

**WHO Geneva**

**Seminar series on Disability**

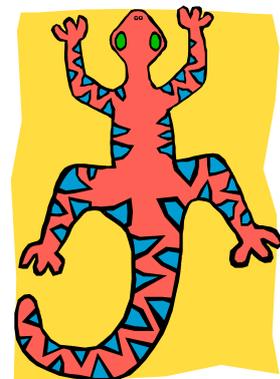
**8 April 2009**

**“MAKING LEMONADE OUT OF LEMONS:  
Stories of despair, determination and resilience of the spirit”**

**A presentation on HIV and disability**

**Alice Welbourn PhD**

**The Salamander Trust**



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**INTRODUCTION**

Good afternoon everybody. It’s a great pleasure to be invited here today to take part in this important seminar. Many thanks to you all, and to Tom Shakespeare<sup>ii</sup> especially, for inviting me and for organising today’s session.

HIV is a disability. This may sound totally obvious to some of you and ridiculous to others. And some people with HIV may not agree with me. That is everyone’s prerogative to which they are of course entitled. So here I’m going to explain why, in *my* view at least, this is so.

Disability, HIV and their relationship are clearly a vast area for discussion and action, and after me, you’ll hear many other issues<sup>iii</sup>. So I’m going to limit my talk very clearly this afternoon to HIV as a disability in itself.

Tom was kind enough to ask me to give my personal view, given that I am myself HIV positive and have been for 20 years this year, and that although I consider myself to be very fortunate in many respects compared with many, I have myself, to some extent, experienced some of the debilitating issues – both physical and mental - which I am going to be talking about.

Today I’d like to look at the physical and especially the psychological consequences of an HIV diagnosis on people, and ask the question to what extent it makes any *sense* to think of HIV *per se* as a disability. I have taken as my reference point the 2006 Convention<sup>iv</sup> [2] on the Rights of Persons with Disabilities. In my view it resonates soundly with the experiences of many millions of people living with HIV.

The Convention begins by discussing the inherent dignity and *worth* and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world. Let’s see what other words in its language struck strong chords for me.

[3]

*Dignity,  
Worth,  
Rights and freedoms  
Convention on the Elimination of Discrimination Against  
Women  
Convention on the Rights of the Child  
Attitudes towards people with a condition  
Equal opportunities to influence policy, plans and practice..*

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*Sexual and reproductive rights of all*  
*Stigma – phobias and “-ism”s*  
*Women and girls*  
*Peace and security – non-violence*  
*Access to all parts of life*  
*Responsibilities*  
*Protection for and by family members*

And these words are just mentioned in the *preamble* to the main Convention. Let’s see what other words jumped out at me as I read on:

[4]

*Reasonable accommodation*  
*Awareness raising and respect education from primary school*  
*Accessibility to work, transport, schools, leisure,*  
*housing, medical facilities, health*  
*Appropriate communication – and to me this speaks not just*  
*about Braille and sign language, but also the means by which we work*  
*together – by using participatory non-formal approaches, rather than just*  
*formal meetings and written reports*  
*Right to life and care, treatment and support*  
*Protection in conflict zones*  
*Training of judiciary, police, prison staff, health,*  
*education, social work and other staff*  
*Prevent... Cruel, inhuman or degrading*  
*treatment*  
*Security within and outside the home*  
*Promote physical, cognitive and*  
*psychological recovery...*

[5]

And finally.....  
*Legislation to outlaw abuse*  
*Liberty of movement*  
*Privacy and confidentiality*  
*Fertility protection*  
*Insurance*  
*Equal Quality of care from health professionals*  
*Health and Life Insurance*  
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Now I can hear some of you thinking “well that’s all very well but that just basically covers what everyone wants: why don’t we all just call ourselves disabled? - surely, saying that people with HIV are disabled just makes a mockery of disability.” But I think that’s missing the point. Sure, we all feel discriminated against one way or another at some stage in our lives, on the grounds of our [6] skin colour, our gender, our age, our sexual orientation, our religion, what country we come from, our weight – you name it<sup>v</sup>. *None* of these discriminatory attitudes is just. But that’s another

argument. The point here is that this Convention chimes extraordinarily closely with the many and repeated issues raised by people with HIV around the world in relation to our own experiences of living with this bug in our bodies. I love this document. It's very *people*-centred - and this is what so often feels *missing* from the world of HIV. Our identities get reduced to a bunch of letters and our worth, our validity as *people* gets lost in our [7] *invalid* - or in-*valid* - status. We are experiencing many of the issues on these slides consistently over time, owing to our medical condition and I believe this convention is of enormous relevance to our lives.

