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Rhetoric and reality. . .

Courage to bridge the gap and realise human rights in everyday daily life with HIV

Lucy Stackpool-Moore

The 3rd conference of the Association for the Social Sciences and Humanities in HIV (ASSHH) was hosted in South Africa in 2015 and had a thematic focus on 'rhetoric and reality'. *This was interpreted differently by the different speakers, panellists and participants, covering many different ideas (stigma, HIV testing, quality of services, identity) in a variety of different disciplines (research sessions, workshops, films and spoken word poetry). For me, the ASSHH conference was a luxury to step outside the busy day-to-day routine and think critically and reflectively about human rights, HIV, and the complexity of identity in the context of HIV and law.*

In this article, I pull together some of my reflections about the presence of the law in everyday life for women living with HIV. This is based on my thoughts at the conference, as well as some research in Malawi in 2010-2012 that I worked on with David Kamkwamba, Gift Trapence, George Kampango, Ruth Kundecha and Milliam Simkonda Kumwenda, who were associated

Mujeres Adelante
A NEWSLETTER ON WOMEN'S RIGHTS AND HIV

Editorial...

With the need for critical thinking and discourse on issues of women's rights and HIV continuing, this edition of the ***ALQ/Mujeres Adelante*** explores some of the remaining gaps between women's rights and women's realities, and continuing challenges for women to claim their agency, realise their rights, and access services.

Acknowledging the progress made, the various contributions in this edition highlight the seemingly persistent gap between '*rhetoric and reality*', and raise questions as to the '*actions*' required to ensure that the much needed '*transformative change*' for women and by women moves from being a '*potential*' to becoming '*reality*'.

Legal environments have been part of the discourse on women's rights and HIV for a long time – as they are as much a '*pre-requisite*' to ensure that women's rights are protected and advanced in all aspects of the AIDS response, as a '*barrier*' for women to claim agency, realise rights and access services. Exploring both the '*potential and impotence*' of the law in the context of HIV in Malawi, **Lucy Stackpool-Moore** discusses the extent to which the '*complexity of identity*' impacts on the gap between '*rhetoric and reality*' of legal protections in the daily lives of women living with HIV. She examines the concept of '*intersectionality in action*', illustrates how '*intersecting and complex layers of individual identity*' impact on women's '*notions of and access to justice*', and argues that as long as gender and power inequalities prevail, the extent to which women living with HIV are in the position of '*forging the gap between rhetoric and realities*' will be limited by the very same.

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In this issue

with the network of journalists living with HIV (JONEHA), the Centre for the Development of People (CEDEP), the Malawi Network of Networks of People Living with HIV and AIDS (MANET+), and the Family Planning Association of Malawi (FPAM) respectively.

HIV AND THE LAW: THE POTENTIAL...

Law can have a profound impact on the lives of people – especially those who are vulnerable and marginalised. For example, this can be a positive force for change; through judicial and legislative action that has improved access to life-saving treatment and protected people living with HIV against discrimination. Or where the law has guaranteed equal inheritance and property for women and girls, it has helped to mitigate the social and economic burden caused by HIV and AIDS. It can equally be a negative force for change in jurisdictions where criminalisation occurs of HIV transmission, exposure and non-disclosure or behaviours associated with high HIV vulnerability, such as same-sex sexual acts, the selling or soliciting of sex, and aspects of drug possession or use. Increasingly attention has been paid to creating enabling legal frameworks to mitigate the causes and consequences of HIV, yet in many countries, legal frameworks that further entrench structural inequalities persist.

...a luxury to step outside the busy day-to-day routine and think critically and reflectively about human rights...

HIV AND THE LAW: THE REALITY...

The degree to which people living with and closely affected by HIV are conscious of the law and enforcement mechanisms – including the various laws that could protect, as well as those that could punish – needs further attention. Some research that I did and spoke about at the ASSHH conference focused on the potential and impotence of law in the context of HIV in Malawi. The research was undertaken in 2010-2012 and the methods used were a one-country qualitative case study (Malawi), and action-research involved purposive and snowball sampled qualitative interviews (n=100) with law commissioners, opinion leaders, life story participants (people

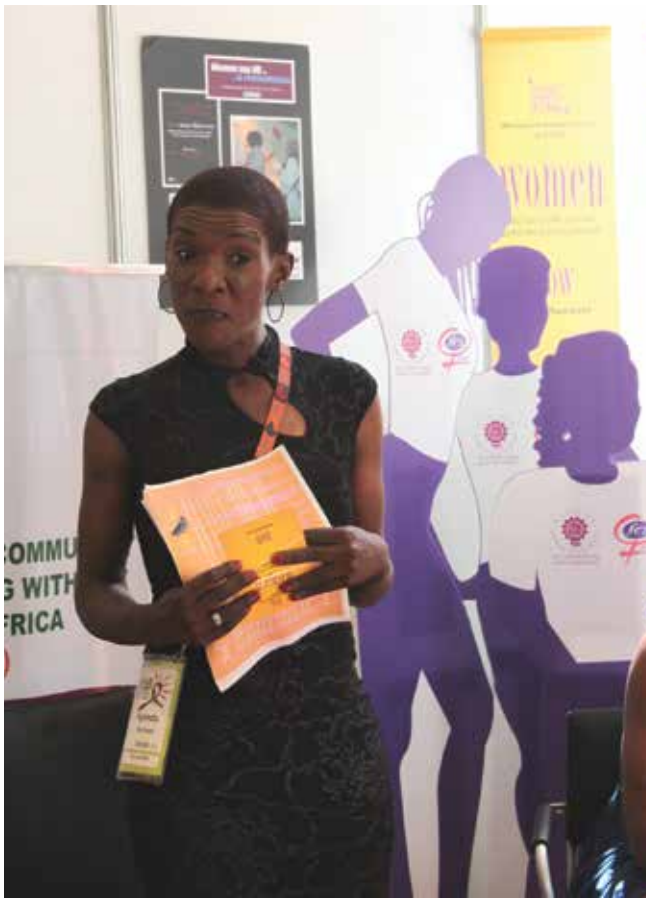
...the complexity of identity in the context of HIV and law...

The impacts of and reasons for diminishing funding for women's rights work in the context of HIV has equally been part of the discourse for quite some time. It is within this context that **Jacqui Stevenson**, **Luisa Orza** and **Tyler Crone** raise a wide range of questions as to the '*costs of funding women's rights work*'. Based on the premise that the '*progress on achieving gender equality is limited by a lack of funds*', the article highlights the many challenges faced by especially smaller women's rights and feminist organisations – from being '*squeezed out of bigger funding*' opportunities to a lack of access to '*sustainable funding at smaller level*' and the costs of fundraising. Emphasising the need for women's rights to be '*continuously and explicitly prioritised*' and funded, the authors conclude that there is '*huge potential for transformative change*', if only there were funds.

