

# Our Rights - issue 6, January 2009



*This newsletter contains pictures. To get straight to the stories from the contents list, place your cursor anywhere on the headline you want to read and click enter.*

*For further news stories, you can go online to the DAA News Network. Go to <http://www.daa.org.uk/> We look forward to hearing from you. Thank you!*

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## **Lead Stories**

### **Tanzanians with Albinism are being slaughtered**

*BBC news reports in 2008 catalogue almost 30 brutal deaths of Albino Africans in Tanzania. The Guardian reported in November 2008 of "horrific murders of albinos in Tanzania" and "children hacked to death for their body parts" that have "shocked the nation". And recently, the president of Tanzania also acknowledged that people with albinism in Tanzania are at great risk of being murdered.*

*He called these killings "shameful and distressing to the nation."*

*Yet despite such evidence and admissions, little safeguard and protection is being offered to this vulnerable population.*

*Over 8,000 Tanzanians are known to have albinism. But unofficial statistics estimate much higher numbers. Disabled People International reports on the odious practice of murdering people with albinism for their body parts, which witch doctors in the country use in magic potions they claim will bring people good luck, is still practiced in Tanzania.*

*"It is said that body parts taken from the albinos are sold in Tanzania. They put the body parts on gold mines, and this brings gold to the surface. What you have to do after is just take the gold. Or fishermen use these body parts for catching big fishes which keep gold in their bellies," explains Richard, who is 19 years old and lives in fear as someone, who has albinism. He was alerted by his neighbour and ran away to hide in the forest.*



*The picture shows Francine, who was brought to the police station of Ruyigi by a neighbour for protection.*

*"Buyers from as far away as the Democratic Republic of Congo, Burundi, Kenya and Uganda believe the legs,*

*genitals, eyes and hair of people with albinism can help them achieve instant wealth. The youngest victim so far was seven months old," reports The Guardian.*

*Article 3 of the Universal Declaration on Human Rights states that, "Everyone has the right to life, liberty and security of person. This basic right is reiterated in the Convention on the Rights of Disabled People.*

*Yet people with a physical difference, namely that of having white pigments, are believed either to be cursed or to have magical powers and supernatural properties.*

*Even when protected, Tanzanian albinos continue to face discrimination in schools or in the workplace. "People believe a woman who has an albino child has been cursed and that the whole family will now suffer bad luck. In olden days midwives killed the babies at birth but now that there are health centres, albino babies do survive." says Ernest Kimaya, chairman of the Tanzanian Albino Society.*

*Further reports can be found at <http://www.guardian.co.uk/world/2008/nov/16/tanzania-humanrights>*

### **Raped and Doused in Acid**

*Three young men filmed themselves raping a 16-year-old girl with learning difficulties before dousing her in caustic soda. On January 16th the court sentenced them. They were given what campaigners called 'insultingly low' sentences.*

*The rapists were locked away for up to nine years but are likely to serve just half their terms and be released while still in their early 20s. One of them will be freed in just two-and-a half years, it was claimed.*

*Kathryn Stone, Chief Executive of VOICE UK, stated "these sentences don't come close to reflecting the*

*brutality and horror of this attack. They send completely the wrong message to society and it's ironic it comes on the day the Government says how it will tackle crime against people with learning disabilities."*

*In a joint statement, four learning disability charities criticised what they called the 'insultingly low' sentences. Richard Curen, chief executive of Respond, said:*

*'These sentences are another injury and I fear it will take even longer for her to recover.'*

*This is yet another example of low sentencing when crimes are committed against disabled people. The UN Convention re-affirms our rights and equal worth.*

*Under Article 5 countries are to recognize that all persons are equal before the law and must guarantee disabled people equal legal protection.*

*Read the full story at*

**<http://www.voiceuk.org.uk/news.htm>**

*Further information about VOICE UK, and organisation supporting people with learning difficulties, who are victims of crime, go to:*

