



report back

**Bridging the Gap: Addressing
contentious and neglected issues at
the intersection of SRHR and HIV**

Report on Phase I, April 2009

TABLE OF CONTENTS

I.	Background	2
II.	Mapping Emerging Trends and Neglected Issues at the Intersection of Sexual and Reproductive Health and Rights and HIV	3
III.	Overview of Accomplishments	5
IV.	Outcomes and indicators	8
V.	The Way Forward	14
VI.	Annexure A	16
VII.	Annexure B	25
VIII.	Annexure C	26

I. BACKGROUND

A number of challenging gender and human rights issues have emerged parallel to, and stemming from, the growing attention to, and demand for, the integration of reproductive and sexual health and rights and HIV-related policies, programs, and interventions.

With support from the Packard Foundation Population Program, the ATHENA Network has formed a Reference Group to identify and address emerging trends and neglected issues at the intersection of sexual and reproductive health and rights (SRHR) and HIV, with a core focus on the priorities and perspectives of women living with, and affected by, HIV. Current ATHENA Reference Group members include the AIDS Legal Network, Center for Reproductive Rights, Health Systems Trust, ICW, ICW Southern Africa, Ipas, Namibia Women's Health Network, and the Salamander Trust.

The Reference Group is a resource both for all ATHENA Network members and for the broader gender, sexual and reproductive health (SRH), human rights, and HIV communities. While our reach is global, the initial primary focus of the Reference Group activities

and interventions are on developments and trends in Southern Africa, with specific reference to the experience, expertise, and priorities of HIV positive women.

As a network, ATHENA, has been actively engaged in bridging diverse sectors and bringing together local and global perspectives, in considering a number of the issues and trends we are addressing as a formal Reference Group, including the gender implications of the WHO/UNAIDS provider-initiated HIV testing guidance; the linkages between gender-based violence and HIV; the gender implications of medical male circumcision as an HIV prevention strategy; and, advancing reproductive choice for women living with HIV. Our objective is to build from and strengthen this body of ongoing collaborative work, as well as the important parallel work of ATHENA members and partners. This includes, for example, the participation of ICW in the Achieving Universal Access to Comprehensive PMTCT Services Forum; the Ipas-ICW multi-country reproductive rights training and advocacy project; the litigation and advocacy of the Center for Reproductive Rights around the practice of coercive sterilization; the efforts by Health Systems Trust to engage treatment access in South Africa within a continuum of care for women and from an SRHR perspective; the AIDS Law Quarterly (ALQ) bulletin published by the AIDS Legal Network; and the ongoing engagement

in related community building work by Stepping Stones (www.steppingstonesfeedback.org).

To date, the Reference Group has held a three-day strategic retreat in London in late October 2008, with a subsequent consultation with the newly appointed United Nations Special Rapporteur on the Right to Health, Anand Grover, in New York City. Reference Group members also organized around and participated in the 2008 International AIDS Conference in Mexico City, the WGNRR Regional Consultation in Cape Town, and the 2008 AWID International Forum on Women's Rights and Development. Various advocacy materials developed and produced during Phase I have been launched and widely distributed at the 2009 South African National AIDS Conference.

In summary, we have:

- 1) Strengthened the leadership and capacity of women living with HIV to advocate for and achieve SRHR
- 2) Mapped and prioritized emerging trends and neglected issues at the intersection of SRHR and HIV
- 3) Analyzed these emerging trends and neglected issues with a public health and human rights lens and published our findings through a policy brief, case studies, and fact sheets
- 4) Piloted a human rights

documentation project by women living with HIV in Namibia, focusing specifically on positive women's experiences in health-care settings, particularly when seeking sexual and reproductive health services

- 5) Catalyzed new initiatives to address identified priorities, such as a partnership with the AIDS Vaccine Advocacy Coalition to launch a 'Women's HIV Prevention Tracking' initiative around the roll-out of medical male circumcision for HIV prevention
- 6) Built an advocacy agenda, that includes a dual focus on public health and human rights
- 7) Disseminated our findings at international, regional, and national SRHR, gender, and HIV forums

The Reference Group, a global initiative, has strong leadership and participation from southern and less economically developed countries, and its members contribute a wide range of diverse expertise, including peer education, program implementation, policy development, public health research, human rights advocacy, and community mobilization. In addition, the Reference Group facilitates a unique space for engagement and discourse at a time of great opportunity to influence, engage, and advance parallel processes, such as the GNP+ and the ICW Amsterdam

Consultation for Advancing the Sexual and Reproductive Rights of Persons Living with HIV; to respond to the increased attention to leveraging funds from the Global Fund to Fight AIDS, Tuberculosis, and Malaria for preventing perinatal transmission, as well as for the integration of HIV and reproductive and sexual health and rights; and to engage with, and participate in, continued international, regional, and national forums of relevance. Further, the Obama Administration has placed a renewed emphasis on women's health and human rights, particularly women's sexual and reproductive health and rights. This change in political leadership has opened new spaces and expanded opportunities for the Reference Group to influence and engage with central institutional leaders in the HIV and AIDS response, as well as in the sexual and reproductive health and rights field.

II. MAPPING EMERGING TRENDS AND NEGLECTED ISSUES AT THE INTERSECTION OF SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS AND HIV

We have found

in numerous recent policy debates and legislative trends an absence of a critical gender or human rights analysis – and a continuing gap between the reproductive and sexual health, gender, human rights, and HIV communities. Most importantly, we have seen an absence of consistent attention to or sustained engagement with the experiences and expertise of women living with HIV, which addresses sexual and reproductive health and rights in a comprehensive, coherent manner. As part of our work to bridge these gaps, we have mapped below the emerging trends and neglected issues around which

...we have seen an absence of consistent attention...which addresses sexual and reproductive health and rights in a comprehensive, coherent manner...

...we hope to bring more attention [to] laws that mandate HIV testing...without attention to the potentially harmful consequences...

we will focus our collaborative advocacy and launch new initiatives, as well as to which we hope to bring more attention.

- *Disturbing trends in legislation*

- Legislation which criminalizes HIV transmission from a pregnant woman to her fetus and thereby jeopardizing the health and lives not only of her baby, but of her older children also – as well as herself. An example can be found in Sierra Leone with indications of similar legislative trends being considered in the SADC and other regions.¹
- Laws that mandate HIV testing for pregnant women and/or their babies after delivery and mandate disclosure of the woman's serostatus without attention to the potentially harmful consequences, such as stigmatization and discrimination within the family, abandonment and intimate partner violence.