Now let me explain further why I find that so many of these issues relate to positive people. We all know about many of the *physical* impairments associated with HIV for many people - peripheral neuropathy, lipodystrophy, blindness, speech impairment, memory loss, repeated shingles attacks and so on. There are other physical challenges associated with medications, such as my friend who has to self-inject 3 times a day, despite her phobia of needles, or another friend who feels entirely debilitated by the physical and mental side-effects of interferon. But today I'd like to focus especially on the psychological dimensions of HIV - a chronic aspect which I think has been far too greatly overlooked. I do appreciate the WHO report <sup>vi</sup>to the Executive Board last November, which focused on HIV and mental health, which is great - but I still feel that there was too much emphasis in that document on mental health linked to drug use. Personally I feel that mental health issues are experienced by a far wider group of positive people also.

The abstracts<sup>vii</sup> from Mexico included many many presentations on chronic clinical depression amongst positive people and their families of all ages and genders around the world. The first shock of HIV diagnosis and the post-traumatic adjustments that need to take place are rarely adequately supported, particularly, I would argue, for women learning of their diagnosis during pregnancy<sup>viii</sup>. A close relative of mine, a doctor, is expecting her first child and is amazed by how nothing had prepared her for the intense protective anxiety she has felt for this little one from its earliest days in her womb. How much worse to imagine the terror of discovering one has a life-threatening condition whilst carrying such a precious cargo. Positive women from [8] Namibia have recently documented how, after compulsory testing during pregnancy, health staff have subjected them to extremes of verbal abuse and to coerced sterilisation after labour<sup>ix</sup>. It's not just Namibia. Such experiences are deeply traumatic<sup>x</sup> and demand huge emotional and physical resources and resilience to deal with - for the rest of their lives. Thus many women - whether positive or not - in many countries now feel exceptionally wary of accessing even family planning, let alone ante-natal services when they know that if they test positive they could be thus degraded, abused and violated<sup>xi</sup>. Such staff behaviour does nothing to reduce unplanned pregnancies or to promote safe motherhood, thereby jeopardising both prongs 1 and 2 of the PMTCT guidelines by their actions, and adding to maternal - and child - mortality statistics<sup>xii</sup>.

In preparing this talk, I did a quick survey of positive women on email listservs around the world<sup>xiii</sup>. On top of these widely reported sexual and reproductive rights abuses by health staff, women also listed discrimination and abusive practices across a range of issues. There were the women who had lost their jobs once their status was known, the women who can't sell food or soap any more because their clients fear it's contaminated. There are women told to keep quiet about their HIV by their bosses in case customers go elsewhere, and highly skilled women who have been so long away from work with illness that all their former confidence has deserted them. There are women who see colleagues with breast cancer around them cherished by other colleagues, who wish that they could hope for similar support. Positive people who are also drug users describe the double stigma when addiction isn't seen as a disease and work opportunities are impossible<sup>xiv</sup>. There are positive transgender outreach workers, beaten up by the police<sup>xv</sup>. And there are positive doctors and nurses who live in terror of their colleagues finding out and their losing the jobs they love. In relation to property and inheritance rights, there are widows accused of witchcraft and thrown out of their homes once they've finished nursing their husbands who have died from AIDS-related illnesses. On the housing front, positive people have had bricks through their windows, death threats and dog excrement through their doors<sup>xvi</sup>; thousands of positive women experience physical, sexual and psychological abuse from partners and other family members in their homes, so that they have no place of safety to turn to<sup>xvii</sup>. Positive gay men have been killed in their homes. Transport problems also abound and the sense that life is closing in when positive people can no longer move around freely or when their vehicles get vandalised (see xvii also)<sup>xviii</sup>. Positive women especially spoke about the huge strain on their families also – with their children being ostracised at school<sup>xix</sup>. Partners of positive men with haemophilia have spoken of the immense stress in their lives of poverty, repeated bouts of their partners' ill-health and chronic depression experienced by them both<sup>xx</sup>. There are people hounded by their neighbours, the media, even social services and political representatives if their positive status is revealed.

Many positive people decide to go back to studying - if they can - after coming to terms with their diagnosis – to study healthcare, psychology, social development, the law... but many also find it hard to access courses on a part-time basis so they can pace their studies alongside just coping.