**<http://www.voiceuk.org.uk/>**

*Valuing people now sets out the Government's strategy for people with learning disabilities for the next three years. The Report can be downloaded here:*

**[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_093377](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377)**

## **Comment:**

**Inauguration of Barak Hussein Obama.**

*On 20th January 2009, the man who had become the 44th President of the USA proclaimed an 'end to the petty grievances and false promises, the recrimination and worn-out dogmas, that for far too long have strangled our politics'.*

*He said that the time had come to carry forward the 'promise that all are equal, all are free, and all deserve a chance to pursue their full measure of happiness'.*

*He said that 'greatness was never given', that 'it is not a path for the faint-hearted' but it has been the 'risk-takers, the doers, the makers of things – who have carried us up the long, rugged path toward prosperity and freedom'.*

*For fifteen minutes he waged his individual battle against political expediency and fought for peace, freedom and equality. We have not heard words like this for a very long time. His speech did not contain the one sound-bite beloved of the media - every word mattered. He did not favour one excluded group or make lists of the powerless.*

*As Jesse Jackson said – 'he was bigger than our race'.*

*And that, for me, was the most important aspect of Barak Obama's inaugural speech.*

*It did not matter that he did not mention disabled people, or indigenous people or sexual orientation. He made it quite clear that it was his profound belief that the gift of freedom is for every single person.*

*Fighting for freedom must be for everyone and the responsibility of everyone. You cannot get freedom for one country or person or tribe or creed at the expense of another. You cannot free yourself without freeing others.*

*Obama sent a message to the world. It will now be up the world to make the most of it and not ruin its chance for peace and freedom through jealousy, small-mindedness, pride or arrogance.*

*Alice Walker, the black feminist writer, said it all: ' the baton must be passed to those who have the radiance to carry it'.*

*Rachel Hurst, Director DAA*

## **In the News:**

### **Dying man 'not worth saving'**

*A disabled man was apparently left to die by two paramedics, who decided that his life was not worth saving.*

*Barry Baker from Brighton phoned the Ambulance Services when he collapsed with symptoms of a heart attack. The phone line remained open and the subsequent conversation between the paramedics was overheard.*

*When the attending paramedics saw the messy flat and cluttered living conditions, they felt it was not worth saving this man's life. Mr Baker had progressive arthritis, but refused to ask for any assistance. He did enjoy regular trips out and used to work for the Department of Work and Pensions until his early retirement. Without assistance, however, he did not manage to keep his house clean.*

*Two South East Coast Ambulance Service NHS Trust workers were arrested on 5 December on suspicion of neglecting to perform a duty in public office contrary to common law.*

*The paramedics, aged 44 and 35, have been suspended from their jobs and bailed until later this month while an investigation is carried out.*

Read full details at  
<http://www.guardian.co.uk/society/2009/jan/03/paramedic-arrests-brighton-barry-baker>

### **Designer Babies?**

*In London the first baby was born free of a genetic variation linked to breast cancer. This sparks fears that more 'designer babies' will be selected.*

*Disabled people are concerned that their lives are seen as not worth living, as doctors will increasingly screen-out genetic defects, unwanted differences and impairments.*

*The baby girl was born to parents, who received fertility treatment in London.*

*"This little girl will not face the spectre of developing this genetic form of breast cancer or ovarian cancer in her adult life," said Paul Serhal, head of the Assisted Conception Unit at UCL Hospital.*

*The husband's grandmother, mother, sister and a cousin have all been diagnosed with breast cancer. Several embryos were screened. Two embryos found not to have the faulty BRCA1 gene were implanted, and one grew to full pregnancy. The other embryos were deemed not worth saving and discarded.*

*Today there are already over 60 conditions for which pre-implantation genetic diagnosis (PGD) is available. With the birth of this baby girl, the UK is showing that it is more liberal in its bioethics laws than other European countries, where such embryo-selection is prohibited.*

*Pre-implantation genetic testing (PGD) is a technique used to identify genetic defects in embryos created through in vitro fertilization (IVF) before pregnancy. This can be used when one or both genetic parents has a known genetic*

