

# **Our Rights - issue 2, August 2008**

## **DAA's newsletter for Disability Lib.**

In the interest of solidarity, this newsletter is sent around by email to disabled people and their organisations across the world, and we invite you to forward it freely. We have provided links to internet sites, web pages and video clips, but understand that not all links are technically accessible to all users. From October Our Rights will be available in electronic format and on our website. For our contact details follow this link <http://www.daa.org.uk/>

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### **Welcome Hello from DAA**

Thank you to all of you who took the time to respond to our first issue. We are delighted to be back! We have had replies from around the world.

"I am very happy indeed to get the DAA Newsletter - this is one newsletter that I eagerly look forward to. The articles provided me with new insights and sharpen my understanding."

"Great newsletter!"

"I access DAA website regularly and will disseminate DAA newsletter to all my contacts."

"Have just read your first bulletin and I am impressed with its coverage."

"thanks a lot for your nice news letter. Hope it can help my people in bangladesh."

Thank you for all your comments. We have improved our technical set-up, so fewer newsletters should land in Junk or Spam email boxes. From October you can access the newsletter on our website. You can request picture supported and word versions. We continue to strive to make our articles interesting, relevant and accessible. Please let us know how we are doing. This edition has two main themes: the body politics of bio-ethics and inclusion. We will also tell you again who we are and what we hope to achieve. Enjoy!

Email: [mysay4daa@live.co.uk](mailto:mysay4daa@live.co.uk)

### **Disability LIB partners**

The project has its own website and central office.

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Telephone: 0844 800 4331

Email: [contact@disabilitylib.org.uk](mailto:contact@disabilitylib.org.uk)

**[ALFIE Tara Flood recognised for Inclusion Now campaign work](#)**

The Social Inclusion Campaign Award from the Sheila McKechnie Foundation was given to the director of ALLFIE, Tara Flood. Tara is also chair of DAA. Tara and the Alliance run a campaign 'We know inclusion works'. This is in response to the negative reporting in the media. You are invited to send your stories about how inclusion works to [info@allfie.org.uk](mailto:info@allfie.org.uk)

"Inclusion for me is about society, which respects the humanity of its people." says a disabled young person in Nottinghamshire. "Inclusion happens when everyone feels appreciated and welcome to participate."  
Centre for Studies on Inclusive Education.

Inclusion is going to school with your friends. "I kept asking myself what words a mother would use to explain to her daughter why they did not want her at her school. Except that she was disabled. If my daughter had only been black, and not disabled too, would the school have been able to do the same?"  
Preethi Manuel mother of Zahrah.

### **Disabled by Society .... Our stories: Body Politics Excluded because of crooked teeth**

The media reported that a nine-year-old girl called Lin was moving her lips, but did not actually sing at the opening of the Olympic Games in China. The beautiful voice we all heard was from a different girl, the seven year-old Yang Peiyi. Apparently Yang was not shown on stage nor on television, because she has crooked teeth. Her face and her smile were regarded as not photogenic enough, so she was hidden to avoid damaging China's international image.

Often we find disabled people are hidden, out-of-sight and at the margins of society. Society's underlying cultural preferences in terms of the body and mind is for a particular image of beauty and health: a superficial one.

Our impairment difference is treated like a 'stigma', a characteristic that is deeply discredited within one's

society and for which we are rejected. Our difference, it seems, is challenging.

"I experienced a nervous breakdown 20 years ago. Despite recovering from that, then going on to achieve academically and build a good marriage, my family remain wary of me. My sister is bringing up her child to refer to me as "crazy". She even considers it funny to do so. I have tried to express how hurtful I find this, but my feelings have been overlooked."

7th August 2008, Guardian 'Stigmatised by my own family'

In a unique research called 'Shout' almost 4,000 mental health service users were involved. The charity Rethink found that 87% of people said they had direct personal experience of stigma and discrimination and reported the negative impact of stigma on their lives.

The damage caused was wide-ranging; the areas affected include employment, family, friendships, neighbours, accessing education, reporting crime, relationships with health professionals, and feeling confident enough to visit the shops, go to the pub or take part in activities in the community, it says.

