awareness-raising, strengthening coalitions and networks, and rights advocacy.

In the second round of 2009 grantmaking, applicant organizations may apply within one of two categories: a) single organizations or partnerships and b) national DPO coalitions. Grants to single organizations will range from USD 5,000 to 30,000 and support efforts to build voice and visibility and to develop rights-based advocacy and monitoring on the CRPD. Grants to national DPO coalitions will range from USD 30,000 to 70,000 and will support advocacy toward ratification of the CRPD, passage of specific legislation to accord with the CRPD, or the production of shadow reports.

Interested organizations are urged to review the full eligibility criteria and application details posted at the Fund’s website, <http://www.disabilityrightsfund.org/grant.html>. Any questions on the proposal process should be directed to [info@disabilityrightsfund.org](mailto:info@disabilityrightsfund.org)

by August 15. **The deadline for applications is September 15, 2009.**

DRF's donors include the Aepoch Fund, the American Jewish World Service, an anonymous founding donor, the Australian Government's International Development Assistance Agency – AusAID, the Open Society Institute, The Sigrid Rausing Trust, and the United Kingdom's Department for International Development.

## **Horror Stories**

### **Editorial**

We have introduced a new item to our contents - 'Horror Stories' - in which we will report the many, many accounts of disabled people living in hell on earth - sometimes in institutions and often in their own homes.

We must never forget these individuals. It is the violations they endure which demonstrate how we are really viewed and treated.

**Inhumanity to one of us is inhumanity to all.** It is what our organisations are all about - ensuring that this no longer happens.

We need to use these stories to get policy makers, governments and the general public to understand that our fight for rights is very serious and is completely justified. These stories are crucial evidence in our struggle.

### **Horror Story 1: Malaysia: Disabled left chained and naked in care home**

Journalists from *The Star* reported on the terrible conditions disabled people were found in at the Taman Sinar Harapan home in Kuala Kubu Bahru. Following a tip-off, they found about 30 men, naked, some chained up, caged and covered in their faeces and urine in locked rooms.

The home has about 200 residents comprising men, women and children, some of whom are mentally and physically disabled. Visits

to individual rooms reveal even more horror – residents, young and old, naked and confined in cages.

Half of the men were locked behind bars like animals in a zoo while the others were able to move about in the front portion of the room. Those in the “jail cells” were segregated so that they would not harm their non-violent room-mates.

Most of them looked no older than 50 but they were just skin and bones and some looked extremely frail. One resident was lying on his stomach on a wooden bench and had soiled himself. There was a considerable stench. Fans were installed inside the room for better ventilation but that was the only luxury the men had. There were no beds, no toilets and not even blankets to keep them warm on cold rainy nights.

Those who were not in the “jail cells” were given beds but without any mattresses or pillows. They were chained to the bed frame with metal chains and a steel lock.

“Chaining mental patients to their beds and leaving them to run in the nude is sheer abuse and inhumane,” says Prof Dr Mohamad Hussain Habil, Asean Federation for Psychiatry and Mental Health President. “There is also no excuse for welfare officers to be ignorant about the proper care for patients because there are training workshops available at the University of Malaya.”

Dr Fadzil Man, a private psychiatrist also agreed that the patients should be given medicine along with proper care such as counselling and other therapies.

Asked to comment on the standard of care mental health patients in Malaysia receive, Dr Fadzil said there was still room for improvement.

On how disabled people were normally treated in the wards, he revealed that the most common way was to sedate those who were hyper-active and might cause harm to themselves or others.

“Of course, it’s been known that some privately run shelters and homes who take in disabled people do not provide the necessary and proper care for them.

“They are treated in such horrible ways, sometimes worse than animals just because they aren’t able to verbalise their feelings and thoughts,” he said.

He told *The Star* that cases of patients being chained, undressed and caged up were not unheard of.

“Normally these patients are what we call the ‘critical’ ones and family members who can’t cope with them just leave them at shelters or sometimes completely abandon them.”

Source The Star online

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