*difference or defect. Testing is performed on an embryo to see if it also carries this genetic code.*

*In contrast, pre-implantation genetic screening (PGS) refers to techniques where embryos from presumed chromosomally normal genetic parents are screened for one or more extra or missing chromosomes.*

*PGS is a step further towards 'designing' babies by screening out what is unwanted in pregnancies with no known genetic variation of either parents.*

*Michael Aston from the Life charity says: "The big question is, where is it going to stop?"*

*Disabled people are concerned about the 'slippery slope' dressed-up as progress.*

<http://news.scotsman.com/uk/39Designer39--fear--after.4862568.jp>

<http://www.physorg.com/news150711051.html>

### **"I don't want to be cured of Autism"**

*exclaims Anya Ustaszewski. She argues for a more diverse world. Anya is against pre-natal testing or screening and reminds people that it is society that disables, not the medical condition, a label or impairment.*

*"As someone on the Autism spectrum, I strongly oppose any kind of "cure" for autism; I also oppose prenatal testing and the eugenic elimination of autistics, as well as any research that could lead to these outcomes."*

*"The autistic rights movement, which is allied to the wider disability rights movement, believes that people on the autistic spectrum are disabled more by society than by their autism. Like many members of this movement, I consider autism to be a part of natural human variation that should be accepted and respected, as with any other human difference."*

Read the full article by Anya Ustaszewski, click here <http://www.guardian.co.uk/commentisfree/2009/jan/14/autism-health>

### **Disability Equality: Promoting Positive Attitudes**

*In December, a research study by The Children's Society found that about a third of children said they did not learn about disability at school.*

*Under the Disability Equality Duty of the DDA the education system has a duty to promote positive attitudes towards disabled people. This may best be achieved by learning **with** and learning **from** disabled people, rather than about them.*

*The UN Convention on the Rights of Disabled People signals a shift in thinking about disabled people, from objects of care and special treatment to subjects of rights. However, in schools this understanding of disability equality is far from becoming a reality.*

*"34 percent of schools that taught disability equality incorporated it into social activities, including school trips and joint sports days with special schools." reports The Children's Society.*

*Disabled people and their organisations argue for inclusion to promote positive attitudes.*

*Disability Equality in Education affirms that parents and professional should be allies to young disabled people by*

- *Empowering disabled children to have a strong sense of self as disabled people*
- *Join the struggle to stop segregative practice*

- *Building strong peer relationships with disabled and non-disabled peers.*

*"The movement for Inclusive Education is largely misunderstood and under-reported in the media", argues the Alliance for Inclusive Education. They have produced a DVD for everyone who wants to work towards a society built, not on **exclusion**, but one in which all people are brought up to live well together.*

*To read the full research go to*

[http://www.childrenssociety.org.uk/whats\\_happening/media\\_office/latest\\_news/10836\\_pr.html](http://www.childrenssociety.org.uk/whats_happening/media_office/latest_news/10836_pr.html)

*For details about ALLFIE and the Inclusion DVD go to*

<http://www.allfie.org.uk/pages06/resources.html#dvd>

### **Hammersmith judgement: Disabled people to Pay**

*In November, three disabled people took a case against Hammersmith Council arguing that they should not be charged for assistance in the home.*

*The High Court ruled in favour of the west London borough in a judicial review, allowing means-tested fees of up to £10 an hour to come into effect this month.*

*Hammersmith previously did not charge for such services, and disabled people based their arguments on a manifesto promise not to introduce the charges and expected that this should remain so.*

*In addition, campaigners argued that the Council failed to consider the impact such a change in policy would have on the most vulnerable in their community.*

*Kevin Caulfield, chair of HAFCAC, said "This judicial decision sadly demonstrates that institutionalised*

*discrimination against disabled and older people that require independent living support is alive and well."*

*Disabled people feel discriminated against, as other council services, such as the use of library, schools or refuse collection, are free at the point of service delivery.*