The coerced and forced sterilisation of women living with HIV remains a reality, despite legislative provisions clearly stipulating that no medical procedures can be undertaken without a person's consent. Revisiting the gap between legal provisions and forced sterilisation realities, **Eva Kennedy** shares some of the human rights responses and discourse in the attempt to end forced sterilisation from across the region. Recognising this ongoing practice as a '*gross and unjust violations of women's fundamental human rights*', she advocates for medical practitioners to respect women's rights and be held accountable if they fail to do so; for women to be '*empowered to claim agency*' and realise their rights; for the '*world to move forward and protect women's rights*'; and for forced sterilisation of women living with HIV to be '*put in the distant past, where it so rightfully belongs*'.

With biomedical interventions for HIV continuing to progress, Pre-Exposure Prophylaxis (PrEP) for HIV '*opens up a world of opportunities when it comes to HIV prevention*'. Discussing the social and gendered context of HIV prevention '*choices*', **Emma Aldrich** explores the opportunities and challenges of PrEP for women. Highlighting the benefits of '*greater agency and greater options*' for women, she also cautions about the '*risks and unintended consequences*' of the '*social context around the use of PrEP*', and the associated threat of '*coercion*' and other rights abuses, if not taken into account. Arguing that there are '*more questions than answers*' and '*no quick wins*', she concludes that the benefits of PrEP for women will only become '*real*', if we '*actively seek to prevent coercion and prioritise women's individual agency*'.

The links between the use of hormonal contraceptives and women's risks of HIV acquisition has been part of the critical discourse and women's rights and HIV for some time. Analysing the



living with HIV and those most vulnerable to transmission), reflections of the action research team, and a review of legal and policy documents. The results showed that while stigma remains a challenge in Malawi, HIV is part of everyday life. Legal consciousness was not apparent in the everyday lives of most of the people living closely with HIV, and significant challenges to law enforcement and access to justice remain.

I would like to highlight two of the really interesting findings from that research that illuminate the distance between rhetoric and reality, when it comes to law and HIV. First, the participants in the research did identify a desire for law to have a role in the response to HIV, even though in their life stories none of the participants had effectively engaged the formal legal system to seek redress for episodes of injustice or discrimination they had experienced. The life stories indicated that the traditional authorities are a much more prominent source of justice in their lives. Consciousness of the direct link between law and HIV was not always clear for participants. Yet, what was most interesting from the results, was that almost everyone expressed that law did have a role to play in the response to HIV for a range of reasons, including preventing discrimination, promoting human rights, ensuring access to treatment and regulating against gender inequality. This showed that law had a symbolic role in governing personal and social norms (rhetoric), even if not functionally implemented in reality.

…this can be a positive force for change…

Second, the participants in the research were all very different in terms of age, gender, sexual orientation, income level,

'*power dynamics of body and choice*', **Vicci Tallis** provides a feminist analysis of women's contraceptives in South Africa. She discusses the concepts and realities of women's autonomy in the context of patriarchy, power, and women's bodies '*as a site of struggle*'; introduces a history of contraceptive policy and practice in South Africa; and explores some of the autonomy, rights and safety issues for women using hormonal contraceptives. Emphasising that women's right to '*safe, accessible, affordable, available and appropriate contraceptive choices*' should be located with the framework of the right to the highest attainable standard of health, she argues that women's bodies and choices are '*shrouded in politics of autonomy and power*', and thus '*human rights issues are evident that cannot be ignored*'.

The recurring theme in all the articles seems to be the pervasive gap between '*policy and practice*' and maintained distance between '*rhetoric and reality*' impacting on the extent to which women in all their diversity are in the position to claim agency, realise rights, and access services – thus impacting on the effectiveness of the women's rights and HIV response. Despite the many '*commitments*' and '*legal protections*' on '*paper*', in '*reality*' women's risks and vulnerabilities to HIV and rights abuses continue to be defined as much by the '*social contexts*' that are gendered, powered and unequal, as by the '*dynamics of inequality centred on the complexity and layering of identity*'.

The '*distance*' between the '*policy*' of women's rights protections and '*practice*' of women's rights violations in the context of and the response to HIV will arguably persist as long as we fail to ensure that '*women's rights and agency are front and centre*' of not only the critical discourse on and response to women and HIV, but also the '*funding environment*' for women's rights work. Thus, without '*championing women's individual agency*' and actioning '*transformative change*' for and by women, the progress made in the women's rights and HIV response will be '*nullified*' by the perseverance of the '*disabling*' social (and funding) environments; with '*potentials*' and '*promises*' remaining only that, with little to no impact on women's daily lives and choices. To move forward and '*fast track*' women's rights and agency, it is time to '*redefine*' the agenda, truly '*address*' the '*power dynamics of body and choice*', '*prioritise*' women's realities, risks and needs '*continuously and explicitly*', and '*transform*' the social contexts limiting women's rights and agency – not in '*rhetoric*', but in '*reality*' and with '*actions*'…

JOHANNA KEHLER

and lifestyle. For example, some were parents, others were not; some were married or in long term relationships, others were not; some lived in villages, others in cities; some went to church, and others did not; some had finished university, others had only completed some levels in primary school. These factors, as well as gender, HIV status, and sexual orientation were all important factors that seemed to influence how or if people knew about the law and its enforcement mechanisms. In other words, the day-to-day reality of law in the everyday lives of people – in all their diversity and multiple layers of identity – is much more nuanced than the de-contextualised '*legal subject*' that is universally assumed in laws and statutes.

…legal frameworks that further entrench structural inequalities persist…

INTERSECTIONALITY IN ACTION…

The concept of '*intersectionality*' – to borrow from critical race theory and feminist legal studies – describes the coming together of dynamics of inequality centred on the complexity and layering of identity. The concept is built on recognition of identities that exist apart from each other, within and shared between individuals. The concept has gained momentum (and criticism) since 1989, when '*intersectionality*' was first coined by Kimberle Crenshaw in a seminal article that disentangled the dual axes of race and gender and showed how women of colour can be marginalised within patriarchal anti-racism movements and/or racist feminists. Crenshaw was responding to what she perceived to be an elision of difference in identity politics, where women of colour may experience a kind of double-discrimination, which is unique and is the combined effects of race- and sex based discrimination. Even though women of colour may also experience discrimination that is

…the potential and impotence of law…

similar to white women (sex discrimination) or men of colour (race discrimination), the potential double-discrimination from the combination of both sex and race had not yet been articulated.

Two examples from the life stories collected in the research provided concrete examples of how this translates into reality, particularly when viewed through a gendered lens. Mavis (not her real name) described that she had had direct experience with the police in relation to a complaint of domestic harassment, but it had been ineffective mainly because of gender inequality and the fact that the police favoured her husband. '*The police did nothing just because most of the policemen here are his friends…they were not supportive*'. Mavis is a woman living with HIV, who works as a school teacher and also cared for three children (two of her own, and her nephew). Josephine (not her real name) also described how gender inequality was a barrier for her in seeking formal justice. She explained how her former husband had beaten her, but that she had never used the law to help her even though she had wanted to. '*I wanted to use law when my husband mistreated me. I wanted to go to court to sue him but I never did that*' said Josephine. Josephine was unemployed at the time of the interview and hoped to finish her schooling. She has two sons and lives in a rural town, is living with HIV and a leader in the local women's HIV support network.

