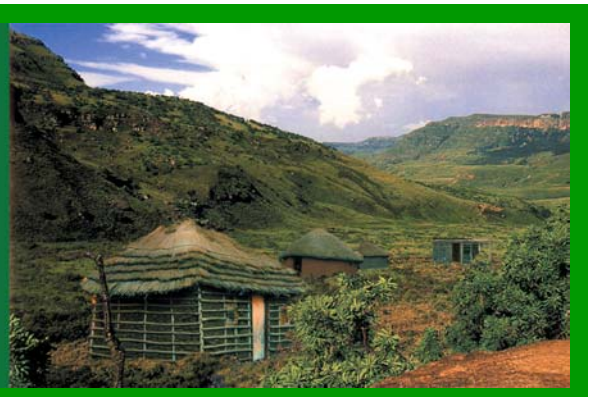
The MRC KwaZulu-Natal AIDS Forum

# KZNe News



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## Ed's say:

Many countries have, until recently, been dependent on existing public health laws and regulations when addressing HIV/AIDS-related situations and their impact on society.

Recently, as the HIV/AIDS epidemic continues to grow, countries worldwide are adapting legislation in the hope that these specific standards may adequately deal with HIV/AIDS issues affecting everyday life.

The MRC AIDS FORUM and HIVAN (the centre for HIV/AIDS Networking) currently co-host a three-venue Forum which aims to clarify some of the recent developments in this field. The first Forum saw the AIDS Legal Network (ALN) present an in-depth look at

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## Towards a year of delivery for children:

*After seven years in the making, the Draft Children's Bill was finally handed over to the Minister of Social Development in January, but there is still a long way to go.* ***PAULA PROUDLOCK****, of the Children's Institute (University of Cape Town), describes the process, and stresses the importance of civil society helping to speed the Bill's passage through Parliament so that 2003 will be the Year of Delivery for Children.*

The Draft Children's Bill is on its way to Cabinet and is expected to be tabled in Parliament for debate and passage during 2003.

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## NEXT FORUM

SAAVI

(the South African AIDS vaccine initiative)

May 2003

Glenmore Pastoral Centre, Durban

12:30

The Bill has the potential to take us many steps forward in our struggle to realise children's constitutional rights to survival, development, participation and protection.

**What is this Bill about?**

The Bill will replace the 1983 Child Care Act. The current Act provides a regulatory framework for providing for children in need of care. It focuses on the child once the child has already suffered abuse and neglect and provides for the reporting, removal, court processing, and placement of children. In contrast, the new Bill recognises that besides providing a system for supporting children who have suffered abuse and neglect, we also need to focus on preventing abuse and neglect from occurring, and supporting families to care for their children. The new Bill, therefore, emphasises poverty alleviation strategies: an inter-departmental approach to caring for children's survival, development and protection needs; a comprehensive social security system; and a fundamental, comprehensive commitment to the prioritisation of children's rights.

**Where are we in the law reform pipeline?**

In 1996, a decision was made that we needed to review and re-write the 1983 Child Care Act. This decision was influenced by the need to bring all policy and legislation in line with our new democratic values, the new Constitution, our International law obligations and the real needs of children in South Africa. Therefore, in 1997, Cabinet instructed the South African Law Commission (SALC) to review and re-write the 1983 Child Care Act.

The SALC began its process in 1997 and published an Issue Paper in 1998. This was followed by more research and a series of consultations that culminated in a Discussion Paper in 2001. After more research and consultation, the Final Report and Draft Bill were handed over to the Department of Social Development in January 2003. The Department of Social Development is now responsible for taking the process forward. Owing to the intersectoral nature of the Bill, an Inter-Departmental Steering Committee has been established to steer the process. This Committee is chaired by Mr Ashley Theron in the Department of Social Development (Tel: 012 312-7771 or ashley.theron@socdev.gov.za)

The Department has begun a process of discussions with all the affected government departments. These include Local Government, Education, Health, Correctional Services, Safety and Security, and Justice. These discussions are essential due to the responsibilities that the Bill confers on many other government departments.