*We all pay our council tax, but disabled people are still seen as a 'burden' and have to pay extra.*

## **UN Convention for Disabled People:**

### **UK Government criticised for delay - wavering on Rights of Disabled People**

*Ministers had plans to ratify the UN Convention on the Rights of Disabled People by the end of 2008. It is now hoped that ratification will be achieved by spring 2009. The delay has come because ministers have been working on a series of reservations - or opt-outs.*

*A report by the Joint Select Committee on Human Rights (4 January 2009) strongly criticises the government for a "lack of transparency" and an "unacceptable" failure to adequately consult disabled people over the proposed opt-outs.*

*The report said that in addition to missing its deadline of Dec 2008 for ratification, it was proposing as many reservations as all other states combined. The Committee said that this undermined the Government's commitment to ensuring full and equal rights to disabled people.*

*Several areas are of concern, such as the commitment to inclusive education and equal opportunities for all disabled children. A number of government departments are discussing possible reservations to articles in the*

*Convention. This would dilute our rights and is unacceptable to disabled people.*

*Read the full story at  
<http://news.bbc.co.uk/1/hi/uk/7810211.stm>*

*A transcript of the session is accessible from the DAA News Network, where you can leave a comment (follow the links from our website) at <http://www.daa.org.uk/>*

### **Letter in The Times**

*On the 3rd December to promote the International Day of Disabled People, a coalition of 31 disabled people's organisations, the UNCCC, published a letter in The Times.*

*"Sir, The Government has set itself the ambitious target of achieving equal rights and opportunities for disabled people in the UK by 2025.*

*However, its recent announcement that it intends to ratify the UN Convention on the Rights of Persons with Disabilities with reservations suggests its commitment is wavering.*

*Disabled people in Britain are still being denied basic rights...."*

*To read the full letter, go to Times online  
<http://www.timesonline.co.uk/tol/comment/letters/article5275170.ece>*

### **Convention Updates**

*Convention sign-ups JANUARY 2009*

*137 signatories to the Convention*

*81 signatories to the Optional Protocol  
46 ratifications of the Convention  
26 ratifications of the Optional Protocol*

*Oman ratified the Convention on 6-1-2009  
Bulgaria signed the Optional Protocol on 18-12-2008  
Sweden ratified the Convention on 15-12-2008  
Sweden acceded to the Optional Protocol on 15-12-2008*

## **International News:**

### **What we did on International Day**

#### **Bangladesh:**

*On 3rd December 2008, the International Day of Disabled People, campaigners and friends in Bangladesh came together to raise awareness of disabled people's rights. This was organised by the National Alliance of Disabled Peoples Organizations (NADPO) a national network of Disabled Peoples Organizations (DPOs).*

#### **London:**

*"I had the day off work and met up with old and new friends in the Disabled People's Direct Action Network (DAN), blocking the traffic in Whitehall outside Downing Street to protest against the governments plan for welfare reform." says Richard Downes, Direct Action Coordinator of Brent Advocacy Concerns.*

*More information about this and a photo from the action exists on Richard's blog which can be found at*

**<http://detrich.wordpress.com/2008/12/03/action-against-welfare-reform-proclaimed-in-the-queens-speech-whilst-dan-protested/>**

#### **Northern Ireland**

*"To mark International Day of Persons with Disabilities 2008, the Centre on Human Rights for People with*

*Disabilities (CHRPD) at Disability Action hosted a panel debate on the Northern Ireland context of The Convention on the Rights of Persons with Disabilities.*

*Gerry Kelly, Junior Minister, Office First Minister and Deputy First Minister (OFMDFM), gave the opening address and stated publicly OFMDFM's commitment to working with the CHRPD on the Convention and its implications and application in Northern Ireland.*

*Over 120 key political, disability, private and public sector stakeholders attended the event.*

*Colin Harper, Manager Centre on Human Rights for People with Disabilities at Disability Action said: "It is vital that disabled people and all key stakeholders understand how the Convention will impact and benefit people in the Northern Ireland context. The Convention will increase the level of protection of disabled people's human rights but will also be an effective lobbying tool for people with disabilities."*