So you will see that many of the issues raised in my mini-survey – the rights to work, safety, housing, transport, respect, dignity, health care – are severely compromised by an HIV diagnosis, and that the psychological consequences of this are undoubtedly immense and chronic. As one positive woman put it “doctors don't treat the *causes* of depression, just its symptoms.” Many of these stories are from Britain also<sup>xxi</sup>. [9] This is the headline I woke up to in my local paper last month<sup>xxii</sup>. No wonder so few of us are open about our status, not daring to risk losing all that we have invested in our lives and those of our families. In the UK there are

still only about 30 women out of 25,000 with HIV who dare to talk in public about our status. So the idea that access to ARVs would somehow wipe out stigma is a hollow hope. The widespread introduction of criminal legislation too now, I think you can imagine, has added an extra huge layer of fear, anxiety and trauma to our already over-secretive existences<sup>xxiii</sup>. [10] And in Britain this also carries an extremely racist bias<sup>xxiv</sup>.

This is one reason why I think the role of GIPA and of treatment activism [11] has been so huge in the history of the HIV movement<sup>xxv</sup>. There are so many of us who just want to make sense of our diagnosis, to put something back, to find the silver lining, to ensure that others don't have to experience all that we have. Call it our coping strategies if you will – but if it keeps us a bit more sane, a bit less chronically depressed, is that not something which should be recognised and welcomed, rather than endured out of political correctness? Positive people are an immense untapped and barely utilised resource<sup>xxvi</sup>. I understand from Tom that the mainstream disability movement worldwide does feel that it has been successful in being well represented, here in WHO and elsewhere, in the promotion and creation of policies and practices, such as independent living, direct payments and the disability rights legislation. I look forward to the day when people with HIV can feel equally successful in our efforts to achieve good representation also.

I never cease to be humbled by the extraordinary resilience of the thousands of positive people I have had the great privilege to meet since my own HIV diagnosis in 1992. After a string of emails recounting to me some of the awful things that had happened to them over the years, one positive woman decided it was time to up the beat and swap back to the positive track. She wrote us the following: [12]

*"Hi Ladies, I just wanted to share my good news with you. I passed my MSc in Social Development and Health from \*\*\*\* University and just got the results. I am very pleased with myself.*

*This HIV has made me a very focussed person and I don't think I would have done all that I have, if it was not for the diagnosis!!!*

*I got a lemon and I am trying to make lemonade and it feels great all the time!!!*

*"Cheers ladies for all the good work we are achieving together."*

Making lemonade out of lemons. What a great image. Personally I hope that this Convention on the Rights of People with Disabilities and seminars like this one today will enable many more of us who've been dealt lemons in life to learn how to make lemonade – so that we can share it freely and widely, openly – and safely – with all around us, wherever we are in the world.

**"Making Lemonade out of Lemons: Stories of Despair, Determination and Resilience of the Spirit"**

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[13]

Thank you.

*Thank you! to Tom Shakespeare, Karusa Kiragu, Alana Officer, Amandine Bollinger, Maria de Bruyn, Fiona Hale, Doortje Braeken, Nigel, plus Beri Hull, Jeni Gatsi, Heidi Nass, Carmen, Fiona, Julie, Joyce, Ruth, Hosana, Isabel, Fran, Supecha, Maire, Tembeni, Shari, Thandie, Susan, Sue, Veritee and many other courageous positive people of all ages who have shared their stories from around the world.*

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<sup>i</sup> Highlighted numbers in square brackets refer to the slide number in the accompanying powerpoint presentation. This can be accessed at [www.salamandertrust.net](http://www.salamandertrust.net)

<sup>ii</sup> Dr Tom Shakespeare, WHO Consultant on Disability, Organiser of the Seminar series of which this forms one part.