- *Gaps in realizing women's*

reproductive choices and rights in the context of HIV

- An absence of robust attention to the needs and desires of women living with HIV in initiatives to advance sexual and reproductive rights and health in the context of HIV
- An absence of far-reaching attention to ensuring and advancing access to family planning based on modern contraceptive methods, emergency contraception, and safe, legal abortion for women living with HIV
- An increasing body of evidence documenting coerced and/or forced sterilization of women living with HIV
- An absence of attention to advancing the right to safe, healthy motherhood for women living with HIV, including no mention of post-abortion care in HIV-related programs and policies
- An absence of attention to

maternal mortality in the context of HIV and AIDS

- Inadequate access to prevention services for HIV positive pregnant women, who are blamed for infecting their unborn child and then treated as vectors of disease
- Absence of treatment guidelines at the regional and national levels for women of reproductive age in the context of HIV and AIDS
- Need for access to treatment and services for HIV positive women outside the perinatal setting
- HIV prevention and treatment programs that do not engage men in partnership with women
- *Failure to place HIV prevention, treatment, and care strategies in a SRHR framework and continuum of services*
- Need for increased access

to vaccinations (e.g., for HPV), screening and treatment for reproductive tract infections (e.g., genital herpes) and cancers, particularly breast and cervical cancer among HIV positive women

- An absence of consistent, evidence-based inclusion of infant feeding measures in programs to reduce perinatal transmission of HIV, including attention to breastfeeding, as well as guidance on overcoming barriers (difficulties in avoiding mixed feeding) and using means to make feeding safer (heat treatment of breast milk, wet nursing, etc.)
- Unmet need for female condoms and clarity on other forms of contraception that would be best suited for women, and especially positive women
- An absence of a critical gender analysis of medical male circumcision as an HIV prevention strategy

- *Inadequate responses to the intersection of gender-based violence and HIV*
 - Need for greater attention to HIV as both a cause and consequence of gender-based violence
 - Need for greater availability

of, and access to, services for survivors of sexual violence, such as post-exposure prophylaxis (PEP), emergency contraception, and safe, legal abortion, as well as psychological support and legal aid

- *Lack of consistent attention to the sexual and reproductive rights and health of adolescents in the context of HIV*
 - A need to comprehensively address the sexual and reproductive desires of positive youth
 - A need for comprehensive HIV prevention strategies that work for adolescent girls
- *Gaps between the sexual and reproductive health, gender, human rights, and HIV communities*
 - Too often there is a lack of collaboration and shared understanding across sectors, such that

human rights advocates do not apply a sexual and reproductive health framework or women's rights advocates who fail to partner fully with networks of women living with HIV

III. OVERVIEW OF ACCOMPLISHMENTS

As part of the 'Bridging the Gap' initiative and with the support of the Packard Foundation Population Program, ATHENA has:

- Brought a sexual and reproductive health and rights framework to the Women's Networking Zone at the 2008 International AIDS Conference in Mexico City (AIDS 2008), as evidenced by the female condom space, the streams of sessions on the sexual and reproductive health and rights of women living with HIV, and the various articles highlighting realities and

...gaps in realizing women's reproductive choices and rights in the context of HIV... [include] inadequate access to prevention services for HIV positive pregnant women, who are then blamed for infecting their unborn child and treated as vectors of disease...

...an absence of consistent, evidence-based inclusion of infant feeding measures in programs to reduce perinatal transmission of HIV...

challenges at the intersection of SRHR and HIV, which were published in the *Mujeres Adelante*, the daily newsletter jointly produced by the ATHENA Network and the AIDS Legal Network

- Inserted a focus on reproductive choice, breastfeeding, and the right to safe, healthy motherhood for women living with HIV at the symposium '*Impact of AIDS on human development: Reproduction in the social context*' and a focus on the gender-based violence faced by HIV positive women at the symposium '*Political crises, sexual violence, and AIDS*' at AIDS 2008
- Convened a strategic retreat to launch the ATHENA SRHR and HIV Reference Group with partners, namely the AIDS Legal Network, Center for Reproductive Rights, Health Systems Trust, ICW, ICW Southern Africa, Ipas, Namibia Women's Health Network, and the Salamander Trust in London, October 2008²
- Convened an ATHENA

consultation with the United Nations Special Rapporteur on the Right to Health, Anand Grover, in New York City, October 2008, with participation by the AIDS Legal Network, Center for Reproductive Rights, Namibia Women's Health Network, ICW, and POWA (People Opposing Women Abuse)³

- Co-convened, with the Center for Reproductive Rights, a roundtable conversation to discuss key trends and challenges in sexual and reproductive health and rights with the Special Rapporteur on the Right to Health, Anand Grover in New York City, October 2008⁴
- Mapped emerging trends and neglected issues at the intersection of SRHR and HIV, with particular attention to the priorities and experiences of women living with HIV, to further facilitate debates within and beyond existing partnerships and coalitions
- Linked outcomes from the London retreat, and the consultation with the Special

Rapporteur on the Right to Health, to the African Regional Consultation of the World Global Network for Reproductive Rights by '*Bridging the Gap*' technical experts Jennifer Gatsi (Namibia Women's Health Network) and Marion Stevens (Health System Trust, South Africa)

- Linked outcomes from the London retreat, and consultation with Special Rapporteur on the Right to Health, to the 2008 AWID International Forum on Women's Rights and Development in Cape Town, South Africa, through Reference Group members AIDS Legal Network, Center for Reproductive Rights, Health Systems Trust, ICW Southern Africa, and the Namibia Women's Health Network
- Linked outcomes from the London retreat, and consultation with Special Rapporteur on the Right to Health, to the partners forum of ARASA, the AIDS and Rights Alliance of Southern Africa, through Reference Group member AIDS Legal Network
- Supported the participation of Veronica Kalamba of the Namibia Women's Health Network and facilitated the inclusion of ICW Lesotho in an ATHENA led training on gender, SRHR, and community building in Lesotho in November 2008

- Contributed to the AIDS Legal Network hosted South African national conference on the criminalization of HIV transmission in November 2008, which brought forward some of the issues raised in our retreat, and also featured 'Bridging the Gap' technical expert Jennifer Gatsi, as a speaker on coercive sterilization of HIV positive women in Namibia
- Convened a December 2008 Skype call briefing on legislative trends responding to HIV and AIDS, and their impact on the SRHR of women living with HIV, by experts Johanna Kehler of the AIDS Legal Network and Richard Pearshouse formally with the Canadian HIV/AIDS Legal Network
- Provided technical and financial support to the Namibia Women's Health Network to launch a pilot human rights documentation project by HIV positive women in Namibia on their experiences in health care settings, particularly when accessing SRH services
- Participated in the January 2009 Compact Working Group of the International Women's Health Coalition meeting to link parallel initiatives, and bring forward substantive priorities identified through the Packard process to partners and leaders in the SRHR field

...too often there is a lack of collaboration and shared understanding across sectors, such that human rights advocates do not apply a sexual and reproductive health framework or women's rights advocates who fail to partner fully with networks of women living with HIV...

- Coordinated and produced a series of blog posts on SRHR and HIV (hosted by open Democracy) during the 53rd Commission on the Status of Women in March 2009 where the priority theme was '*The equal sharing of responsibilities between women and men, including care giving in the context of HIV/AIDS*', and the review theme was the '*Equal participation of women and men in decision-making processes at all levels*'
- Partnered with the Center for Reproductive Rights to submit an oral statement on '*Human Rights Violations at the Intersection of HIV/AIDS and Reproductive Health*' to the 53rd Commission on the Status of Women⁵
- Catalyzed new initiatives to address identified priorities included
 - Partnering with AVAC, the AIDS Vaccine Advocacy Coalition, to develop a community-based monitoring project, focusing on the implications for women of medical male circumcision as HIV prevention, that will formally be launched in July 2009
 - Constituted a working group specifically focusing on the implications for women of the criminalization of HIV transmission, and formed a partnership with the Health and Law Initiative of the Open Society Institute to produce an advocacy paper that is currently under development
 - Contributing to a parallel initiative, led by Health Systems Trust and 'Bridging the Gap' technical expert Marion Stevens, to produce an issue brief on the need for treatment guidelines for women of reproductive age in the context of HIV and AIDS, as well as the subsequent launch of a process to develop such guidelines at the 2009 South African National AIDS Conference

- Produced the following key publications as part of the **Bridging the Gap** series, launched by Reference Group members at the 2009 South African National AIDS Conference
 - *‘Mapping Emerging Trends and Neglected Issues at the Intersection of Sexual and Reproductive Health and Rights and HIV’*, as an outcome document from the London retreat
 - Fact Sheet on *‘HPV, Cervical Cancer, and HIV: Screening and Prevention’*, authored by Fiona Hale
 - Policy Brief *‘Developing a Human Rights Framework to Address Coerced Sterilization and Abortion: Articulating the Principle of Free and Informed Decision-Making’*, authored by the Health Equity and Law Clinic, International Reproductive and Sexual Health Law Program of the University of Toronto
 - Case Study *‘Documenting Human Rights Violations in Healthcare Settings: Experiences of HIV Positive Women in Namibia’*, containing the direct documentation of the Namibia Women’s Health Network members that participated in the pilot documentation project under Jennifer Gatsi’s guidance

...it has been tremendous to sit round the table with such inspiring women from South and North together, and to learn to know them and about their work...