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## Ed's say:

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the HIV vaccine trial Participants Bill of Rights.

Later this month, Ann Strode of the HIV/AIDS Vaccine Ethics Group (HAVEG) and Brendon Christian (formerly of the ALN) will present "Employment law & HIV/AIDS: your rights as an employee" and "Our roles in responding to HIV/AIDS in the workplace" at the second Forum in Mtunzini.

In November a final presentation will be given at the Pietermaritzburg Forum.

**Marlijn van Berne**

## HIV and the law: useful addresses

- HIV and the law (Centers for Disease Control): www.hivatwork.org/law/law.htm
- HIV and the law (UNDP): www.undp.org/hiv/publications/issues/english/issue11e.htm
- Criminal law and HIV/AIDS: www.aidslaw.ca/maincontent/issues/criminallaw
- AIDS legal bibliography: www.qrd.org/qrd/browse/aids.legal.bibliography
- HIV & AIDS Treatment Action Campaign (TAC): www.hri.ca/partners/alp/tac/campai.shtml
- Avoidance of using criminal law for HIV/AIDS: www.actupny.org/reports/bcn/BCNlawagainst.html
- The dentist, HIV and the law: www.hivdent.org
- HIV and family law: www.lambdalegal.org

*If you have any suggestions you wish to share with the Forum ,contact E-NEWS editor at the following address:*

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**What lies ahead?**

The Department of Social Development will continue to hold discussions and negotiations with the affected government departments in order to prepare a new draft of the Bill that incorporates their comments and concerns. This new draft will then be presented to Cabinet for approval.

Somewhere amid these inter-departmental discussions and the presentation to Cabinet, civil society needs to be given a formal opportunity to comment on the draft Bill. While civil society had many opportunities to comment on the Issue Paper and Discussion Paper, the Department has not yet provided a formal opportunity for comment. This would best be achieved through publishing the Bill for comment in the *Government Gazette* and giving civil society organisations adequate time to digest the 300-page document and compile written submissions to the Department. The Department would need to consider all these comments and re-draft the Bill incorporating the comments where appropriate. This should ideally be done before the Bill is presented to Cabinet.

The Portfolio Committee for Social Development has already started grappling with the draft Bill and will continue to do so while waiting for the final version to be tabled in Parliament.

Once Cabinet has approved the draft Bill, it will be sent to the State Law Advisors and then finally tabled in Parliament. The Portfolio Committee on Social Development will then take the process forward through a series of briefings, public hearings and committee discussions. Other parliamentary committees may also be involved due to the inter-departmental nature of the Bill.

Civil society will then again have an opportunity to engage with the Bill through making oral and written submissions to Parliament. After hearing these submissions, Parliament has the power to change the Bill to incorporate the concerns raised by civil society and the members of parliament. The final Bill, as proposed by the Portfolio Committee on Social Development and the Social Services Select Committee, will be voted on and passed by Parliament.

Once Parliament has passed the Bill, it will be sent to the President for signing into Law. It will then become the Children's Act. After the Department of Social Development has allocated a budget, set up the necessary structures, appointed and trained the new staff, and drafted the regulations, the Act will be implemented. Implementation will in all likelihood happen in phases.

**How long will this process take?**

The research, consultation and drafting process has taken seven years so far. If a positive outlook is taken, we can anticipate another two to four years before the Bill is finally passed and implementation begins.

**What are the factors that can influence the timeframes?**

***Political commitment***

The draft Bill envisages many changes that will have implications for all government departments. These include resource implications from both a human capacity and a financial perspective. This requires all government departments to commit to the principle of 'children first' and to put their plans and resources behind that commitment. The Minister of Social Development and the Portfolio Committee for Social Development are committed to the principle of children first and they want the Bill processed in 2003. They can use their influence to speed up the process.