<sup>iii</sup> Other presentations in the seminar were by:

Dr Susan Girois of Handicap International, which focused on the new WHO Policy Brief on HIV and Disability

([http://www.who.int/disabilities/jc1632\\_policy\\_brief\\_disability\\_en.pdf](http://www.who.int/disabilities/jc1632_policy_brief_disability_en.pdf))

UNAIDS, WHO and UNOHCHR (2009) 'Policy brief: HIV and disability', Geneva: WHO

and by Sharon Peake and Myroslava Tataryn of Health Canada and AIDS-Free World respectively, about an international summit meeting about HIV and Disability, held in Ottawa in March 2009 (<http://www.aids-freeworld.org/content/view/243/66/>) and (<http://video.google.com/videoplay?docid=-3877365997980916501&ei=oav5SZW8MJzp-Abyt8DbCQ&q=double+discrimination+>)

**Key documents about Disability as a factor exacerbating vulnerability to HIV also include:**

AIDS Portal (2008) 'People with disabilities', *AIDS Portal*; available at:

[http://www.aidsportal.org/overlay\\_details.aspx?nex=58&qclid=CKrlocSPvJkCFQ6vQwod\\_2zv4w](http://www.aidsportal.org/overlay_details.aspx?nex=58&qclid=CKrlocSPvJkCFQ6vQwod_2zv4w)

Africa Campaign <http://www.africacampaign.info/>

Babu, M and de Bruyn, M (2008) 'Beyond Barriers: Disabilities and AIDS', Oral Abstract Session, Mexico: XVII International AIDS Conference;

<http://www.aids2008.org/Pag/PSession.aspx?s=277>

Cichocki, M (2007) 'Is HIV a Disability? The Law Says It Is: So What Are Your Rights in the Workplace?', *about.com*; available at:

<http://aids.about.com/od/legalissues/a/disability.htm>

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DFID (2007) 'Helping a forgotten minority: Disability and HIV/AIDS in Zambia', London: *DFID*; available at:  
<http://www.dfid.gov.uk/casestudies/files/africa/zambia-disability.asp>

Handicap International [http://www.handicap-international.org.uk/page\\_66.php](http://www.handicap-international.org.uk/page_66.php)

Healthlink Worldwide and the Family AIDS Caring Trust (FACT) (2007) 'Disability and inclusion: HIV, sexual health and disability in Zimbabwe', *Healthlink*; available at: <http://www.healthlink.org.uk/projects/disability/hiv.html>

NAT (2006) 'HIV and your Disability Scheme', London: *NAT*; available at:  
<http://www.nat.org.uk/Media%20Library/Files/PDF%20documents/HIV-disability-equality-scheme.pdf>

Rohleder, P *et al.* (2009) 'HIV/AIDS and disability in Southern Africa: a review of relevant literature', *Disability & Rehabilitation*, 31(1):51 – 59, January Cape Town, South Africa: Human Sciences Research Council; available at:  
<http://www.informaworld.com/smpp/content~content=a908489109~db=all~jumpType=rss>

Tataryn, M. (2008) 'Emerging from war, finding a voice: Intersections of disability and HIV/AIDS in conflict and post conflict settings', *AIDS-Free World*  
<http://www.aids-freeworld.org/images/stories/Docs/icasa%20paper%20final.pdf>

'The Disability Discrimination Act 1995', *Nam*, available at:  
<http://www.aidsmap.com/cms1007532.asp>

'UN Convention on the Rights of Persons with Disabilities' (2008)  
<http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALPROTECTION/EXTDISABILITY/0,,contentMDK:21340640~pagePK:210058~piPK:210062~theSitePK:282699,00.html>

World Bank and Yale University (2004) 'HIV/AIDS and Disability: capturing hidden voices', *World Bank*; available at:  
<http://siteresources.worldbank.org/DISABILITY/Resources/Health-and-Wellness/HIVAIDS.pdf>

World Bank (2008) 'Disability and HIV/AIDS: Fact sheet', New York: *World Bank* available at: <http://v1.dpi.org/files/uploads/publications/factsheet.pdf>

World Bank studies – available at:  
<http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALPROTECTION/EXTDISABILITY/0,,contentMDK:20208464~pagePK:148956~piPK:216618~theSitePK:282699,00.html>  
and at: <http://cira.med.yale.edu/globalsurvey/Fact%20sheet.pdf>

See also WHO publications:

Catalan, J; Collins, P; Mash, B and Freeman, M (2005) *Mental Health and HIV/AIDS: Psychotherapeutic Interventions in Anti-Retroviral (ARV) Therapy for second level care*, Johannesburg: WHO, Module 5

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Cournos, F; Wainberg, M and Horwath, E (2005) *Mental Health and HIV/AIDS: Psychiatric care in Anti-Retroviral (ARV) Therapy for second level care*, Johannesburg: WHO, Module 3