- Facilitated broad access to, and dissemination of, the various **Bridging the Gap** publications beyond the 2009 South African National AIDS Conference, in that the documents will be available at the ATHENA Network and the AIDS Legal Network webpages shortly, and the documents will be broadly disseminated during various other regional and international event, such as the July 2009 SVRI (Sexual Violence Research Initiative) Forum in Johannesburg and the IAS Conference on Pathogenesis, Treatment, and Prevention in Cape Town

- 1) Increased global and regional **linkages** between SRHR entities and advocates and HIV entities and advocates

My experience of sitting around the table brought on the strength we make as partners through sharing experiences and motivation to carry on with our work for the betterment and quality of life of women living with HIV.

– Jennifer Gatsi, Co-Founder Namibia Women’s Health Network and Advocacy Officer, ICW Namibia

It has been tremendous to sit round the table with such inspiring women from South and North together, and to learn to know them and about their work.

– Alice Wellbourn, Salamander Trust

Sitting around the table, sharing experiences, and engaging in discourse of sexual and reproductive health and rights realities and challenges in the context of HIV and AIDS was a great opportunity and

IV. OUTCOMES AND INDICATORS

By building nodes of activity and strengthening individual and institutional relationships at the intersection of SRHR and HIV, we contributed to achieving the following in the long-term:

moment of 'bridging the gaps' between regions, between movements and between women and human rights activists committed to the full and equal realization of sexual and reproductive health and rights in the context of HIV.

– Johanna Kehler,
AIDS Legal Network

- 2) Increased global and regional **attention** to and visibility of the sexual and reproductive rights of women living with and affected by HIV

...[F]or us in Namibia is that we are becoming more and more visible both to positive women, ministry of health and other stakeholders as we are seeing the increase of enquiries and consultations.

– Jennifer Gatsi, Co-Founder
Namibia Women's Health
Network and Advocacy
Officer, ICW Namibia

As one example of this, Johanna Kehler of the AIDS Legal Network kindly offered to publish a piece that I had written about criminalisation of HIV transmission as it affects women, specifically in relation to childbirth, in the AIDS Law Quarterly. I appreciate this opportunity to collaborate hugely.

– Alice Welbourn,
Salamander Trust

In addition to the increased discourse about the sexual and reproductive rights of women living with, and affected by, HIV and AIDS, facilitated by the ATHENA Network and its Reference Group both at a regional and global level, it was a great collaborative experience of facilitating greater attention to, and visibility of, emerging issues in the context of sexual and reproductive rights in the context of HIV and AIDS – leading to the culmination of ongoing debates and discussions in a series of publications disseminated at regional and global events, such as the 2009 South African AIDS Conference.

– Johanna Kehler,
AIDS Legal Network

- 3) International **platforms** where the most directly affected grassroots women can share experiences

...to have this direct link, involvement and input of grassroots women's groups into this work is exceptional and hugely rewarding and inspiring...

It is wonderful to see how ATHENA is now publishing and disseminating the material from Namibia about sterilization in wider circles than were previously being reached. To have this direct link, involvement and input of grassroots women's groups into this work is exceptional and hugely rewarding and inspiring.

– Alice Welbourn,
Salamander Trust

The interest in, and positive feedback about, the publications launched and disseminated at the 2009 South African AIDS Conference was a great experience, which most certainly highlighted both the dire need of materials focusing on the intersection of sexual and reproductive health and rights and HIV and a lack of available discourse and debate spaces about emerging and contentious issues, such as the coercive and/or forced sterilization of positive women.

– Johanna Kehler,
AIDS Legal Network

- 4) **Ensuring reproductive choices** for women living with and affected by HIV in Southern Africa and globally

Again, what is happening in Southern Africa to women needs much more publicity than it has received to date. One recent example of

...the positive feed back received by regional networking partners about, the 'bridging the gap' documentations – both during and beyond the 2009 South African AIDS Conference – has been a great experience in ensuring the realization of women's reproductive choices...

ATHENA collaboration was the production of two ATHENA fact sheets - one by Fiona Hale of a paper on HPV/HIV and the other on attitudes and practices experienced by positive women in Namibia as documented by the Namibia Women's Health Network.

These have been prepared for distribution at the South Africa National AIDS conference in Durban; and also contributed to a workshop held in the UK to discuss the development of DFID's maternal, sexual and reproductive health and rights strategy.

– Alice Welbourn,
Salamander Trust

Recognizing that creating an opportunity and space for rights-based debate and discourse lead by women, and especially positive women, is an essential step towards ensuring the full realization of reproductive choices for women infected with, and affected by HIV, the collaborative efforts to develop, produce,

and subsequently release and distribute the various publications at the 2009 South African AIDS Conference has to be seen as a great step towards ensuring reproductive choices for women living with, and affected by, HIV. Further, the regional distribution of, and the positive feed back received by regional networking partners about, the 'bridging the gap' documentations – both during and beyond the 2009 South African AIDS Conference – has been a great experience in ensuring the realization of women's reproductive choices.

– Johanna Kehler,
AIDS Legal Network

Through:

- 1) Enhancing the capacity of HIV positive women to advocate for and achieve SRHR

As a woman living with HIV, I for one feel hugely supported by ATHENA, as a sounding board for ideas and as a source of huge wisdom, insights and experiences. I find the materials

produced by other members of this group are always willingly shared thoughtful, thorough and valuable resources.

– Alice Welbourn,
Salamander Trust

Thanks for putting the materials together. It is really appreciated as it will give us the tools to deliver for the audience to discuss and deliberate on the issues.

– Jennifer Gatsi, Co-Founder
Namibia Women's Health
Network and Advocacy
Officer, ICW Namibia

The materials developed and distributed carry the potential to both contribute to the discourse and debates about sexual and reproductive health and rights in the context of HIV and to enhance the extent to which positive women are in the position to advocate for the access to, and realization of, sexual and reproductive health and rights.

– Johanna Kehler,
AIDS Legal Network

- 2) Enhancing the capacity of HIV and AIDS organizations to integrate SRHR in their work
- a. Particularly to support and advance the priorities of HIV positive women

ATHENA continues to provide valuable linkages between organizations working on these vital issues helping to build a truly international picture of the reproductive and sexual health issues facing women living with HIV. It was wonderful to work with people who are on the cutting edge of such important issues and to jointly drive those initiatives forward.

– Liz Tremlett, Chair,
ICW UK Board

Since the various publications are informed by positive women's lived realities, these documents are indeed a great tool for organizations to not only further integrate, but also adequately respond to, sexual and reproductive health and rights in the context of HIV.