…legal consciousness was not apparent in the everyday lives…

Even though the law was ostensibly absent in the reality of daily life and HIV among the participants in this research, it was nevertheless still perceived to have a potential role in the national HIV response. Few people questioned the rhetoric or the applicability of the law to

HIV. The examples from Mavis and Josephine show how gender can have an impact on if or how someone seeks protection or support from law enforcement mechanisms – as well as how gender (and power dynamics with their husbands) might have an impact on the level or quality of support that is received. The examples illustrate how intersecting and complex layers of individual identity – including gender, employment, rural/ urban characteristics – also influence notions of and access to justice. The stories of Mavis and Josephine give a snapshot of how layers of identity might influence access to justice for different reasons. These reasons include gender and power inequalities with their husbands, or circumstances as care-givers or leaders in the community, or income levels, or education levels and legal literacy about access to justice in their communities, or HIV positive status, or a combination of some of all of these factors. These two examples describe the concept of intersectionality in action.

BEYOND THE CONFERENCE SPACE…

Will there be a tangible outcome from the ASSHH conference for bridging the gap between rhetoric and reality? Of course it is still too early to say. There did seem to be only a small number of young people and young researchers at the conference – one of whom was Duncan Moeketse, an inspiring young leader and innovator as well as student of sociology. One of the highlights for me was witnessing one of the lecturers from his University connect with him after the insights he shared as a speaker on a panel about the *Greater Involvement of People Living with HIV and AIDS* (GIPA) principle 20 years on. Hopefully the connection will be as fruitful for Duncan as it was for the lecturer to listen to his perspective! A hope for future conferences, including ASSHH, is for more initiatives to give scholarships and other travel opportunities for young people living with HIV and interested in social sciences to participate in the conference conversations and present on their ideas.

…'we need to have the courage to see justice being done'…

…traditional authorities are a much more prominent source of justice…

One of the real benefits of a small, fairly niche, social science conference was that it brought together a variety of minds and disciplines with a shared interest in the nuances and the complexity of individual experiences, as well as population level studies. Sometimes the social science results presented were embedded within larger clinical trials, other times they were stand-alone specific and discreet areas of enquiry and critical reflection. By providing a space to openly – and unashamedly – debate ideas and new thinking emerging from small scale and predominantly qualitative research findings, it enabled us all to remain mindful of the exceptions as well as the consensus in thinking about all aspects of HIV, gender, and sexuality. The inclusion of music, poetry and social spaces also recognised the fundamental role of hearts, as well as minds in framing how we engage with, respond to, research, live with, and relate to HIV. The heart can be just as powerful as the mind in forging a connection between rhetoric and reality.

…bridging the rhetoric of human rights in the context of HIV with everyday reality in the diverse personal contexts of living with HIV…

For me, as a researcher, activist and programme implementer in HIV and human rights, the ASSHH conference provided an opportunity to step out of my own day-to-day reality, pause, reflect, critically discuss this research and other issues, and think differently perhaps about my own work and contribution. I have the privilege to work with lots of different people with multiple identities in many different contexts around the world. Listening to one of the other life stories, in the words of Patience (not his real name), '*we need to have the courage to see justice being done*'.

The final take home message for me, as well as for my colleagues and participants in the research – was about courage, combined with perseverance, motivation and passion for bridging the rhetoric of human rights in the context of HIV with everyday reality in the diverse personal contexts of living with HIV.

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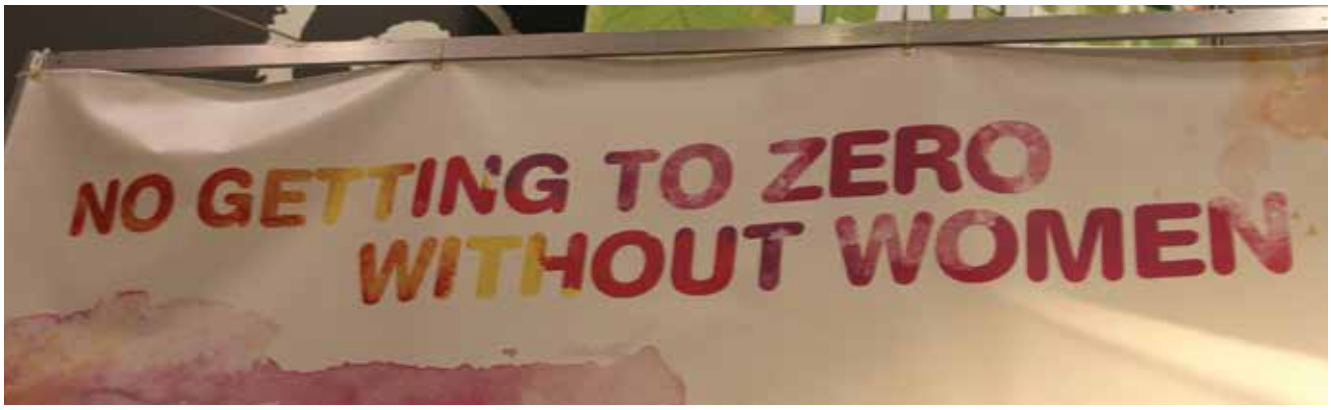
All the things we could do, if we had a little money...

The costs of funding women's rights work[1]

Women constantly work without being paid, without being recognised and without being honoured, it's the same old stuff and we need change. [Activist speaking at ATHENA event]



Jacqui Stevenson, Luisa Orza, Tyler Crone

All organisations depend on funding. From major international organisations with multi-million dollar budgets to small community collectives surviving on small change, funds are what keeps things going, allow work to thrive and scale up, and ensure you can make a difference. In the HIV field where we work, funds may come from government development agencies, international foundations, the Global Fund, or national sources, as well as private trusts and foundations. Who gets money, how much, and what for are all contentious issues.

Rarely transparent, funds often come with hoops and loopholes that make it hard to get a clear sense of how well they are allocated and used. Some funds also come with ideological conditionalities such as the '*global gag rule*' on US government funding, first imposed by the Reagan administration, which prohibited organisations in receipt of funds to provide or be seen to '*promote*' abortion. Small, locally and community led organisations are squeezed out of bigger funding opportunities, because they are small, but are often unable to access sustainable funding at smaller levels. This has a huge impact on what is done, and for whom.

For women, and women's rights, this adds up to a picture where progress on achieving gender equality is limited by a lack of funds. Women are not at the decision-making tables, women's voices are not heard on the big platforms, and the ability of women-led initiatives to achieve change is limited by lack of money.

BIG MONEY

Making big change, at scale, takes big money. Often, governments and foundations identify an area where there is an opportunity for significant change, and allocate big funds to target it. Sounds good? The problem is, that it takes lots of work to identify an area for change. It is impossible to access funds without evidence of need and potential impact, but gathering evidence also takes resources. This can lead to the problem of huge areas in need of changes being overlooked, because there are no funds available to evidence this need.

Often the work to gather evidence is led and done by grassroots and community organisations, with little funding or support. Then, once they have begun to build an evidence base and a case for the specific area of intervention, big funds open up, for which they are too small to be eligible. So large national and international organisations come in and get the funding, and small local organisations are left to operate on a shoestring.