Kelly, K and Freeman, M (2005) *Mental Health and HIV/AIDS: Organization and Systems Support for Mental Health Interventions in Anti-Retroviral (ARV) Therapy Programmes*, Johannesburg: WHO, Module 1

Sweetland, A; Lazarus, R; Freeman, M; Saloner, K (2005) *Mental Health and HIV/AIDS: Psycho-social Support Group in Anti-Retroviral (ARV) Therapy Programmes*, Johannesburg: WHO, Module 4

WHO and Southern Africa AIDS Trust (2004) *Mental Health and HIV/AIDS: Basic Counselling Guidelines for Anti-Retroviral (ARV) Therapy Programmes*, Johannesburg: WHO, Module 2

<sup>iv</sup> Full text of the Convention at <http://www2.ohchr.org/english/law/disabilities-convention.htm>

<sup>v</sup> See Aikman, S; Unterhalter, E and Boler, T (2008) *Gender Equality, HIV and AIDS: A Challenge for the Education Sector*, London: Oxfam GB; available at: [http://publications.oxfam.org.uk/oxfam/add\\_info\\_061.asp](http://publications.oxfam.org.uk/oxfam/add_info_061.asp)

Hoare, J and Welbourn, A (eds) (2008) *HIV and AIDS: Working in Gender and Development*, London: Oxfam GB; available at: <http://publications.oxfam.org.uk/oxfam/display.asp?&K=9780855986032;>

Welbourn A, Kilonzo F, Mboya TJ and Mohamed Liban S (2008) *Stepping Stones Plus: exercise "In the Spotlight"*, Oxford: Strategies for Hope, p17

<sup>vi</sup> WHO (2008) *HIV/AIDS and mental health: Report by the Secretariat of the World Health Organization*, New York: WHO, Executive Board 124<sup>th</sup> Session, 20<sup>th</sup> November; available at: [http://www.who.int/gb/ebwha/pdf\\_files/EB124/B124\\_6-en.pdf](http://www.who.int/gb/ebwha/pdf_files/EB124/B124_6-en.pdf)

See also:

Wazakili, M; Mpofu, R; Devlieger, P (2009) 'Should issues of sexuality and HIV and AIDS be a rehabilitation concern? The voices of young South Africans with physical disabilities', *Disability & Rehabilitation*; 31 (1):32-41

<sup>vii</sup> See <http://www.aids2008.org/mainpage.aspx?pageId=174>, especially volume 2.

<sup>viii</sup> See ICW (2008) *HIV Positive Women, Pregnancy and Motherhood*, ICW; available at: [www.icw.org/files/briefingpaper-%20motherhood%2009-08.pdf](http://www.icw.org/files/briefingpaper-%20motherhood%2009-08.pdf)

Rochat, T J; Stein, A and Richter, L (2008) 'Women's feelings, attitudes, and experiences on learning their HIV status during pregnancy in rural South Africa', Mexico: XVII International AIDS Conference; available at: <http://www.aids2008.org/Pag/Abstracts.aspx?AID=6872> --

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Rochon, D (2008) 'HIV-Positive Women & Health Care', *Women's Health and Urban Life*, Vol 7 (2):31-50, available at:  
<https://tspace.library.utoronto.ca/handle/1807/16688>

Sandelowski, M and Barroso, J (2003) 'Motherhood in the Context of Maternal HIV Infection', *Nursing & Health*, 26:470-482; available at:  
<http://ebn.bmj.com/cgi/content/extract/7/3/90>

<sup>ix</sup> See ATHENA, AIDS Legal Network and Namibia Women's Health Network (2009) 'Documenting Human Rights Violations in Healthcare Settings: Experiences of HIV Positive Women in Namibia', *ATHENA*; available at:  
[http://www.athenanetwork.org/docs/ATHENA\\_NWHN\\_Case\\_Studies.pdf](http://www.athenanetwork.org/docs/ATHENA_NWHN_Case_Studies.pdf)

ICW (2009) *The Forced and Coerced Sterilization of HIV Positive Women in Namibia*, ICW; available at:  
<http://www.icw.org/files/The%20forced%20and%20coerced%20sterilization%20of%20HIV%20positive%20women%20in%20Namibia%2009.pdf>

Welbourn, A (2008) 'Into the Firing Line...: Placing young women and girls at greater risk', *AIDS Legal Network*, Sep-Nov:14; available at:  
[http://www.salamandertrust.net/resources/ALQDoubleEdition08Criminalisation\(2\).pdf](http://www.salamandertrust.net/resources/ALQDoubleEdition08Criminalisation(2).pdf)