– Johanna Kehler,
AIDS Legal Network

- 3) Enhancing the capacity of SRHR organizations to integrate HIV in their work
- a. Particularly to support and advance the priorities of HIV positive women

Working with ATHENA has been invaluable on a number

...being part of ATHENA-coordinated panels and developing materials in collaboration with other organizations also allows us to learn from others and leverage our own area of expertise for maximum effect. ...

of fronts. For example, building relationships with international, regional, and national partners in both sharing information and strategies and developing linkages between groups working on reproductive rights and those working on HIV who might not be in contact otherwise. The kind of communication that ATHENA facilitates also allows for the identification of global and regional trends in terms of rights violations, such as coercive sterilization, and developments of harmful legislation and work on formulating a well-informed response. Being part of ATHENA-coordinated panels and developing materials in collaboration with other organizations also allows us to learn from others and leverage our own area of expertise for maximum effect. A network like ATHENA serves an essential role by bringing together committed individuals and organizations in pursuit of the

common goal of protecting the SRHR of positive women.

– Elisa Slattery,
Africa Legal Program,
Center for Reproductive Rights

**With support from the
Packard Foundation, we:**

- 1) Contributed a gender-based and human rights analysis and framework for joint advocacy at the intersection of SRHR and HIV;

Gender and human rights always feel at the core of all we discuss together and I feel we have an honest open, respectful and supportive relationship in the group, which is expertly and sensitively coordinated by Tyler Crone.

– Alice Welbourn,
Salamander Trust

The collaborative initiative to develop and produce these first pieces of a series of human rights-based documentations about the intersection of sexual and reproductive health and rights and HIV has been as much a great experience of

learning and sharing between gender, human rights and HIV activists, as well as created a unique space to both contribute to existing debates and to highlight the need for further rights-based analysis and discourse.

– Johanna Kehler,
AIDS Legal Network

- 2) Strengthened linkages between academia, research, law, policy, the experiences and expertise of women living with HIV, and community mobilization;

One of the beauties and strengths of the group is the multiple talents, skills and experiences which its various members bring to our very rounded table. This is a rare experience and one which I, for one, cherish.

– Alice Welbourn,
Salamander Trust

From where I sit, it seems ATHENA is doing a wonderful job of making the linkages between SRHR and HIV, and between individuals and institutions internationally. For me, it is very powerful to be able, through ATHENA, to continue the linkages I already had through my work with ICW, and to make new ones. I'm really happy to be able to use the fact I'm studying for a Masters in Public

...I'm really happy to be able to use the fact I'm studying for a Masters in Public Health programme to access, summarise and critique existing literature on priority issues...

Health programme to access, summarise and critique existing literature on priority issues (as identified by ATHENA members) at the intersection of HIV and women's SRHR, and to make it available to advocates through ATHENA's dissemination capacity. A by-product of that is the awareness-raising on HIV and women's SRHR that I hope is happening among my fellow MPH students at Northumbria University - approximately 30 UK students (all working within the UK health system, and many with either an SRH or an HIV remit) and approximately 15 international students (from China, South Asia and Africa).

– Fiona Hale, former International Network Manager, ICW and current Master's Candidate in Public Health

The process of development, production and distribution of the various publications highlights but one of the examples of not only strengthened linkages

between different stakeholders contributing to a rights-based analytical framework which is both informed by positive women's lived realities and led by women themselves. Further, the publications are designed as advocacy tools assisting in the mobilization of communities, including communities of women living with HIV.

– Johanna Kehler,
AIDS Legal Network

- 3) Applied strategies from the SRHR movement to HIV and AIDS and from the HIV and AIDS movement to SRHR in order to articulate and coherently address emerging trends and issues that span topics such as focusing HIV testing in perinatal settings, disturbing legislative trends that would criminalize the transmission of HIV from a mother to her foetus, and strategies that advance and ensure true reproductive choices for women living with HIV.

I feel that there is a real sense

of mutual and freely shared learning going on between us which I find very creative.

– Alice Welbourn,
Salamander Trust

Ipas is pleased to have participated in the London consultation to identify areas of sexual and reproductive health and rights that have been/continue to be neglected or that receive insufficient attention in relation to HIV/AIDS. We have advocated for many years for increased attention to the issues of unwanted pregnancy and abortion care for HIV-positive women and are happy to see other ATHENA Network members incorporating these areas into their work as well!

– Maria de Bruyn,
Senior Advisor, Ipas

From the preparatory discussions for the London retreat to the launch and distribution of the publications at the 2009 South African AIDS Conference, there has been a strong common commitment to further the access to, and realization of, sexual and reproductive rights in the context of HIV, as well as the strong common understanding of the need to continuously raise and put on the agenda the commonly neglected issues relating to the intersection

of sexual and reproductive health and rights and HIV. It has been a great experience to participate in these processes; to facilitate issues of SRHR and HIV becoming more and more an integral part of agendas and initiatives, and to contribute to enhancing a common voice across movements, sectors and activists.

– Johanna Kehler,
AIDS Legal Network

We achieved this in the short-term by:

- 1) Increasing visibility of and attention to the SRHR of HIV-positive women and women affected by HIV (e.g., young women, pregnant women, sex workers, refugee women, lesbian women, survivors of violence), as well as the linkages between SRHR and HIV
- 2) Strengthening relationships between the gender, SRH,

human rights, and HIV communities

The period of the Mexico Gag Rule and restricted PEPFAR funding created a context which led to the rise of the treatment movement which had a limited lens on the feminized epidemic and the devastation and relentless erosion of the sexual and reproductive health and rights in the spaces we work in. The Packard supported process has enabled spaces, reflection and confidence for collective organization for us to reassert a lens which confronts SRHR and HIV/AIDS directly. We still have a long way to go but we have at least had the courage to remedy this in a context where we have generally been silenced, or referred to as ‘collateral damage’. In doing so we have begun to name and unpack the continuum of issues that twin HIV/AIDS and SRHR and need urgent addressing

– Marion Stevens,
Health Systems Trust

We are about to embark on learning from ATHENA members how to develop the opportunities with positive women in Austria and Germany to create a special community space for them and for us all in Vienna. The experience of ATHENA members over the

...we still have a long way to go but we have at least had the courage to remedy this in a context where we have generally been silenced, or referred to as ‘collateral damage’..

...most of the women thought they did not have rights to question health workers on the violations and thought what the health worker says is always right...

past four International AIDS conferences is unique in this regard.

– Alice Welbourn,
Salamander Trust

I have found the writings of Marion Stevens especially helpful in this regard. Also Maria de Bruyn's contributions to the group are always immensely helpful. Another example of ATHENA collaboration was the provision of blogs by various ATHENA members for the Open Democracy UK-based news and current affairs website during the Commission on the Status of Women. Information about SRHR and HIV in the UK is marked by its paucity. The collaboration with ATHENA members to bring these issues through high quality blogs to a new audience across the UK and beyond was greatly appreciated by the OD editor and myself.

– Alice Welbourn,
Salamander Trust

V. THE WAY FORWARD

A unique opportunity is at hand to bring multiple perspectives and diverse global actors into conversation within a SRHR and HIV framework to identify ways to apply lessons learned from the SRHR field to their intersection with HIV, and vice versa, and to enable mutual support and dialogue to sustain activism in a global context, which does not have safe and regular spaces for this agenda.