The Stigma Shout report can be found at

[http://www.rethink.org/how\\_we\\_can\\_help/campaigning\\_for\\_change/moving\\_people/stigma\\_shout.html](http://www.rethink.org/how_we_can_help/campaigning_for_change/moving_people/stigma_shout.html)

But this problem goes deeper. If a girl can be excluded for crooked teeth, where does it end? Our society allows science and law to de-select disabled lives.

For impairment reasons they tamper with genetics in an attempt to screen out difference. We have laws that allow late abortion because of so called 'defects'. We allow bio-ethics to de-select impairment.

In 2004, UKCPD (formerly the British Council of Disabled People) asked "Can human rights apply if we select children or value people's quality of life on the basis of their genetic make-up or impairment?"

<http://www.bcodp.org.uk/library/genetics/3disabhr.pdf>

<http://www.guardian.co.uk/society/2008/aug/06/mentalhealth>  
<http://www.guardian.co.uk/society/2008/aug/07/mentalhealth.familyandrelationships>

## **Disabled by Society ... Our Stories: Your Say on last month's theme: Forced Interventions Being an Un-Person... (8'47'')**

"This is from a handout I gave while speaking at training for staff who work with people who have developmental disabilities. It is about what it means to be dehumanized and it applies to a far greater group of people than the original audience. It is, to make it clear, something that is done to us by other people, not something intrinsic to who we are.

Being an Un-person means that people talk in front of you as if you aren't there... It means that your existence seems to fill people with disgust and fear. ... If you communicate with behaviour, you will be punished, restrained, drugged or put in a behaviour program."

[http://www.youtube.com/watch?v=4c5\\_3wqZ3Lk](http://www.youtube.com/watch?v=4c5_3wqZ3Lk)

### **Sceptical**

A sceptical view was expressed about the usefulness of the Convention. How does it protect the rights of people with mental health issues?

"My organization are skeptical on the UN Convention re Legal Intervention for people with mental health issues and the sense of disabled people being able to join the armed forces."

For a discussion of how different Articles in the Convention can work together, go to page 47 in this 2007 publication:

[http://www.riglobal.org/publications/RI\\_Review\\_2007\\_Dec\\_WORDversion.doc](http://www.riglobal.org/publications/RI_Review_2007_Dec_WORDversion.doc)

The text of Article 12 can be accessed at

<http://www.mindfreedom.org/kb/mental-health-global/united-nations/article-12-un>

### **The UN Convention on the Rights of Disabled People**

This year (2008) we celebrate 60 years of the United Nations Convention on Human Rights, the first international commitment on human rights.

A web campaign <http://www.everyhumanhasrights.org/> urges us to embrace the values and goals of the Declaration. To protect the rights of our fellow global villagers and to encourage others to do the same in our communities, workplaces and schools. We are asked to affirm these principles:

“Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.” Every Human has Rights

However, **our rights** as disabled people are not spelled out specifically. It makes no specific mention of the meaning of rights as disabled people. Our experience is that we are often invisible, excluded or forgotten. We are not always included into the general phrase of ‘human’ inhuman rights.

That is why we needed a specific convention and why we are campaigning for our countries to ratify the Convention of the Rights of Disabled Persons.

### **UN Convention text resources:**

Details of the Convention on the Rights of Disabled People can be found at

<http://www.un.org/disabilities/default.asp?navid=12&pid=150>

<http://www.un.org/disabilities/convention/conventionfull.shtml>

Easy Read version of the Convention

<http://www.officefordisability.gov.uk/docs/international-agreement-rights-disabled-people.pdf>

For Easy Read versions of the Convention’s extra agreements (Optional Protocols) go to

[http://www.hreoc.gov.au/disability\\_rights/convention/nz.htm](http://www.hreoc.gov.au/disability_rights/convention/nz.htm)

A child-friendly text of the Convention can be accessed at

[http://www.unicef.org/Child\\_friendly\\_CRPD.pdf](http://www.unicef.org/Child_friendly_CRPD.pdf)

### **Inclusion means ... being given a £50 gift token?**

A grammar school in Lincolnshire, England, did not listen to a boy with Autism when planning and arranging the 11-plus entrance exam. Under the Disability Discrimination Act any barriers to learning have to be removed, for

example by making alternative arrangements or providing reasonable adjustments.