<sup>x</sup> Stratshope audio files: <http://www.stratshope.org/d-audio.htm>

ICW (2007) *Report of ICW Workshop on Motherhood for Positive Women*, ICW; available at: [www.icw.org/node/318](http://www.icw.org/node/318)

<sup>xi</sup> See Kehler, J (2008) 'personnal communication', in Welbourn, A (2008) 'Into the Firing Line...: Placing young women and girls at greater risk', *AIDS Legal Network*, Sep-Nov:19; footnote 11; available at:  
[http://www.salamandertrust.net/resources/ALQDoubleEdition08Criminalisation\(2\).pdf](http://www.salamandertrust.net/resources/ALQDoubleEdition08Criminalisation(2).pdf) pp14-19

Eyakuze, C; Jones, D A; Starrs, A M and Sorkin, N (2008) 'From PMTCT to a more comprehensive AIDS response for women: a much needed shift', *Developing World Bioethics*, 8 (1): 33-42

Stevens, M (2008) 'From HIV prevention to reproductive health choices: HIV/AIDS treatment guidelines for women of reproductive age', *African Journal of AIDS Research*, 7(3): 353-359

Stevens, M (2008) 'Towards treatment guidelines for women of reproductive age: recognising the right to choose', *Agenda*,75: 67-77

<sup>xii</sup> Empathetic and supportive sexual and reproductive health services for HIV-positive young people – whether positive since childhood, or whether having acquired HIV as young adults – are also severely lacking.  
See for example

Engenderhealth and ICW (2006) *Sexual and Reproductive Health for HIV-Positive Women and Adolescent Girls: Manual for Trainers and Programme Managers*, New York: Engenderhealth; p.52; available at:

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[http://www.icw.org/files/srh\\_manual\\_final%20pdf-Nov-06.pdf](http://www.icw.org/files/srh_manual_final%20pdf-Nov-06.pdf) see page 52 especially.

Young women's dialogue report: eg <http://www.icw.org/node/343>

Welbourn A, Kilonzo F, Mboya TJ and Mohamed Liban S (2008) *Stepping Stones Plus: Session 04 "Supporting Health Staff to help us" – MPMTCT/Young People's Health Services*, Oxford: Strategies for Hope (<http://www.stratshope.org/t-plus-manual.htm>)

WHO and UNICEF (2008) *More Positive Living: strengthening the health sector response to young people living with HIV*, Geneva: WHO [http://whqlibdoc.who.int/publications/2008/9789241597098\\_eng.pdf](http://whqlibdoc.who.int/publications/2008/9789241597098_eng.pdf)

Aikman, S; Unterhalter, E and Boler, T (2008) *Gender Equality, HIV and AIDS: A Challenge for the Education Sector*, London: Oxfam GB, Chap 2,3 and 7; available at: [http://publications.oxfam.org.uk/oxfam/add\\_info\\_061.asp](http://publications.oxfam.org.uk/oxfam/add_info_061.asp)

The mental health issues faced by young people owing to relationship problems, even without an HIV diagnosis, are also not adequately recognised:

Jewkes, R *et al.* (2008) *Stepping Stones Study: Fact sheet on young people's health and sexual practices in villages and townships of the rural Eastern Cape*, South Africa: MRC; available at: [http://www.steppingstonesfeedback.org/wp-content/uploads/2009/05/stepping\\_stonesfactsheetsouthafricamrc.pdf](http://www.steppingstonesfeedback.org/wp-content/uploads/2009/05/stepping_stonesfactsheetsouthafricamrc.pdf)

<sup>xiii</sup> These listservs are ICW Members, Women's Asia-Pacific Network, ICW Europe and Pozfem UK. All are closed list-servs for HIV positive women.