*The photo shows from left to right: William Crawley BBC Northern Ireland, Evelyn Collins Chief Executive Northern Ireland Equality Commission, Gerry Kelly Junior Minister,*

*Office First Minister and Deputy First Minister, Peter O' Neill Chief Executive Northern Ireland Human Rights Commission and Dr Colin Harper Manager at the Centre on Human Rights at Disability Action. Front - Monica Wilson, Chief Executive Disability Action*

*"We have been lobbying with other disability organisations throughout the UK to ensure that the UK Government ratifies the Convention in full. The UK Government currently has 4 areas it is considering reserving on, including education and capacity law. If the Convention is ratified with reservations, the UK government would in effect, be declaring its willingness to accept less than the agreed international standard for the protection of the Human Rights of disabled people across the UK" explains Colin Harper.*

*For further information on the UNCRPD and the work of CHRPD contact Gráinne Teggart at Disability Action on 02890 297880 or [grainneteggart@disabilityaction.org](mailto:grainneteggart@disabilityaction.org)"*

## **Mental Health and Human Rights Abuses in Bulgaria**

*On the 3rd December 2008, the International Day of Disabled People, three organisations came together in Bulgaria to express their deep concern over the situation of disabled people living in mental health institutions in Bulgaria.*

*To draw attention to the human rights abuses, the World Organisation Against Torture (OMCT), the Bulgarian Helsinki Committee (BHC) and the Mental Disability Advocacy Center (MDAC) sent a number of letter to members of the Bulgarian Parliament and Government, officials and elected representatives in the European Union, and the United Nations Special Procedures mandate holders.*

*The three organisations say that disabled people with mental health issues in Bulgaria, "frequently face social*

*exclusion and severe human rights violations, including violence and ill-treatment”.*

*Regardless of their skills and capabilities, people living with mental health conditions are often deemed incompetent, deprived of their legal capacity and placed under guardianship. Their rights to make their own decisions are taken away and other basic human rights denied, including the right to have meaningful relationships, to marry, to vote, to work, to take legal action and to seek judicial remedies.*

*Violations of basic rights have far reaching consequences, which are discussed in full in the press release report.*

*To read the full report, go to DAA News Network, where you can leave a comment, at <http://www.daa.org.uk/>.*

### **Where were you on 3rd December 2008?**

*We would love to hear your story. Please leave a comment about what you did, the event you took part in and people you met on our DAA website or send an email.*

*To view stories and photos go to our DAA web site at the DAA News Network.*

**“One of the Best Articles on Euthanasia you will ever read...” says Not Dead Yet, USA.**

**If doctors who won't kill are 'wicked,'  
the world is sick**

*By Licia Corbella*

*Calgary Herald - Saturday, January 10. 2009*

*Talk about Orwellian. A woman described as a "leading expert in ethics" has declared that doctors who refuse to kill their patients are "genuinely wicked." I'm not making this up.*

*Mary Warnock, a British baroness told the Northern Ireland Forum for Ethics in Medicine and Healthcare this past Monday, that doctors who refuse to break their Hippocratic oath are evil.*

*It seems that virtually every day, I read another story that proves the world--and what is accepted as good and true --is being turned on its head.*

*Referring to terminally ill patients who make a written request to be killed when they reach a certain point in their illness, Warnock said: "There are doctors, we know, who don't pay any attention (to those written wishes to be killed).*

*"But that seems to me a genuinely wicked thing to do--to disregard what somebody had quite explicitly said, that he wants to die . . . "*

*This is the same old bird (she's 84) who argued that people who have dementia or Alzheimer's disease have a "duty to die" because they are a burden to society and their families.*

*"If you're demented, you're wasting people's lives--your family's lives--and you're wasting the resources of the National Health Service," she said a few months ago.*

*There was a time when such statements would be described as wicked and the orator as well.*