My experience of sitting around the table brought on the strength we make as partners through sharing experiences and motivation to carry on with our work for the betterment and quality of life of women living with HIV. It also strengthened my resolve to train women on documentation of violations and through this I have observed that a number of women interviewed were also being conscientised about these violations. Most of the

women thought they did not have rights to question health workers on the violations and thought what the health worker says is always right. During the documentation, according to the interviewers whom I had followed up telephonically to check on their experience, when they were documenting said that they had never seen such sense of women asking so many questions as most of the time when discussing other issues they always take what's being presented to them and never ask any questions. So for me the importance of training core groups of women to provide information on SRHR and also sensitises the women themselves on reporting these violations and also advocating within their local health centres, constituencies etc. I believe if women do this in numbers rather than individually, it will make a huge impact and at the same time the people responsible for violations will start to see that there is Big Sister watching them. I would also suggest that we look at how positive women can be empowered to influence media on raising their issues especially when it comes to policy, campaigning and advocating for their sexual reproductive rights (young

women being denied family planning if they do not also use condoms or being told you are too young to engage in sex or health workers using scare tactics of telling young women that they will get cancer or their chances of falling pregnant will be reduced etc). I also would want the partnership in the future to look at documenting sexual reproductive health violations in the Southern Africa countries and come up with a report as it will show the patterns and how common they are and justify the capacity enhancement of SRHR organizations to integrate HIV in their work, contribute a gender-based and human rights analysis and framework for joint advocacy and strengthen linkages between academia, research, law, policy, the experiences and expertise of positive women and community mobilization. One last thing to mention for us in Namibia is that we are becoming more and more visible both to positive women, ministry of health and other stakeholders as we are seeing the increase of enquiries and consultations.

– Jennifer Gatsi, Co-Founder Namibia Women’s Health Network and Advocacy Officer, ICW Namibia

...I believe if women do this in numbers rather than individually, it will make a huge impact and at the same time the people responsible for violations will start to see that there is Big Sister watching them...

The Reference Group will carry forward the ‘*Bridging the Gap*’ initiative through:

- Expanding the linkages between the gender, human rights, sexual and reproductive health, and HIV communities;
- Building the leadership and capacity of positive women to advocate for SRHR; and,
- Creating new platforms and mechanisms for joint advocacy to raise the visibility of neglected and emerging issues at the intersection of SRHR and HIV.

Specific activities will include:

- A continued series of fact sheets, case studies, and policy briefs on identified priorities and emerging issues
- Building from the pilot documentation project of the Namibia Women’s Health Network to replicate and expand the project in other sites
- Specific advocacy around and attention toward the African Commission on Human and Peoples’ Rights

- Linkages to the SVRI Forum 2009, presentation of findings and outcomes
- Specific advocacy around and attention toward the 2009 and 2010 International AIDS Conferences in Cape Town and Vienna

REFERENCES:

1. <http://www.heraldtribune.com/article/20080111/NEWS/801110356/-1/newssitemap>
2. Summary notes from the Strategic Retreat are included in Annexure A.
3. Summary notes from the consultation with the United Nations Special Rapporteur on the Rights to Health are included in Annexure B.
4. Summary notes from this consultation are included in Annexure B.
5. A copy of the CSW Oral Submission is included in Annexure C.

Summary notes from Strategic SRHR and HIV Retreat

The ATHENA Network Secretariat convened a strategic retreat in London from 23 – 25 October 2008, with institutional support from ICW.

Participants included:

- Tyler Crone, ATHENA, global
- Maria de Bruyn, Ipas (and ATHENA Steering Committee member), global
- Sophie Dilmitis, World YWCA and ICW European Regional representative for the International Steering Committee, global
- Jennifer Gatsi, Namibia Women's Health Network and ICW Namibia
- Johanna Kehler, AIDS Legal Network, South Africa
- Helen Kirkland, ICW International Network Co-Manager, global
- Gcebile Ndlovu, ICW Southern Africa
- Marion Stevens, Health Systems Trust, South Africa
- Liz Tremlett, ICW UK Board Co-chair, global
- MariJo Vazquez, ATHENA Steering Committee, Spain
- Alice Welbourn, Salamander Trust and ICW representative, global
- Wezi Thamm, ICW European Regional representative for the International Steering Committee, global
- Lilian Sepúlveda, Center for Reproductive Rights, global
- Amandine Bollinger,

Salamander Trust (and meeting minutes)

- Belinda Tima, ICW sterilization UK Board Co-chair, global
- Ale Trossero (part) IPPF, global

BACKGROUND AND AIM

The meeting took place at a time of renewed emphasis on women's health and human rights, particularly women's sexual and reproductive health and rights.

The objectives for the meeting were:

- To identify the ways ATHENA has helped with its work on specific issues, such as cervical cancer
- To map the expertise within ATHENA
- To identify ATHENA's niche/ significant experience, as well as its strategic positioning
- To identify three to five issues for ATHENA to focus on for an advocacy agenda in the next couple years
- To look at systems and processes for checking into emerging issues

- To come up with terms of reference for how this group works

The retreat, its agenda, and facilitation were jointly shared and developed by participants in advance of our time together and onsite.

Day 1: Thursday, 23 October 2008

The meeting commenced with in-depth discussions and debates around a number of issues and questions pertaining to ATHENA as a network, its role and expertise, as well as ways to build on its strength and to further enhance its role as a role player in regional and global discourse on emerging and contentious issues at the intersection of sexual and reproductive health and rights and HIV.

Some of the questions raised included:

- Who are we?
- What do we want?
- What has Athena done well?
- Where can we improve, what can we do better?
- How do we relate to each other as different organizations?

- How do we integrate our work with that of other organizations/structures?

WHO ARE WE?

Mapping the reality to which ATHENA is responding to, the following issues and needs were identified:

- There is a great need to give a voice to positive women, as women are often left with feelings of alienation, are silenced, lack capacity, and are stigmatized
- There is a need to integrate SRHR with issues of positive women

Exploring the question of ‘who are we?’, the following points were raised:

- ATHENA as a safe space to share ideas and to learn from one another
- ATHENA is a unique space, where positive women and women’s movements come together
- ATHENA is a network that has respect for GIPA principles, with meaningful involvement
- ATHENA gains strength and credibility from our diversity, including the possibility to meet people from different areas

- Members of ATHENA are all concerned about what happens in the life of women and girls, and how this specifically impacts on their risks and vulnerabilities

- ATHENA is a space that recognises the importance of having a wide range of skills brought together to be able to explore issues differently, which makes us together more strong

- ATHENA provides support to organizations in their attempts to equip women with tools to make their lives better

- ATHENA can help to engage with policy makers at a higher level

- ATHENA represents a network platform and an opportunity for strengthening linkages

By mapping specific agendas, ATHENA is like glue that holds together all the different synergistic activities

What do we want?

Some of the issues raised included:

- A forum where we can identify and discuss emerging issues, e.g., medical male circumcision as an HIV prevention tool

- Influencing the advocacy agenda, and ensuring women’s leadership on the agenda
- A forum where member organizations can ask questions and engage in discourse, facilitated by the ability to put people in touch with each other
- Facilitating and ensuring a consistency on emerging and contentious issues, and feeding them into campaigns
- Not to be limited by over-specified objectives, but open to respond to, and be involved in, new and developing debates

WHAT HAS ATHENA DONE WELL?

It emerged during the discussion that ATHENA has been particularly successful in ensuring visibility both as an organization and organizational topics and agendas at various international events; in providing ‘safe spaces’ for linking, sharing and debating; in affording technical support to member organizations; and as a forum for information and resource sharing. Some of the identified highlights included:

To date, ATHENA has done really well with its communication network in terms of resources, and as a think tank for work and policy.