...women's voices are not heard on the big platforms, and the ability of women-led initiatives to achieve change is limited by lack of money...

A recent analysis[2] of access to funding for HIV by women's organisations in Uganda noted that:

...even with organisations that have had access to funding, this has not been without numerous challenges.

Highly technical proposals are required by the donors yet most women organisations lack the technical staff or funds to hire consultants to develop proposals. The donor also requires organisations to possess several years' experience of managing donor funds and robust financial, monitoring and evaluation and governance systems in order to grant funding. This perpetually keeps women organisations stunted since they cannot get the experience unless they are funded in the first place.[3]

This final point is especially important – without sufficient, core and sustainable funds it is impossible for an organisation to establish itself and develop, and without funds to deliver work, it is impossible to get the experience needed to access funds to deliver work (think of it like someone looking for their first job, constantly told they need experience to apply).

The analysis also found a range of restrictions on donor funding, including limited overheads that are insufficient to cover staffing and office costs. Limitations on staff funding lead to over work, stress and burnout, and can limit the quality and impact of the work organisations can do.

…huge areas in need of changes being overlooked…

This lack of access to big funds restricts the ability of women's rights organisations to lead the big, transformative changes it takes to address harmful gender norms and achieve gender equality.

SMALL MONEY

Unable to access larger funds, local, community, and other small organisations, including new and forming

organisations, rely on smaller funding pots. These are often project-based, and once-off. The challenge with this is that they often do not cover core costs, such as office and staffing costs, and do not provide any sustainability or certainty in the funding base to allow the organisation to develop and grow. The once-off nature of project funding can also limit impact and reduce the ability to reach and engage people.

For example, a community based organisation is given $3000 to run a series of community focus groups to discuss a particular issue. The funds cover venue costs, refreshments, participant expenses, and a few days of staff time to prepare for the focus groups, write up the results, and evaluate the project. There is no cover for staff time to actually develop the project idea and seek further funding for it (the free labour inherent in all funding bids, see below for more). No money to keep the office running and the computers working, which is nevertheless essential to the project. No funds to cover the ongoing work to build and maintain links between the organisation and individuals and communities, to ensure that participants can be recruited into such project. And no funds to develop the skills or capacity of the organisation or for any follow up. All these associated activities, accrued in each project, are unfunded.

...limitations on staff funding lead to over work, stress and burnout, and can limit the quality and impact of the work...

JUMPING THROUGH HOOPS

All funders have requirements, many of them stringent and challenging.

Lengthy and complex funding applications, and monitoring and evaluation forms are time-consuming and often difficult to complete. There might be financial requirements – such as the funds representing no more than a given percentage of your organisational income. This can be a big barrier for small organisations, which are able and working to grow but prevented from accessing medium or large grants because, effectively, they have not already received one. For example, if a given fund, of $50,000, can be no more than 25% of your overall income, only organisations with incomes of $200,000 a year can apply, preventing smaller organisations from accessing the funds they need to grow. Other requirements, such as having external audits, formal accounting systems, and similar, prevent community and grassroots organisations accessing any funds, including funds they need in order to get formal systems in place.

…applying for funding is an onerous task, which takes up a significant amount of staff or volunteer time, with no guarantee that any funds will be realised in return…

IT COSTS MONEY TO GET MONEY

Applying for funding is an onerous task, which takes up a significant amount of staff or volunteer time, with no guarantee that any funds will be realised in return. This adds up to a significant loss of the individual applying organisations, but is even more troubling when we calculate how many hours of unpaid women's work go into seeking funds.

For example, UN Women stated that:[4]

In response to its 16th Call for Proposals, which closed on 23 January 2012, the UN Trust Fund received 2,212 applications from 121 countries for a total value of

nearly $1.1 billion. Civil society organizations made up nearly 90% of these applications, attesting to the largely unmet demand for resources to address violence against women on the ground.

Based on our colleagues' experience at ATHENA, submitting a first round funding application to the UN Trust Fund took about 10 days to develop, working with partners, gathering background materials, as well as developing the proposal, work plan, monitoring and evaluation framework and other essential materials. That is 10 days of unfunded staff time, in an organisation with no core cost funding.

…43 years of unpaid women's time for no resources, for one grant submission on an annual funding cycle…

Only a fraction of applications are taken forward to grant-making. In the 2012 funding round, 17 of the 2,212 applications eventually received funds[5], after developing another '*fully fledged*' proposal, which involves even more work than the original. Work that does not retrospectively get compensated. That leaves the approximately 10 days of unpaid work of 2,195 organisations resulting in no resources. 21,950 days/365 = over 60 years of work going in to attempting unsuccessfully to get resources … on one call for proposals! If you view a working year as more like 250 days, allowing for people to have weekends and holidays off, then the number of unpaid years goes up to 87! Let's say not everyone does as much work on their initial application as we did, perhaps only 5 days' work. That's still 43 years of unpaid women's time for no resources, for one grant submission on an annual funding cycle. Let's imagine that on average each organisation

does three applications a year – at the skinny figure of 5 days per application, that's over 120 years' worth of women's unpaid resources being put into seeking resources every year, the vast majority of which will not translate into any funding. Or any impact in realising women's rights.

MONEY GETS MORE MONEY

All this adds up to a landscape where larger organisations get more funding, and others struggle, or even disappear. This is compounded by the global recession, and a decreasing donor focus on HIV, meaning the overall funding is reducing. Increasingly too, governments and foundations look to single large grantees, over coalitions and multiple medium grants, that allow smaller organisations a foothold. This is often seen as reducing administrative and other burdens, but in practice means that multi-million dollar organisations get and hold the big money and small organisations can at best look to be sub-grantees.

AWID's research[6] in 2010 found that the combined income of 1,1000 women's organisations was approximately $106 million US, which they compare to the income in that year for Save the Children International and World Vision International of US$1.442 billion and US$2.611 billion respectively. Not only do the bigger organisations enjoy better ability to access funding, but they also benefit from administration fees on large grants, and bank interest and investment income off huge budgets. So the big organisations get bigger, and smaller organisations cannot hope to compete.

…smaller organisations cannot hope to compete…

WHERE THE MONEY GOES

More, this adds up to a picture where generic organisations get the funds. If your organisation is specialised with one community or group, or in one area, it is increasingly difficult/challenging to access funds. In a given country, you may see the national HIV organisation accessing the global and governmental funding, while the women's groups, violence prevention organisations, LGBT organisations and others struggle. It reduces diversity in civil society, in both organisations and approaches, and creates a rocky terrain for new groups to form, a particular impediment for newly affected communities, youth-led organisations and others.

…essential that gender equality and women's rights are continuously and explicitly prioritised…

WHAT NEXT?