***Costing of the Bill***

The Bill has not yet been costed and this could delay Cabinet approval. However, the Department of Social Development is in the process of commissioning the costing and there is also no legal reason why the costing and cabinet approval processes cannot run in parallel, in order to prevent unnecessary delays in the process. There is also talk of the Bill being approved and tabled in segments in order to allow the less-costly and less-controversial aspects to go through first.

**2004 is an election year**

This means that 2003 is the year of delivery. This could help ensure that children's rights are prioritised and the passage of the Children's Bill is promoted. On the other hand, if the Bill does not make it to Parliament by September 2003, it could be held back to prevent its passage being split between the old Parliament and the new Parliament that will come into office in April 2004.

***Public participation and pressure***

Law reform processes tend to be prioritised if there is substantial public support and public pressure advocating for the passage of the Bill. Therefore, if civil society organisations work together and ensure that their opinions, evidence and experiences are heard by the decision makers and the media, the likelihood of the Bill's passage being prioritised is increased. A National Working Group, which has representation from key child sector alliances and umbrella organisations, was established at a civil society workshop held in Cape Town in March 2003. This Working

Group will be promoting opportunities for broader civil society participation in the law reform process.

**What do we need to do now?**

The best interests of the child are promoted if the organisations that work directly with children are able to participate actively in the law reform process. The consultation process begun by the SALC therefore needs to be continued by the Department of Social Development and Parliament. Government has a constitutional obligation to promote public participation in the law reform process.

Civil society organizations, in turn, need to get ready to participate actively. We need to read the Bill and Report, write short summaries and easily understandable articles on the Bill and our opinions of it, in order to disseminate the information to more organisations and the public in general. We all need to have discussions with other organisations, the media, service providers, and decision makers in order to debate the Bill and its policy choices.

Spread the word and ensure that the Department and Parliament hear children's voices above the many calls for delivery in 2003.

If you would like more information on the Bill, related law reform processes or the Working Group activities, please go to the following websites:

www.law.wits.ac.za/salc/
www.childrenfirst.org.za
www.uct.ac.za/depts/ci
www.acess.org.za
www.communitylawcentre.org.za
www.childjustice.org.za
www.saspcan.org.za
www.pmg.org.za
www.contacttrust.org.za

If you would like a hardcopy of the Draft Bill and Report sent to you in the post, or more information about the Bill or the civil society process, please contact Zama Mvulane at the Children's Institute on 021 689-5404 or zama@rmh.uct.ac.za

**Source:** ***ChildFIRST # 08 FIRSTalerts***

# HIV vaccine trial Participants Bill of Rights

*Proposed version*

**Section 1 – Informed consent**

1.1 Every participant in a HIV vaccine trial has a right not to be subjected to medical or scientific experiments without his or her independent and informed consent.

1.2 Informed consent can only be given if a participant is provided with a full disclosure of all relevant information relating to the trial. This information includes, but is not limited to:

- information about the nature, purpose, scope and duration of the trial;
- information about the practical procedures, nature and scope of the medical intervention and whether placebos are involved;
- information about the actual and foreseeable risks; actual and expected benefits to participants and to society, and potential psychosocial implications for the trial participants;
- information about the voluntary nature of the participation and the right of the participant to refuse to take part in the trials.

1.3 Every participant has a right to be presented with all relevant information in a way that he or she will be able to understand. This includes access to trained staff capable of explaining the information in a manner and in a language that a participant can understand.

1.4 After being provided with all the relevant information, every participant has the right to choose or to refuse to take part in the trial and to choose whether to involve family, friends or partners in such a decision.

1.5 Every participant has the right to refuse to sign a written informed consent document unless the document contains no more or no less than all the relevant information set out in this section and unless this information has been conveyed to the participant in the manner set out in this section.

1.6 Every participant has a right not to be pressured or unduly influenced to provide informed consent. In particular,

every participant has the right to consider all the relevant information for at least 24 hours before deciding to provide informed consent.