His mother said: "We knew he would struggle with the change in surroundings. Our primary school head teacher suggested we ask if he could sit the test there, or at least in a room on his own. But when I went to the school I was told, 'No, we don't make any allowances'."

As the barriers of unfamiliar surroundings, a crowded room full with unfamiliar people were not removed, the boy was extremely distressed and failed the exam.

The ombudsman Anne Seex said the school had not considered its duties under the Disability Discrimination Act.

The boy was admitted to another grammar school on the basis of his exam results at the end of primary school (called SATs) and his junior school's recommendation.

The school has apologised, has given the boy a £50 gift token and agreed to handle future cases differently.

<http://news.bbc.co.uk/1/hi/england/lincolnshire/7542948.stm>

[http://www.timesonline.co.uk/tol/life\\_and\\_style/education/article4460621.ece](http://www.timesonline.co.uk/tol/life_and_style/education/article4460621.ece)

## **International News**

### **Canada**

Paul and Barbara-Anne Chapman had sold their home in Britain and bought a farmhouse in Nova Scotia, Canada. The local authorities supported and welcomed them.

However, when the family arrived at the airport a border guard refused them entry. Several questions were raised about their work permit, clearance for their black Labrador and about their daughter Lucy, who has Angelman syndrome.

The family claim they were told by a border guard that because Lucy is disabled she would never be allowed into the country, and that she had a lifetime ban.

Mrs Chapman said: "My dog was allowed to stay. My dog has a higher status than my daughter in Canada, just because she is disabled."

Canada's immigration rules in section 38 do have a clause that states that you are not eligible for immigration if you would make an excessive demand on health and social services. Presently, "excessive demand" is usually defined as exceeding \$15,000 of publicly funded health care costs over the next 5 years. However, in certain family applications, children are exempt from this rule of no entry due to health care costs.

The Convention on the Rights of Disabled People places obligations on countries to protect disabled people's rights and freedoms. This includes the right to free movement and residency.

Entry to one's own country is specifically mentioned in Article 18 of the Convention: "Are not deprived, arbitrarily or on the basis of disability, of the right to enter their own country."

Entry into another country is protected in Article 18, where it says that disabled people should "not be deprived, on the basis of disability, of their ability to obtain, possess and utilize ... relevant processes such as immigration proceedings, that may be needed to facilitate exercise of the right to liberty of movement."

Mr and Mrs Chapman hired a Canadian lawyer to fight the decision.

<http://www.un.org/disabilities/default.asp?id=278>

<http://www.telegraph.co.uk/news/worldnews/northamerica/canada/2519496/Canada-refuses-entry-to-disabled-girl.html>

**Sex in the City... and world-wide.**

Research has shown that disabled people are being denied the choice to full sexual relationships.

“I want to meet a girl I can become friends with, take to the pub and the cinema and then after a couple of months see where it goes,” Joseph Greene, 23.

The national charity Family Planning Association FPA has organised an information and poster campaign about the right to have sex and relationships. FPA gives people information and advice about sexual health. This is particularly important in view of the continuing rise and impact of HIV (see reports below).

Easy Read, posters and campaign info at

<http://www.fpa.org.uk/news/campaigns/current%5Fcampaigns/detail.cfm?contentid=1021>

<http://news.bbc.co.uk/1/hi/uk/7540103.stm>

[http://www.fpa.org.uk/products/learning\\_disabilities\\_publications/detail.cfm?contentid=1037](http://www.fpa.org.uk/products/learning_disabilities_publications/detail.cfm?contentid=1037)

‘Let’s talk About Sex’ was launched in June 2008 for young people with life-limiting health conditions, in a bid to open up a taboo subject and to better support these young people to have the opportunity to experience relationships and explore their sexuality, in a safe, supportive and empathetic environment.

<http://www.act.org.uk/content/view/153/1/>

Our rights and dignity in connection with these personal areas are protected in the Convention. **Article 23** of the Convention on the Rights of Disabled People specifically refers to forming relationships and accessing age-appropriate information, reproductive and family planning education.