In 2013, AWID published the report *Watering the leaves, Starving the roots*[7], which details how growing focus on '*women and girls*' in development, has not translated into funding and support for the roots of change – women's organisations. In a 2010 survey, the median income of over 740 women's organisations was just $20,000 US. The issues AWID identified have a long history and continue today (this excellent recent piece[8] highlights the history and ongoing challenges of the under-resourcing of women's rights work). This lack of funding and systemic under-resourcing of women's rights work has been called a form of gender based violence and a violation of women's human rights.[9]

The International Community of Women living with HIV Eastern Africa (ICWEA) recently published a rapid situation analysis of access to funding by organisations of women living with HIV, gender and women human rights organisations in Uganda.[10] Their analysis found there are many barriers to women's organisations and

networks accessing funds, and called for enhanced technical assistance, funding calls specific for women's organisations, increased partnership and knowledge sharing with funding bodies, and institutional support.

In addition to these recommendations, if we are to see real change in the funding of women's rights organisations, it is essential that gender equality and women's rights are continuously and explicitly prioritised, including in the allocation of funds (and that gender '*mainstreaming*' is not used as an excuse to lose gender from the agenda). Further, funders, including all governments, trusts, international NGOs, and UN bodies, must recognise that gender equality and women's rights have not been achieved, and recommit their efforts, and their funds, to supporting more progress. It would also be beneficial for funders and the public to recognise that splashy social media campaigns and celebrity endorsements do not make change, and for funds to be refocused on supporting the women who do. Funders and other actors must recognise that women's rights and feminist organisations are essential partners in achieving gender equality, and act to repair the disconnect between focus on women and girls, and funding for the organisations that can make change on women's rights. There is huge potential for transformative change, if only the funds are there to make it happen.

…there is huge potential for transformative change, if only the funds are there to make it happen….

FOOTNOTES:

1. An earlier version of this *article was originally published by the Huffington Post.*
2. ICWEA. 2014. Are women organisations accessing funding for HIV and AIDS? [www.icwea.org/wp-content/uploads/downloads/2015/04/ICWEA-Report-Are-women-accessing-funds-for-HIV.pdf]
3. *Ibid.*
4. UN Women. 2013. Inventory of United Nations system activities to prevent and eliminate violence against women. [www.un.org/womenwatch/daw/vaw/inventory/Inventory-February-2013.pdf]
5. See www.unwomen.org/en/trust-funds/un-trust-fund-to-end-violence-against-women/grantees.
6. See www.awid.org/news-and-analysis/20-years-shamefully-scarce-funding-feminists-and-womens-rights-movements.
7. See www.awid.org/publications/watering-leaves-starving-roots.
8. See www.awid.org/news-and-analysis/20-years-shamefully-scarce-funding-feminists-and-womens-rights-movements.
9. Welbourn, A. 2012. The gender politics of funding women human rights defenders. [www.opendemocracy.net/5050/alice-welbourn/gender-politics-of-funding-women-human-rights-defenders]
10. ICWEA. 2014. Are women organisations accessing funding for HIV and AIDS? [www.icwea.org/wp-content/uploads/downloads/2015/04/ICWEA-Report-Are-women-accessing-funds-for-HIV.pdf]

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Move forward and protect women's rights...

Forced sterilisation realities

Forced sterilisation is a controversial and invasive medical practice with an extensive and unpleasant history. Long since denounced by human rights activists around the world, the practice has been cast into light in recent years as it targets women living with HIV. Although there has been a reaction by human rights groups and grassroots organisations against the practice, with well-publicised cases occurring in Namibia and Kenya, new evidence shows that many women are still being sterilised against their will.

Eva Kennedy

There are clear guidelines in place for if and how the procedure of sterilisation should be done, and human rights groups are working to raise awareness and empower women to ensure that these guidelines are followed and that the patient is in control of the decision. In spite of these efforts, more and more women are coming forward to complain that procedures are not being followed and that they are still being sterilised against their will. In July, the South African National AIDS Council (SANAC) released a *Stigma Index* in which an alarming 498 women reported that they had been forcibly sterilised, because of their HIV status.[1] In order to stop this human rights violation, we must do more to ensure that medical practitioners respect their patients' rights, and we must all support and empower women in communities, as they strive to achieve equal rights and treatment.

FORCED STERILISATION: THE CONTEXT

Forced sterilisation is the process of permanently ending someone's ability to reproduce without consent.

Forced sterilisation has taken place in many countries around the world including, Puerto Rico, Australia, Germany, and many others. In the United States in the twentieth century the process was done to many African American and Native American women. In many of these countries, notably Germany in the 1940s, the process was part of a eugenics programme aimed at ending what was considered to be '*unfavourable*' genes. The practice has usually targeted stigmatised groups, such as Roma women in Eastern Europe. Forced sterilisation of Roma women was widespread in Czechoslovakia between 1971 and 1991, and it was used as a means of '*controlling the Roma population*'.[2] It is estimated that more than 90,000 women were rendered infertile as a result of these procedures, but it has continued to occur even into the present day, especially in Slovakia where stigma towards Roma people is still widespread.[3]

In a modern context forced sterilisation often targets women living with a genetic or transmittable disease, such as HIV. In recent years, there have been a number of reported sterilisations of women living with HIV in Africa and other parts of the world. In South Africa and Namibia, the practice has made news headlines recently; and last year, five women in Kenya sued the government and two NGOs for forcibly sterilising them, because of their HIV status.[4] The attention that this drew caused many other Kenyan women to come together for a protest against the widespread practice, shedding light on the fact that women living with HIV are regularly being forcibly sterilised in Africa.[5]

…ensure that medical practitioners respect their patients' rights…

LEGAL PROVISIONS VERSUS REALITY

According to the Sterilisation Act passed in 1998[6], in order for a medical practitioner to perform sterilisation, the following requirements must be met: the patient must be over the age of 18; she must be capable of giving consent; she must have been informed about the consequences, risks, and irreversible nature of the procedure in a language that she can understand; and she must have signed the consent form having understood what she is signing.[7] In many cases, however, these procedures are not being followed. Women have reported being made to feel guilty about their

HIV positive status, before being asked to be sterilised, and in many cases being coerced, while they were in labour. In some cases, the doctors even refused medical care to the patients in labour until they signed the consent forms.[8] In a study released in 2011, one woman said, '*No form was ever given to me to read, I was just told to sign*'. Another woman, speaking about the psychological effects of the procedure, remarked that she '*feels like half a woman all the time*'.[9]

Women who have been sterilised are often HIV positive, and women living with HIV are already frequently stigmatised. In a study done by the AIDS Legal Network[10], women reported being evicted from their homes, abused by their families and friends, and being beaten or abandoned by their husbands. One woman said of her husband,

> *He beat me for bringing HIV into his home… That's when I regretted that I agreed to do the stupid HIV test.*[11]

The inability to have children stigmatises these women even further. One woman explained,

> *You find that you lie to your man. You say you have missed your period and then three months later you say you had a miscarriage, because you want this relationship to last.*[12]

…threatening not to birth her child until she signs a consent form…

THE HUMAN RIGHTS RESPONSE AND DISCOURSE

There has been some progress made in the attempt to end forced sterilisation. Numerous human rights

groups have spoken out against the practice, and more and more women are coming forward to tell their stories. In 2012, a judge in the Namibia case ruled that the government did sterilise women living with HIV against their will. The judge did not, however, rule that these women's positive status was the reason that they had been sterilised.[13] More recently, the Women's Legal Centre and the NGO Her Rights Initiative (HRI) have lodged a complaint with the Department of Health over the issue, and they are also suing the KZN Department of Health.[14]

…gross and unjust violation of women's fundamental human rights…

The arguments that are often offered by those in favour of sterilising women living with HIV are that they will pass the virus on to their children, or that they will die and leave their children with no one to look after them. Even if one overlooks the fact that neither of these arguments takes the woman's human rights into account, both points become increasingly illogical as antiretrovirals become increasingly accessible. Between 2008 and 2011, rates of infants who acquired HIV decreased from 9.6% to 2.8%[15], and many women are living long lives with the continued use of medication to manage HIV. In spite of these advances, a study released this year by the Human Science Research Council (HSRC) found that an alarming 498 women had been forcibly sterilised, making it evident that more must be done to protect the rights of women in South Africa.[16] These and other evidence also underscore the dire need to both ensure enhanced access to prevention of vertical transmission of HIV programmes and rigorous measures to guarantee that reproductive decisions are free from coercion and other rights abuses.