*But in Warnock's twisted world of "ethics," doctors who kill are righteous and doctors who refuse to kill are villainous.*

*Black is white, white is black and wrong is right. Murder is merciful and compassionate care, cruel. Somewhere out there, George Orwell is saying, "I told you so."*

*In her Jan. 5 speech, Warnock dismisses the idea that murdering the elderly and "demented" will not lead to a slippery slope of killing infants, depressed teens and others.*

*But that is precisely what is happening in Holland, where euthanasia has been practised since 1980 and has been fully legal since 2002.*

*Currently, infants born with defects are often killed by their doctor, with or without the parents' permission, not that permission makes it any more acceptable.*

*That's not just a slippery slope, it's Mount Everest in a blizzard.*

*The language surrounding euthanasia is necessarily softened by its proponents, calling the active killing of another human being, mercy killing, dying with dignity and choice. But what actually has been shown to happen in places that embrace legalized euthanasia is the antithesis of choice.*

*In a government study in the Netherlands, called Medical Decisions about the End of Life, it was found that in 1990 alone 1,031 patients were actively killed by their doctor without their request and of those people, 14 per cent were fully competent, 72 per cent had never expressed that they wanted their lives ended and in eight per cent of the cases, doctors performed "involuntary euthanasia" even though they believed other options were available.*

*Similar subsequent studies found similar outcomes.*

*So, this form of "choice" actually leads to thousands of people never being able to make a choice--ever again.*

*Even some staunch proponents of euthanasia say Holland is an extreme example. Much better to look to Oregon, where physician assisted suicide (PAS) has been legal since 1997.*

*But in the reports published annually by the state, it's evident that choice is compromised in Oregon too.*

*In 1998, 12 per cent of PAS patients in Oregon said they chose this irreversible course of action because they didn't want to burden their family. That rose to 26 per cent in 1999, 42 per cent in 2005 and 45 per cent in 2007, the last year figures are available. If that were a company's bottom line, champagne corks would be popping!*

*In other words, for the infirm and disabled, the right to die quickly becomes the duty to die. Wanting to live despite being frail or ill increasingly is viewed as selfish in places where euthanasia is the law.*

*That's not empowerment, it's coercion, guilt for living, pressure to die.*

*According to Belfast's daily paper, The News Letter, after Warnock spoke in the debate --which was ironically held in a local church, one of the members of the audience, Avril Robb, a lawyer and a member of the Medical Legal Society, said she had cared for her parents through their terminal illnesses and stated: "I do know that the last months were very precious."*

*That is what many who spend time caring for a dying parent, child or spouse says about a loved one's last days and months. Their vulnerability causes all emotional walls to tumble down and petty problems to vanish.*

*A nurse friend of mine who works in palliative care but had also spent years helping to bring babies into the world*

*says: "I'm convinced that dying can be a more blessed a time than birth."*

*That may sound counterintuitive, but compared to saying that refusing to kill is wicked, it's much easier to believe.*

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*<http://www.canada.com:80/calgaryherald/news/story.htm?id=83835868-7f89-40bd-b16e-8bc961d41b39>*

## **And Finally ...**

### **The Perfect Human**

#### **Candoco Masterclass at the Southbank, London 4<sup>th</sup> February 2009**

*Candoco Dance Company is the contemporary dance company of disabled and non-disabled dancers.*



*Having toured for nationally and internationally for the past 17 years, this year the company performs new works by Hofesh Schechter (*The Perfect Human*) and Nigel Charnock (*Still*).*

*This masterclass focuses on Hofesh Schechter's *The Perfect Human*. The company teaches a morning class,*

*followed by an afternoon of creative tasks based on the choreographers process and working methods.*

*Details, promotional videos and creative photographs about the company can be found at*

*<http://www.candoco.co.uk/>*

*For details contact the South Bank Centre by phone 0871 663 2500 or online at <http://www.southbankcentre.co.uk/all-events/productions/the-perfect-human--candoco-43758>*

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