VISIBILITY

- ATHENA has supported women’s meaningful involvement in the International AIDS Conference in many ways, including through providing support and resources to participants
- ATHENA has been part of the World YWCA reference group for Mexico 2008, and working towards Vienna 2010
- ATHENA has been part of the Women’s Networking Zone, and other women’s advocacy activities at International AIDS Conferences – providing opportunities for access/ linkages with regional and global networks and information, as well as for face-to-face networking; for linking various sectors and issues; and for influencing advocacy agendas
- Women’s Networking Zone in Nairobi and the Town Hall on SRHR in Nairobi – both at the International Women’s Summit on Women’s Leadership on HIV and AIDS in June 2007 in Nairobi, Kenya

‘SAFE SPACE’

- Linking with other organizations and individuals relating to various issues, e.g., the meaningful involvement and participation of positive people
- Providing a ‘*think tank*’ on real, emerging and contentious issues, as well as forum for critical engagement

- Opportunity to discuss global issues among diverse groups of people under a new focus
- Intellectual grounding and providing a sounding board for ideas/processes

TECHNICAL SUPPORT

- Namibia Women’s Health Network: ATHENA assisted on direction on how to provide education, training, and data collection without financial support.
- Support in fundraising for strengthening the network and support provided for directing the network to possible funders
- Review and editing of partner presentations, commentaries, abstracts

INFORMATION/ RESOURCE SHARING

- Information sharing and update with organizations specialising on particular issues, such as Ipas
- Coordination between organizations working on similar related issues
- ATHENA’s list provides good and critical information, that is not always available through other channels – e.g. criminalization of HIV

transmission

- Many reports, policy papers, articles, news, and other items circulated and forwarded to ATHENA members and other organizations, including information from communities and community-based interventions

Moving Forward: Where can we improve, what can we do better?

Moving forward, the meeting discussed ways in which ATHENA can improve its work and impact. Some of the issues raised included:

- Follow through: We’re good at getting conversations started, putting people together, and making statements. There are areas where we created the voice, catalysed action, saw policy change but then we did not have the capacity to follow through.
- Southern colleagues are busy running projects in the field and have less time. A very powerful strategy is to use the media – e.g. the work of Jeni in Namibia has been featured in the media in North America. The media has an aggressive way of criminalizing, as opposed to writing a positive article. We should encourage the media to give more voice to the work of positive women,

- As one hope for the future – it would be great if ATHENA could have more of a capacity building role for women’s groups, instead of just connecting at an international level.
- We need adequate governance and the taking of further ownership to move beyond just representing our organizations.
- We need to identify a way that people, who are not part of ATHENA, can engage with ATHENA activities and discussions.
- It would be good to develop a set of criteria for selection of thematic issues that ATHENA could work on.

Moving Forward: How do we relate to each other as different organizations?

Closely linked to exploring ways of enhancing ATHENA work, was a discussion on how individual member organizations of the ATHENA Network relate to one another highlighting the following points:

- There is a need to be transparent with each other
- ATHENA should forge trust and good relationships between its members

- There is a need for the member organizations to collaborate, share panels and sessions, to bring together and link personal stories with a parallel formal framework
- Recognizing that some of us are part of ATHENA, because of the specific work that we do within our organizations; and so, whilst we are ATHENA members, we also wear organizational hats
- Openness to reflect on ways we work together, to learn from mistakes and improve ways we work together
- Friendship, solidarity, shared concerns, as well as collegiality and support for regional work
- Hope in new ways of addressing issues and organizing ourselves as activists

Moving Forward: How do we integrate our work with that of other organizations/structures?

- There may be some things that we can discuss at ATHENA that our individual organizations do not prioritise, e.g. reproductive choice and HIV
- To reach a variety of key

stakeholders ranging from experts working on public health issues, advocacy, human rights

**Day 2:
Thursday, 24 October 2008**

Our second day began with national perspectives from Namibia and Swaziland. The issues raised with respect to Namibia included strategies for mobilizing young women as advocates; pressing and ongoing issue of coerced sterilization of positive women; and inadequate responses to sexual violence including lack of awareness around and access to PEP and EC. The focus of the Swaziland discussion was on attention to cervical cancer for women living with HIV.

**COUNTRY
PERSPECTIVES**

Namibia

ICW has been working in Namibia since 2005, and has created a platform for positive women to sit around the table with parliamentarians, and bring issues forward. 13 women are currently involved, and the platform is inclusive with village women on board, including both older and younger women, to give broad representation. Dealing with members of parliament can be tricky and requires certain skills, such as being asked which party you’re from, and being able to clarify that you’re not here for politics, but to help out.

The rate of infection of younger women is higher in Namibia, than for older women. However, ICW found that in meetings of positive women, the participating women tended to be older, rather than younger. One young woman was recruited to find positive young women and organise workshops in their villages. Although the presence of older women in the platform is important to bring issues forward, they can overshadow the younger women who will then not speak, out of cultural respect.

ICW organised training for these women to help them design and address questions to parliamentarians, who were invited on the last day of the training along with members of civil society. There was a very disturbing outcome. Some of them had been sterilized without having been informed what sterilization meant.

...I went to family planning to have children and they told me you have nothing to do here, you've been sterilized...

ICW conducted its own investigations in three regions. Out of 200 women interviewed, there were 40 cases of forced sterilization. Some of the cases had happened too long ago to go to court. Three have been given legal assistance to go to court. Others are still waiting, because of collecting of information to go to court.

ICW developed a letter of submissions with partners and

went with sterilized women to submit it to ministers. They promised investigations, they said that they were going to send a circular to all clinics to stop these practices, but so far, Jeni has not seen any written notification. She and her team met some doctors who admitted openly that they sterilized women because the women had too many children.

During the recent outreach in one of our groups, one young positive woman (25 years old) spoke up and informed the meeting that she had just been advised by the doctor at Katutura hospital to undergo sterilization and this is after we had submitted a letter to the deputy minister on sterilization issues and which we expected the ministry to take action to stop this exercise. We put her in contact with legal aid and checked at the clinic, but didn't find the circulars that the ministers had promised. For me it showed that they are not taking us seriously.

...Now what do we need to do? We want to make sure it stops. We need assistance in documenting, women to be empowered in documenting, advocating and lobbying. We've now identified 13 young positive women in 13 regions of Namibia. We need women to be trained to go and identify issues

affecting positive women including forced sterilization, lack of information on sexual reproductive health and rights, but also trained to understand all sorts of advocacy, not just on sterilization.

Jeni is also working in partnership with Ipas, which has provided training in workshop facilitation, gender issues, reproductive rights, and advocacy. One activity carried out subsequent to a training-of-trainers course was mobilization of community members to use a questionnaire for door-to-door enquiries about issues, such as reproductive health priorities and problems, attitudes regarding abortion (which is widely thought to be illegal, but which is actually legal to save a woman's life and physical/mental health, in cases of rape, incest and foetal malformation) and views on baby dumping.

Involving communities is a way of communicating about the issues being faced, such as not having enough medications, TB, no available information on legal abortion in cases of rape (there is a very high level of rape in Namibia), and lack of emergency contraception (EC), even in communities where there is a high rate of rape.

When the unavailability of EC and post-exposure prophylaxis (PEP) was raised with the Deputy

Minister of Health and the person in charge of preventing perinatal HIV transmission, they said that EC and PEP should be available in all communities. However, enquiries at one health clinic in a rural town showed neither EC nor PEP was available. Physicians with whom ICW and Ipas spoke at the University of Namibia HIV/AIDS department think that to the fact that only physicians are allowed to administer EC and PEP.

Jeni now has two women being trained to work as Key Consultants documenting positive women's stories. In future, these two members can re-train other Namibia Women's Health Network members to document positive women's stories in their regions. Jeni's team has arranged that they should be paid for their time.

On the Global Fund CCM, there is one place for a representative of positive people, who is a woman. Jeni has demanded a place specifically for positive women on the CCM also, indeed 2 places, for younger and older women. ICW has also demanded clear criteria for people to sit on the CCM.