MOVING FORWARD

So what can be done to end the forced sterilisation of women living with HIV? Medical practitioners must respect women's fundamental human rights, and women must be empowered to claim agency and be educated about their rights. Recognising that a woman living with HIV has the same rights and dignity as any other person, she is to be afforded the right to control over her own body.

Doctors must not take advantage of a woman who is in labour by threatening not to birth her child until she signs a consent form, and medical practitioners must not coerce, or otherwise manipulate a woman into agreeing to sterilisation. A report issued by UNAIDS and the ATHENA Network suggests empowering women by placing them in leadership roles, educating them about their rights, investing in women's organisations, and getting more people involved in grassroots organising for women's rights.[17]

The practice of forcibly sterilising women living with HIV against their will is a gross and unjust violation of women's fundamental human rights. It must be seen and treated as such. Medical practitioners must respect the rights of women living with HIV, and be held accountable for not doing so. At the same time, it is crucial to ensure women's enhanced capacity to claim agency and to realise rights.

It is time for the world to move forward and protect women's rights, and it is time for us all to put the practice of forced sterilisation in the distant past, where it so rightfully belongs.

FOOTNOTES:

1. Child, K. 2015. *'HIV Positive Women Sterilised Against Their Wishes'.* Times Live.
2. Moller, S. 2010. 'Dis-Information and Mis-Information: Forced sterilisation of Roma women in Slovakia'. In: *ALQ June Edition*, p32.
3. *Ibid*, pp39-40.
4. Smith, D. 2014. *HIV- Positive Women Sue Kenya Government and NGOs Over Sterilisation.* The Guardian.
5. *Ibid.*
6. Sterilisation Act No 44 of 1998. [www.acts.co.za/sterilisation-act-1998].
7. *Ibid.*
8. Koka, J. 2015. *'Forced' Sterilisation of HIV Women Violates Rights.* Mail and Guardian's Centre for Health Journalism, Bhekisisa.
9. Turley, M. 2012. *South Africa: Motherhood denied to HIV Positive Women.* Pulitzer Center on Crisis Reporting.
10. Kehler, J. et al. 2012. Gender violence & HIV. Cape Town, AIDS Legal Network.
11. *Ibid*, pp30-31.
12. Serrao, A. 2015. *Forced Sterilisation: Complaint Lodged.* Johannesburg: IOL News.
13. Roseman, M. 2014. 'Namibia's High Court Finds Government Forcibly Sterilized HIV-Positive Women'. In: *Human Rights at Harvard Law*.
14. Mngoma, N. 2015. *Initiative to Stop Forced Sterilisation.* IOL News.
15. Barron, P. et al. 2012. 'Eliminating Mother-to-Child Transmission in South Africa'. In: *Bulletin of the World Health Organization*.
16. Koyana, X. & Bendile, D. 2015. *Forced Sterilisation of HIV Positive Women Investigated.* Cape Town: Eyewitness News.
17. Orza, L. 2011. *Community Innovation.* UNAIDS & ATHENA Network.

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No Quick Wins...
PrEP for Women

Emma Aldrich

AIDS-related illnesses remain the leading cause of death among women of reproductive age across the globe, and data suggests that the prevalence of HIV among women aged 15 to 24 in sub-Saharan Africa is twice that of young men.[1] *That the HIV epidemic disproportionately impacts on women in Africa is well known and to a certain extent, well-documented and understood. Due to a variety of intersecting biological, social and structural factors, which continue to be interrogated by activists, advocates, researchers and decision-makers, women and girls in Africa shoulder a significant burden when it comes to HIV. Of course, risks and vulnerabilities intersect; they coalesce to become amplified. And it is in these intersections, where gender inequality, biology, and social norms collide, and stigma, discrimination and marginalisation are fostered, that the effects of HIV on women grow ever starker.*

Amongst female sex workers in Nigeria, HIV prevalence is greater than 20%; between 34 and 69% of female sex workers in South Africa are living with HIV, depending on geographical area; and around 70% of female sex workers in Swaziland are living with HIV.[2, 3]

The burden of HIV is felt particularly by transgender women worldwide, and though the data is extremely scarce, evidence suggests that transgender women are especially vulnerable to HIV.[4] Similarly, women who inject drugs are too often made invisible within the larger drug-using population, and thus their risks and vulnerabilities to HIV are compounded.[5] For many women, and especially those considered to be members of *'key populations'* from a public health perspective, barriers around accessing

testing, treatment and care are both a cause and a result of persistent global gender inequality.

As biomedical interventions for HIV continue to progress, the development of a viable Pre-Exposure Prophylaxis (PrEP) for HIV opens up a world of opportunities when it comes to HIV prevention. Oral PrEP containing antiretroviral drug tenofovir (brand name Truvada) is currently recommended by the World Health Organisation (WHO), in addition to and in combination with other HIV prevention tools, particularly for sero-discordant heterosexual couples, for men who have sex with men, and for transgender women who have sex with men.[6] Before 2015 comes to a close it is expected that WHO will release more comprehensive and inclusive guidelines, and will recommend oral PrEP as an additional prevention choice for all people at substantial risk of HIV acquisition. Of course, drug demonstration projects across Africa, Asia, South America and North America, both completed and on-going, indicate that the success of PrEP in preventing HIV acquisition hinges on adherence. The challenges of adherence vary between different groups of people, and just as importantly, from individual to individual. As studies evaluate the practicalities of PrEP (how easy is it to use) and what dosing regimes work best (daily, time-based, and event-based dosing)[7] important insights are being gathered into adherence related challenges.

When it comes to PrEP for women in particular, there are currently more questions than answers. There is growing evidence that PrEP is useful and effective for those who understand it, desire it, and have the capacity to adhere to the drug-taking regime. What, however, are the real benefits for women, in all their diversity, whose vulnerabilities are multiple and intersecting? And what are the risks?