<sup>xiv</sup> Tarrades, C; *et al.* (2006) *A Community Engagement Project : "Silent Voices"*, ICW ; available at : <http://www.icw.org/node/209>

<sup>xv</sup> See also Shivananda Khan, Mexico AIDS Conference presentation in IPPF criminalisation satellite: See "Adding Insult to Injury" under "Criminalisation of HIV" at <http://www.ippf.org/en/What-we-do/AIDS+and+HIV/MexicoAIDSconference2008.htm>

<sup>xvi</sup> See for example Fran (2009) 'Personal Story', *Positively Women magazine*, Winter: 8-9. <http://www.positivelywomen.org.uk/magazine.html>

<sup>xvii</sup> See Amnesty report from South Africa  
Amnesty International (2008) *"I am at the lowest end of all": Rural women living with HIV face human rights abuses in South Africa*, London: Amnesty International; available at: <http://www.amnesty.org/en/library/asset/AFR53/001/2008/en/ebc94db1-f123-11dc-b3df-0fe44bc152bc/afr530012008eng.pdf>

Human Rights Watch (2007) *Hidden in the Mealie Meal: Gender-Based Abuses and Women's HIV Treatment in Zambia*, Human Rights Watch, December, 19 (18,A); available at: <http://www.hrw.org/sites/default/files/reports/zambia1207web.pdf>

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ICW (2008) *Violence against HIV Positive Women Briefing*, ICW (<http://www.icw.org/files/Violence.pdf>)

GCWA (2008) 'Stop violence against Women: Fight AIDS', *What's real*, 2, Geneva: UNAIDS; available at: (<http://womenandaids.unaids.org/themes/docs/UNAIDS%20VAW%20Brief.pdf>);

Physicians for Human Rights (2007) *Epidemic of Inequality Women's Rights and HIV/AIDS in Botswana & Swaziland*, Massachusetts: Physicians for Human Rights (<http://physiciansforhumanrights.org/library/documents/reports/botswana-swaziland-report.pdf>)

<sup>xviii</sup> See ICW Namibia report on bicycle transport problems for positive women to access treatment in Namibia.

ICW (2008) *Transport Hampers AIDS Treatment*, ICW; available at: (<http://www.icw.org/node/393>)

<sup>xix</sup> Strategies for Hope: HIV, Women and Motherhood Project: Shari Margolese audio interview (<http://www.stratshope.org/d-audio-shari.htm>)

<sup>xx</sup> The Haemophilia Society (2001) *Visioning weekend for partners of registrants with haemophilia and HIV, 9<sup>th</sup>-10<sup>th</sup> June*, organised by Babs Evans and facilitated by Alice Welbourn; available at: <http://www.salamandertrust.net/resources/ProcessstressesandvisionsHSwe.pdf>

<sup>xxi</sup> Pozfem report (<http://www.poz-fem-uk.org/resources.html>) and Positively Women magazine – various articles (<http://www.positivelywomen.org.uk/magazinearchives.html>).

See also Anderson, J and Doyal, L (2008) 'HIV-positive African women surviving in London: report of a qualitative study', in Welbourn, A and Hoare, J (eds) 'HIV and AIDS', *Gender and Development*, London: Oxfam GB; available at: [http://publications.oxfam.org.uk/oxfam/add\\_info\\_049.asp](http://publications.oxfam.org.uk/oxfam/add_info_049.asp)

<sup>xxii</sup> 'The HIV Time Bomb', *The Western Morning News*, 28<sup>th</sup> Feb 2009; (<http://www.thiswesternmorningnews.co.uk/news/HIV-TIMEBOMB/article-734923-detail/article.html>)

<sup>xxiii</sup> See Welbourn March 2009 for a variety of references on HIV and criminalisation (<http://www.salamandertrust.net/index.php/page/Resources>).

<sup>xxiv</sup> Rhon Reynolds presentation:- See "Race and Immigration" under "Criminalisation of HIV" at <http://www.ippf.org/en/What-we-do/AIDS+and+HIV/MexicoAIDSconference2008.htm>

<sup>xxv</sup> See Odetoynbo, M; Stephens, D and Welbourn, A (2009) 'Greater involvement of people living with HIV in health care', *Journal of the International AIDS Society*, 12:4; available at: <http://www.jiasociety.org/content/12/1/4>

<sup>xxvi</sup> See Oosterhoff, P *et al.* (2008) 'HIV-positive mothers in Viet Nam: using their status to build support groups and access essential services', *Reproductive Health matters*, 16 (32): 162-170, November; available at: [http://www.rhm-elsevier.com/article/S0968-8080\(08\)32408-2/abstract](http://www.rhm-elsevier.com/article/S0968-8080(08)32408-2/abstract)

**"Making Lemonade out of Lemons: Stories of Despair, Determination and Resilience of the Spirit"**

**Alice Welbourn PhD**

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[www.m2m.org](http://www.m2m.org)

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