Ultimate goal: a National AIDS policy has been drafted, but without consultation. Jeni's team called civil society organizations and put forward suggested changes, and sent it back. The policy was passed without any changes.

ICW-Namibia is now carrying out a follow-up project with different components: education of, and dialogues with, young people on gender, reproductive health, and abortion issues, the piloting of health ethics committees at two community clinics where patients can report bad treatment and rights violations by healthcare workers, advocacy regarding services for survivors of violence (EC, PEP, access to safe legal abortion) in the rural towns of Dordabis and Katatura in Windhoek, implementation of the abortion law and, possibly after the elections, further liberalization of the abortion law.

Swaziland

At a recent meeting of positive women in Swaziland, only 9 out of 104 women knew what the pap smear test was for and were regularly tested.

Gcebile went to the facility to which her group had referred women to get the pap smear test, but the clinic didn't do the test any more. However, they did refer to a second facility that was far away, costly, and took 6 weeks for a result (and communications get lost easily in Swaziland). Action Aid is also working on cervical cancer in Swaziland.

A discussion with the Women's Coalition in Swaziland looked at how much was invested and revealed that \$7,500 is

allocated to cervical cancer screening for the whole country. The Women's Coalition can get access to substantive funding from the Global Fund for women to access facilities for assessing female reproductive cancer. This will be raised as a desirable issue to be addressed by the Global Fund. Bringing chemotherapy into the country will be the next issue.

PRIORITY SETTING

After an in-depth discussion on trends and issues that are of concern and should, therefore, be included in the advocacy agenda of ATHENA, the meeting identified three priority areas

- Legislative/regulation/policy trends – including issues of criminalization, HIV testing, disclosure and health sector reform
- Reproductive choice – including issues of legal abortion, HPV vaccine, cervical cancer screening, female condom access, treatment guidelines, and reproductive health of young, not so young, and positive women
- Emerging and cross-cutting issues – including issues of positive prevention, male circumcision, violence against women, and bridging the gap between sectors

1. Legislative/regulation/policy trends

The issues identified as key for ATHENA were:

- Criminalization: both of transmission, and the implied criminalization of women by forcing them to be sterilized
- Testing and disclosure: although in policy, involuntary testing and disclosure are illegal, it happens in practice, and is, therefore, making achievement of MDGs 3 & 4 even harder; because in South Africa, for example, women will either avoid being tested, or will go to far away clinics for testing in order to avoid disclosure to their communities

In order to enhance the engagement with these issues, the following suggestions were raised:

- Building bridges between medical communities, young lawyers and judges, as is being done in Latin America by the Center for Reproductive Rights
- Allowing local groups to utilise international law to advocate at national level. There is a great need also to include positive women, as in the Parliamentarians for Women’s Health project, where ICW members worked alongside law interns in Namibia, Botswana, Kenya, and Tanzania.
- Responding to the urgent need also to educate positive

women – and women’s rights’ groups on the risks of criminalization laws, so that they understand that they themselves could end up being victims of these laws.

2. Reproductive choice

Priorities identified were:

- A focus on maternal mortality – saving lives by:
 - Avoiding unwanted pregnancies, including emergency contraception and safe legal abortion
 - Giving women access to reproductive tract infection/cancer prevention, screening, diagnosis, and treatment, highlighting technologies such as the HPV vaccine, VIA and cryotherapy
- Changing the discourse about reproductive rights at different stages of HIV positive women’s lives (e.g., young women just reaching puberty, women of reproductive age, women of menopausal/post-menopausal age). This would also be a way to bring in young women to participate actively and to move beyond treatment to prevent transmission toward keeping mothers alive too. This would also include changing the blame-implicit language used in discourse, such as substituting the

original terminology of vertical or perinatal transmission for mother-to-child transmission.

3. Emerging and cross-cutting

Priority issues highlighted were:

- Medical male circumcision as an HIV prevention strategy and its impact on women
- Violence against women
- Young women – engaging young women to ensure young women at the table are on a par with older women
- Bridging local and global initiatives and debates
- Need to identify effective and strategic responsive measures by defining better templates to address emerging issues (such as the SRHR approach)

HOW CAN ATHENA ADDRESS THE PRIORITY ISSUES RAISED?

Suggestions made included the following:

- To create some kind of pilot projects of specific geographical areas to make things happen on a multi-sectoral basis, recognising the critical value of inter-connectedness of information and action. Regions/provinces in Southern Africa could

- To link key actors: law-makers, parliamentarians, positive women, positive men, community-based organizations, school-based (education), and the media.
- To address list of issues as a pilot area to try and input all different sectors and issues, e.g. food security, education, property and inheritance rights etc.
- In Namibia, there is a project to identify a women's organization that can set up a women's clinic where services and workshops can be provided for HIV positive women. However, concern was raised that women-only clinics do not necessarily work. It would be a good idea for more discussion [regions to associate?] to check reasons for success and failure of such initiatives in different countries.

During the ongoing discussion, questions were raised as to the extent to which ATHENA will distinguish itself from NGOs who run projects with local partners, and to ways on concentrating on advocacy in the ATHENA network instead. As organizations often do not look at positive women's issues, ATHENA can take this on, not by going down the program route, but by acting as a catalyst, contributing skills &

connections to enable things to happen, and to turn everything into joint actions – for example using a country, such as Namibia, and the operating model there, as the basis for advocacy in the local region, and then being able to apply the benefits elsewhere in the same region.

18-MONTH 'WISH LIST'

Taking into account the vast skills and expertise within ATHENA, participants around the table were asked what they wanted ATHENA to focus on for the next 18 months. The 'wish list' of ATHENA's focus and activities included:

- Important for ATHENA to continue its great work on information sharing via its listserv
- To see ATHENA make third party interventions (for e.g., testimonies, written expert opinions, declaration letters) that support legal processes at the national/international level
- ATHENA is part of the World YWCA reference group for the International AIDS Conference in Vienna
- There may be possibilities, and better ways, of sharing information through world YWCA e-bulletins and

through the Common Concern magazine so as to avoid reproducing other organizations' work

- Greater involvement and participation of ATHENA members in the '60% list'
- Broader dissemination of ATHENA documents and position papers by members attending different events and meetings
- To see the network strengthened with as much information sharing as possible
- A greater focus on advocacy and prevention issues
- ATHENA needs to be 'ready' for the marathon meeting of the science tracks, deciding on the successful abstracts for the Vienna conference. We need to submit good evidence, for example from Namibia, illustrating scientific method, and showing creative and empowering ways to tackle local issues. We need to be active players in that process with concrete evidence to create sessions in Vienna.
- Preparation for the Vienna conference should result in more than a policy paper, with a broader reach and concrete demands based on substantive research to demonstrate that the phenomenon we are addressing is widespread.