- 1.7 Every participant has a right to leave the trial at any time without losing any of the rights set out in this Bill of Rights. In order to enable participants to exercise this right in a responsible and independent manner, every trial participant has a right to be provided with:
- all relevant new information about the nature and scope of the trial and the nature and scope of the risks associated with the trial as this information becomes available;
- all relevant information about the progress of the trial as well as information about when the results may become available and how these results could be accessed; and,
- all relevant information about the risks, if any, associated with leaving the trial.

**Section 2 – Non-discrimination and human dignity**

2.1 Every trial participant has the right to be treated with dignity and respect.

2.2 Every trial participant has the right not to be subjected to unfair discrimination on any ground, including race, sex, gender, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language, birth, HIV status and economic status.

2.3 In order to protect every trial participant against unfair discrimination, trial participants have the right to:

- appropriate counselling and other assistance aimed at empowering participants to deal with trial related social harms such as stigmatisation and discrimination;
- re-imbursement for any expenses incurred as a result of participating in the trial.

2.4 All trial participants maintain their legal rights and do not waive any of their legal rights by consenting to take part in the trial.

**Section 3 – The right of access to health care services**

3.1 Every trial participant has the right to have continued

free access throughout the trial to the highest attainable standard of preventative counselling about the risks of HIV infection available in the country.

3.2 Every trial participant has the right to have access to free and accurate testing for HIV infection throughout the trial. This right includes a right to have access to voluntary pre-testing and post-testing counselling.

3.3 Every trial participant has the right to have access to free follow-up testing after the completion of the trial in the event of a positive HIV-test caused by the experimental vaccine and not by HIV infection until the test shows a negative result.

3.4 Every trial participant has the right to free access to treatment for any injury or illness caused by study vaccine or trial related procedure.

3.5 Every trial participant who becomes infected with HIV during the trial has the right to free access to the highest standard of health care available in the public health sector.

3.6 In order to safeguard the continued health of trial participants, every trial participant has the right to be informed whether they received a placebo or a vaccine when the study ends or when medically required.

**Section 4 – The right to Privacy**

4.1 Every participant in the trial has the right to privacy and confidentiality which includes:

- the right of every individual participant to have all information about his or her participation in the trial kept confidential; and
- the right not to have any data gathered about an individual which is not directly related to the trial.

4.2 Despite the right to confidentiality guaranteed in 5.1, an individual participant's name and record may be released to institutions or bodies evaluating the efficacy of the study. Individuals may also explicitly wave their general right to confidentiality.

4.3 Every trial participant has the right to be offered a study identification (I.D.) card, confirming participation in the study. This optional card will include a phone number, and/or address, of a person who can provide additional information about trial participation in general but not confidential information about a participant's personal participation, without your consent.

**Section 5 - Responsibilities of trial participants**

5. Every trial participant has a duty to:

- ensure that he or she has a real understanding of the nature and scope of the vaccine trial and to take all reasonable steps to ensure that he or she is able to provide informed consent.
- make an informed decision about participation in the trial after weighing up the information provided regarding the potential risks and expected benefits, and personal implications of participating in the trial.
- inform study staff as soon as possible about any negative consequences to oneself, one's family or community, resulting from association with the trial.
- not attempt to give blood during the trial.

not attempt to determine whether one has received the vaccine or the placebo by getting an HIV test done outside of the study site before the end of the study.

- allow the study-associated laboratory to determine if one is infected with HIV if one has concerns that one may have become infected during the trial.
- keep appointments and to inform study staff as soon as possible to re-schedule an appointment that must be missed.
- treat staff with respect.
- keep confidential others' participation in the study should one get access to this information.
- provide the study staff with complete and accurate study-related information and inform study staff of any changes in one's contact information.
- comply with study requirements to the best of one's ability.
- inform study staff as soon as possible if one is unable to continue or decide to discontinue your study participation.
- provide feedback to research staff that could be used to improve trial procedures and the protection of your rights.