As part of their obligations, countries who have ratified the Convention, have a duty to develop and change customs or practices. This includes working towards a change in attitude towards disabled people and sex.

**Article 4** of the Convention asks governments to develop or change customs and practices which contradict the rights. Community norms, customs and practices of what

people believe or how professionals deal with disabled people may go against the ideals laid down in the Convention.

“What is acceptable in the community is for a disabled person to marry another disabled person so that together they share their curse”, says a disabled local councillor in Uganda.

[http://www.disabilitykar.net/docs/stories\\_women.doc](http://www.disabilitykar.net/docs/stories_women.doc)

### **From Mexico to India: Disability and HIV**

On August 6<sup>th</sup> a very important international panel discussion took place. ‘Beyond Barriers: Disability and HIV/AIDS’ gave information about studies from across the world – Brazil, South Africa, Cameroon, and Canada.

Disabled people were found to be consistently more vulnerable to infection. People with learning difficulties and disabled women are often exposed to riskier situations; women in particular experience more unprotected sex than the general population, often as a result of sexual violence.

A researcher in Kwa Zulu-Natal, where there is no disability-specific sex education, encountered a “let sleeping dogs lie” attitude in schools. As a result, she found that disabled children had little access to education or legal protection and were more vulnerable to abuse and infection.

In Cameroon, a study focused on a young deaf population, found that sexual debut was on the whole earlier and riskier than in the general population.

<http://eliminateaids.blogspot.com/2008/08/beyond-barriers-disability-and-hiv-aids.html>

The Kampala Declaration on Disability and HIV/AIDS is an advocacy tool for all Campaign partners and supporters. We invite you to download this printer-ready version in English, French and Portuguese to disseminate at your various meetings and conferences!

<http://www.africacampaign.info/a-nos-lecteurs-francais/index.html>  
<http://www.africacampaign.info/recent-publication/index.html>

## **A short recent history of the Disability Rights Movement in El Salvador**

This article argues that despite national laws and certain improvements towards disability rights, El Salvador has only made nominal progress in implementing disability legislation and awareness.

In the context of El Salvador's twelve-year armed conflict, 70,000 individuals were killed and another 300,000 people were disabled as a result of war.

However, this estimate conflicts with official statistics released by the Ministry of Economy in August 2008. Jesus Martinez, Director of the Landmine Survivors Network-El Salvador is extremely uncomfortable with the results of this 2008 Census.

"It should include accurate and trustworthy statistics about all of the disabled individuals living in this country." he says.

Disabled people need to be counted in order to be visible in policy action, planning and prioritisation. Article 31 asks countries to find out about disabled people. State parties need collect appropriate information, including statistical and research data, to enable them to formulate and implement policies, which make a reality of the rights in the Convention.

If the Convention marks "a paradigm shift" in attitudes and approaches, then disabled people are not objects that are being counted, but subjects, who have rights and freedoms. As a result of this shift in thinking, ratification of the Convention should also mark a shift in creating a more inclusive society in El Salvador.

<http://upside-down-world.org/main/content/view/1384/74/>

## **Sit-in at Nursing Home**

Demonstrators organised a sit-in and called for closure of a nursing home in Philadelphia. "There is no justice for someone in a nursing home," read a sign held by one of the demonstrators.

The group's goal was to persuade Mayor Nutter to help find homes for 50 or so disabled residents over the next six months, then get out of the nursing-home business. They were successful! Details at:

<http://www.adapt.org/>

[http://www.philly.com/philly/hp/news\\_update/20080818\\_Protesters\\_seek\\_to\\_close\\_Philadelphia\\_nursing\\_home.html](http://www.philly.com/philly/hp/news_update/20080818_Protesters_seek_to_close_Philadelphia_nursing_home.html)

### **And Finally ...**

Discrimination is a putrid shade of yellow

It tastes like stale vomit

It smells like rancid fish

Discrimination reminds me of corruption, anger and despair

And sounds like a hooded coward running scared

Discrimination feels like nobody cares ...

Extract from Bipolar works blog, 2007

### **Thank you for your time.**

We are pleased to hear from you.

Email: [mysay4daa@live.co.uk](mailto:mysay4daa@live.co.uk)

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