…a proliferation of choices for HIV prevention must be a good thing…

GREATER AGENCY, GREATER OPTIONS

There is no denying that the ability to assert individual control over an HIV prevention method could prove

particularly powerful for women, who due to the realities of gendered social norms, are often prevented from acting on their preferences or regarding health-seeking behaviours or practices. A proliferation of choices for HIV prevention must be a good thing. If a woman has a male partner, for example, who refuses to use condoms, she can still protect herself from HIV by using PrEP and can likely do so without his knowledge or approval. For women with an HIV negative status who wish to have children with male partners living with HIV, PrEP could be a great addition to a couple's joint strategy to prevent HIV transmission. In this way PrEP is a welcome addition to the broader package of sexual and reproductive health tools and services that arguably should be made available to all women, and will likely appeal to women who are aware of their HIV risks and vulnerabilities. Additionally, the increased availability and use of PrEP may prove to lessen stigma around HIV, in that people not diagnosed with HIV will be seen to take drugs previously identified only with HIV treatment.

…as with all biomedical interventions, there is a social context…

RISKS AND UNINTENDED CONSEQUENCES

While there are obvious benefits that women can access through using PrEP, there are also a litany of issues and causes for concern raised by some HIV advocates. For example, although PrEP is designed and recommended for use as one tool of many in the HIV prevention toolbox, there are concerns that PrEP may be used in place of other protective, safer sex or safer injection methods for HIV prevention.[8] Additionally, there are many unknowns when it comes to understanding both the long-term effects of Truvada as PrEP, as is the case for HIV drugs more broadly, and also how the drug may interact with other drugs. This is of particular concern for transgender women who use female hormones – is PrEP a safe and effective form of HIV prevention for these particular women? And for women who use recreational drugs – how would these drugs react with PrEP? Studies to date do not suggest serious side effects associated with use of Truvada, however problems including those related to the kidneys, the liver and the bones have occurred. Along this line of inquiry, questions around the possible health effects from Truvada for children whose mothers use PreP during pregnancy and breastfeeding are far from being answered.

As with all biomedical interventions, there is a social context around the use of PrEP that must be taken into account when considering PrEP as an HIV prevention option for women. Gendered social norms that support men to assert power and control over women and women's bodies could contribute to unforeseen consequences. For

some female sex workers, will issues around negotiating condom use make PrEP the most appealing, and possibly a singular method of HIV prevention? Will employers or managers encourage or pressure these women to use PrEP if male clients prefer sex without condoms? Indeed, will some women more broadly be pressured by their partners to use PrEP instead of condoms and if so, what are the broader sexual health and rights implications?

…what are the broader sexual health and rights implications…

Of course, the issue of coercion lies along an extensive continuum of gender violence, and in contexts where women, such as sex workers, are criminalised and/or stigmatised due to their profession, where female drug users are criminalised and stigmatised for their behaviours, or where transgender women and women who love/and or have sex with women are criminalised or stigmatised for their sexual and/or gender identities, the relationship between PrEP, coercion, and gender violence more broadly must be analysed, understood, and accounted for.

In countries like Uganda, where an HIV prevention and control bill criminalises people living with HIV for transmission or exposure to HIV, the increased availability of PrEP could bolster legal arguments that HIV prevention is primarily the responsibility of people living with HIV, and thus people can or should be subject to punitive measures under the law. In addition to increased vulnerability to rights violations from a legal perspective, women may face increased risks of violence. Evidence shows that violence and the threat of violence affect whether, when, how and whom women disclose their HIV status to.[9] It is possible then, that women not diagnosed with HIV, who choose to use PrEP as prevention, may experience violence related to HIV stigma. In a context like South Africa, where women frequently experience coercion when it comes to HIV testing[10] it is possible that health professionals may put pressure on women to utilise PrEP, particularly those they perceive as being most at risk for HIV.

CHAMPIONING INDIVIDUAL AGENCY

From a human rights perspective, a purely biomedical approach to HIV has never been an option. HIV is a disease that exposes and continues to demonstrate the social construction and dimensions of illness. The criminalisation and stigmatisation of *'key populations'*, including women who love and/or have sex with women, transgender women, women who use drugs, and women who sell sex, have continued to block women with heightened vulnerability from accessing critical HIV prevention, testing, treatment and care services; not to mention broader sexual health and rights services. Comprehensive sexual and reproductive healthcare packages must ensure that women's rights and agency are front and centre, and must take pains to not inadvertently reinforce harmful social norms that contribute

to constricting women's choices. PrEP should, therefore, be offered as an option for women to consider, in addition to other HIV prevention tools – with the caveat that it will not be right for everyone or in every season of life. Women's individual risks to HIV can change over time, and over time women should receive the necessary support to make well-informed decisions regarding their healthcare.

As demonstration studies continue, it is critical to ensure that human rights monitoring systems are introduced and implemented, and in this way actively seek to prevent coercion and prioritise women's individual agency. Above all else, we must be wary of perspectives that view PrEP as a quick win when it comes to protecting women from HIV; PrEP is attractive – it will be relatively easy for stakeholders to quantify investment in PrEP and to model associated HIV incident rates over time; undoubtedly the number of women reached with PrEP/on PrEP will become an indicator of success for HIV prevention programmes, particularly for programmes geared towards women at high risk for HIV.

It is, therefore, critical that those invested in ending gender inequality and violence and who are committed to the sustainable empowerment of women, work to answer the questions about PrEP for women that remain unanswered, and seek to ensure research and PrEP demonstration studies engage with the gendered social environment in which women live, make choices, and experience gender violence and other rights abuses.

FOOTNOTES:

1. See also [www.unaids.org/en/resources/presscentre/featurestories/2009/november/20091109women]
2. See also [www.avert.org/] Pages by country.
3. See also [http://swaziland.usembassy.gov/hiv-in-swaziland.html]
4. See also [www.avert.org/transgender-hiv.htm]
5. See also [www.unodc.org/documents/hiv-aids/publications/WOMEN_POLICY_BRIEF2014.pdf]
6. See also [www.who.int/hiv/pub/guidance_prep/en/]
7. See the HPTN 067 (ADAPT) study of Truvada PrEP.
8. See also [www.thewellproject.org]
9. AIDS Legal Network Report Summary: '*If I knew what would happen I would have kept it to myself': Gender Violence and HIV*. 2012.
10. Kehler, J.et al. 2012. *Gender Violence and HIV: Perceptions and experiences of violence and other rights abuses against women living with HIV in the Eastern Cape, KwaZulu Natal and Western Cape, South Africa.* AIDS Legal Network.

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The power dynamics of body and choice...

A feminist analysis of women's contraceptives in South Africa

Contraceptive discourse, be it around choice, accessibility, acceptability or safety has never been apolitical. Programmes that were once labelled as policies of population control and then called birth control, only to be changed to family planning, now go under the discourse of reproductive health.

Vicci Tallis

INTRODUCTION

Reproductive health is, according to Furedi, an expanded agenda in which the underlying agenda of fertility control becomes '*hidden and inconspicuous*': as such, he asserts, the

> *…medicalization of population concern is seldom contested, because it appears to be entirely about the non-controversial subject of health.*[1]

In the past, population discourse emphasised that progress in the so called '*third world*' was dependent on the elimination of traditional values and practice, and the link was made between the dual relationship between poverty and high fertility rates.