- Getting support and strengthened assistance from ATHENA to allow young people to go to court
- ATHENA to support Namibia Women's Health Network on plans for empowering women in documentation, advocacy and lobbying
- To see Eastern Europe & its border regions targeted, since figures show high rates of female infection in the region, but there is no voice to go along. We need to identify information, training, teaching, leadership, and young women's needs, but also to research what is already in place there. We could be checking with other regions what different models have worked in terms of advocacy and activism
- Focus on legal issues and strengthened advocacy through enhanced resources
- Allowing greater external involvement whenever possible
- Identifying a clear mechanism for monitoring GIPA in concentrated epidemic zones (Injecting Drug Users, women and girls, conflict areas)
- Evidence-base around legislative issues and advocacy (e.g. collecting data/cases with respect to fear of criminalization)



- Allowing conversation to take a step further and seeing ATHENA becoming the catalyst for raised issues
- Shifting the discourse and creating new models based on what is happening in Namibia

Summary notes from Consultations with Anand Grover, UN Special Rapporteur on the Right to Health, Center for Reproductive Rights

Focus: Reproductive Choice/Sexual and Reproductive Health of HIV Positive Women

The following issues, closely linked to the outcome of the Strategic SRHR and HIV Retreat in London in October 2008, formed the basis of the discussion:

Health care and health systems

- Coercive sterilization
- Unwanted pregnancy
- Reproductive tract infections and cancers – screening and treatment
- Inadequate sexual violence responses
 - Lack of access to post exposure prophylaxis, emergency contraception, and safe abortion

Legislative trends

- Criminalization including of mother-to-child transmission
- Mandatory/Non-voluntary testing and disclosure

Emerging and Cross-cutting issues

- GBV/VAW and HIV and SRHR
- Male circumcision

Key points from ATHENA and Center for Reproductive Rights SRHR Dialogue

- Need to be engaging more men to work for women's issues
- Lessons to distill from success of the process led by the Lawyer's Collective in India to develop HIV legislation:
 - Involvement of positive people

- Demand bill
- Know law
- Will claim rights

- Advancing the rights of marginalized groups » empowerment » claiming rights » society better off
- Public health community in the United States receptive to human rights strategies and approaches, to build from existing work on structural determinants and social equity
- Question of how to move human rights on the health care agenda in the United States, and how to engage/learn from international work
- International and domestic interface around the rights of refusals in access to healthcare
- Globalization of 'conscientious objection' – has not been addressed by human rights mechanisms
 - For example, the case of Monica Roa in Colombia, where the judge used conscientious objection to refuse to hear case on denial of abortion services
- Right to healthcare without discrimination – yet, discrimination through

conscientious objection, as this impacts on services women need

- With privatization of healthcare, there are fewer public health service providers such that real access to services diminishes
- Need to change way in which we are working, so that there is a bridge from affected communities to policy experts
- Need to change the culture of the conversation, move toward reproductive justice movement – in the US that has resonance with poor people's movements and with women of color
- Opportunity to build a right to health debate in the United States, look to Obama's statements on the right to health
- Opportunity to bring the international human rights framework to reproductive rights and SRH work in the USA
- Opportunity to link national and global movements
- Challenges in the GFATM system – lack of women on the CCMs and the technical obstacles in developing successful proposals

CSW ORAL SUBMISSION

53rd Session – March 02 – 13, 2009

Human Rights Violations at the Intersection of HIV/AIDS and Reproductive Health of HIV Positive Women

Jointly submitted by: The Center for Reproductive Rights and the ATHENA Network

Distinguished Commission Members, thank you for allowing the Center for Reproductive Rights and the ATHENA Network to present an oral submission on human rights violations at the intersection of HIV/AIDS and sexual and reproductive health. Paradoxically, while women bear the burden of caregiving within the HIV/AIDS pandemic, they are often unable to protect their own sexual and reproductive health and rights. This submission will focus on violations of women's human rights in health care settings, including involuntary HIV testing and disclosure and discriminatory practices by health care providers, as well as dangerous legislative trends that further threaten women's rights in the context of HIV.

INVOLUNTARY HIV TESTING AND DISCLOSURE

International human rights standards and medical ethics require medical providers to obtain informed consent for HIV testing and to ensure strict confidentiality of HIV status. Unfortunately, all too often health care providers completely disregard these obligations by testing women and exposing their HIV status to partners,

family members and sometimes even employers without their consent. For instance, only half of Kenya's public health facilities and only 15% of its maternity wards comply with the country's informed consent regulations. Non-consensual HIV testing, especially in the context of pre-natal care, violates women's rights to autonomy, dignity, health, equality, non-discrimination and equal protection before the law. Moreover, non-consensual disclosure of HIV status places women at risk of physical, sexual and psychological abuse, including abandonment, neglect, separation from their children and even ostracism by their husbands, partners or community. Research has also shown that violations of consent and confidentiality discourage pregnant women – regardless of their HIV status – from obtaining health care services, including HIV testing, drug treatment, pre- and post-natal care and means to prevent mother-to-child transmission.

DISCRIMINATION AND VIOLENCE AGAINST HIV-POSITIVE WOMEN IN HEALTH CARE SETTINGS

HIV-positive women also face

discrimination and violence in health care settings, such as coercive sterilization and delays in and denial of reproductive health care services (including abortion care). Such discrimination can be lethal as in the case of Gita Bai, an Indian woman from Madhya Pradesh. Despite experiencing alarming pregnancy-related complications, Gita was discharged after hospital staff learned of her HIV status and forced to give birth on the sidewalk outside of the hospital, ultimately leading to her death.

Women living with HIV also encounter discriminatory attitudes from health care providers regarding their childbearing decisions. This occurs in spite of women's right to make sexual and reproductive choices, irrespective of their HIV status, and the fact that with the appropriate interventions, the risk of viral transmission to newborns can be reduced to less than 2%. These attitudes can manifest themselves in a range of discriminatory conduct including conditioning receipt of anti-retrovirals on contraceptive use and coercive sterilization. A petition was recently submitted by the Center for Reproductive Rights and Vivo Positivo to the Inter-

who was sterilized without her informed consent just moments after delivering her first child in 2002. At no point had she requested sterilization, and although she learned that she was HIV-positive shortly after becoming pregnant, she did not receive counseling on preventing mother-to-child transmission. Sadly, these kinds of violations are not uncommon in Chile or other parts of the world, including South Africa, Namibia and the Dominican Republic.

DISTURBING LEGISLATIVE TRENDS

Exacerbating human rights violations faced by women in health care settings are disturbing legislative trends of criminalizing HIV exposure and transmission. Such criminalization further compromises women's rights and impact women's ability to care for themselves and others – without taking into account women's realities and vulnerabilities, including their vulnerability to violence, abuse and further stigmatization. These laws, often overly broad and poorly drafted, could penalize individuals who practice safer sex and/or disclose their HIV status to their sexual partners, or mothers who transmit HIV to their children, either *in utero* or during labour and delivery. Pregnant women may face the most severe consequences of these laws—especially considering

simultaneous trends of routine and mandatory HIV testing of pregnant women.

CALL TO ACTION

In light of such grave threats to women's human rights, we hope that the Commission in its outcome document for this session will call upon governments to protect the sexual and reproductive health and rights of women living with HIV.

Specifically:

- To ensure that the protection of women's rights, especially the rights to autonomy, sexual and reproductive choice, equality and non-discrimination, are at the center of the response to HIV and AIDS – so as to guarantee that women's risks and vulnerabilities are not perpetuated, but rather addressed and minimized.
- To take pro-active steps to reduce discrimination against HIV-positive women in health care settings, with a particular emphasis on stopping non-consensual HIV testing and disclosure of HIV status, reducing stigma that leads to denial of necessary reproductive health services, and eradicating the reprehensible practice of coercive sterilization of HIV-positive women.

- To pass legislation and policies that require medical providers to obtain informed consent prior to HIV testing and disclosure of HIV status and impose strict confidentiality standards in the context of HIV, and create effective enforcement mechanisms to guarantee these protections.
- Finally, to ensure that HIV legislation and policies focus on protecting the human rights of those living with HIV and the development of comprehensive and evidence-based prevention methods, rather than introducing provisions such as criminalization of HIV transmission which increase women's risks and vulnerabilities.

Thank you.



ATHENA

www.ATHENAnetwork.org



**AIDS
LEGAL
NETWORK**

www.aln.org.za