In South Africa in particular, both in the past and currently, contraceptives have been shrouded in race and gender politics – with a more recent issue being the interface between reproductive rights and HIV and the safety and long term consequences of hormonal contraceptive usage. Klugman (1993) noted that the population trends in South Africa in the late 70's and 80's reflected the discrepancies in power, wealth and education and characterise the history of the apartheid regime – oppression of the masses and '*separate development*'. Fast-forward to 2015 and contraceptive choices and practices reflect a new reality that also reflects power and control albeit in a different way.

Contraceptives should simply enable women to take control of their lives and their fertility; women need accurate and accessible information, an enabling environment to make choices, accessible services and a range of products. However, in a male dominated, patriarchal context where women's bodies are owned, commodified and at the same time both vilified and sanctified, the meaning and usage of contraceptives is far more complex. According to Furedi, the development agenda, within the population control movement is not feminist, and women are used in a structural way. Lingam, noted

> *…the incorporation of women's reproductive rights into the population agenda in practice meant that the rhetoric of the feminist movement was being appropriated, though not its concerns.*[2]

Women's status and health was seen as a means to an end and improving the status of women impacted on curbing fertility and reducing the overall negative impact of the population on the environment and development.

Gready et al highlighted that the

> *…services that are centred around keeping women satisfied with and using a method in order to keep fertility down can easily overlook peoples' needs and human rights.*[3]

It can be asserted that the contraceptive discourse and practice in South Africa and beyond at the very least overlooks needs and rights (especially of women) but is far more insidious, and both in the past and currently, violates and controls the choices and options for the most vulnerable and marginalised women. Unequal power relations are

…the meaning and usage of contraceptives is far more complex…

inherent in the exchange between client and health care provider.[4]

Klugman (1990) noted that the intersection of apartheid and patriarchy strongly circumscribed method choices available to black women.[5] In the present context reproductive health policy and programmes remain a concern, both in terms of women's choice and safety issues.

Correa and Petchsky make the case for a feminist response to contraceptives; they noted the

> *…economic and political changes necessary to create … conditions are a matter not just of development, but of (social) rights, indeed they are a good example of why development is a human right and why women's reproductive rights are inseparable from this equation.*[6]

This paper locates contraceptives within a feminist framework and interrogates the current policy and practice environment for women in general and specifically for women living with HIV. The power dynamics of body and choice are discussed. The history of contraceptives in apartheid and post-apartheid provides a landscape of changing discourse and practice in which to locate the current issues and to provide some suggestions for action.

WOMEN'S AUTONOMY: UNDERSTANDING THE POWER DYNAMICS OF BODY AND CHOICE

Women's bodies, both internally and externally, are contested spaces: and what on the surface should be a simple matter of choice is shrouded in politics of autonomy and power that cuts across women's personal circumstances to a broader political agenda.

Patriarchy and power

In a patriarchal society women are unequal to men and this plays out in all aspects of their lives. Power is contested in all aspects of women's lives: sites of struggle include society (striving for political, economic and social equality), in the community, the household, intimate relationships and with women's own body.[7] Much of the current focus on gender relations focuses on difference and not on power: however, Mills noted in his essay on the oppression of women that it is '*perfectly obvious that the abuse of power cannot be very much checked while the power remains*'[8]: 300 years on this still holds true.

…violates and controls the choices and options for the most vulnerable and marginalised women…

How is the category of women produced and restrained by structures of power? Butler asserted that women are regulated by structures by virtue of being subjected to them, formed, defined and reproduced in accordance with the requirement of those structures.[9] In Young's (2005) theory

on the oppression of women, she articulates the five aspects of oppression: exploitation, marginalisation, powerlessness, cultural imperialism and violence:

- Exploitation – women are oppressed by the nature of their status, power, wealth (or lack of it) and exclusion from decision making at various levels
- Marginalisation refers to a whole category of people expelled from useful participation in social life – women are in many instances marginalised and various identities and diversities are further pushed to the margins – for example, women living with HIV
- Powerlessness refers to the lack of autonomy and status as well as an inferior sense of self.[10]
- Cultural imperialism refers to the way that one group's experiences, cultural expressions and history are defined as superior to all other groups' experiences and histories
- Violence shapes an individual in a group because they are intrinsically conscious and in danger of being subjected to violence. Individuals are targeted for the plain reason that they belong to a group. Violence is a social practice that is constructed by a group yet it is targeted at an individual.

Young defines injustice as referring to oppression and domination and notes

> *…justice should refer not only to the distribution, but also to the institutional conditions necessary for development and exercise of collective capacities and collective communication and cooperation.*[11]

Oppression, a structural concept, immobilises, minimises and diminishes capacity. The conscious actions of many individuals daily contribute to the maintenance and reproducing oppression, but people are only doing their job and do not

…the power dynamics of body and choice…

see themselves as agents of oppression, this is pertinent to the behaviour of healthcare workers.

Women are not powerless however.[12] Ortner[13] asserted that relationships of power and inequality are reproduced by (and therefore can be changed and modified) through practice. Agency, according to Ortner, refers to the self as an authorised social being, with the forms and distribution of agency being culturally and politically constructed. Social life is culturally organised and constructed: in order to maintain and or challenge the gender status quo men and women play what she defines as '*serious games*' with implied actors, rules and goals of the game. The '*game*' is played in a context of webs of relationships and interactions between '*multiple shifting interrelated subject positions*'. Ortner asserted that the stakes of the game are high given that power and inequality pervade the game of life in multiple ways, and that the game is played with intensity. How do serious games relate to men? Ortner questioned whether women are identified by, or are pawns in, male games; whilst women may be relatively independent and autonomous they are at the same time restricted in different sites of struggle. Gender biased rules govern the normative authority of man over woman.

In another theory that disputed women's powerlessness, Kandiyoti[14] posited patriarchal bargaining: even though patriarchal structures exert a powerful influence in the shaping of women's gendered subjectivity and determine the nature of gender ideology in different contexts there is potential for specific forms of women's active or passive resistance. The baseline from which women negotiate and strategise affects the forms and potentialities of their resistance and struggles. Resistance is possible in all sites of struggle although body and intimate relationships tend to be the most difficult.[15] Kandiyoti referred to the cumulative affect of struggle

> *…new strategies and forms of consciousness do not simply emerge from the ruins of the old and smoothly produce a new consensus but are crafted through personal and political struggles.*[16]

Body as a site of struggle

At the most fundamental level women are linked to the material world by their bodies[17]: for the most part they are objects, objectified and owned. Bodily autonomy is not a given: women's bodies are seen as the property of men, an ownership that is exchanged amongst men (for example, through marriage). Body is the site where resistance is first enacted, the site in which gender is constructed, inscribed and performed.[18]

…shrouded in politics of autonomy and power…

Bodily integrity or autonomy has two elements: the right not to be alienated from sexual/reproductive capabilities and affirmation to enjoy

the full potential of body;[19] however, within a patriarchal society bodies are a site for subjection and oppression. Douglas asserted that '*women's bodies are continually reshaped, covered and uncovered according to prevailing ideology*'[20]. Women's bodies are not seen in a homogeneous way; the presentation and meaning of women's bodies happens across race, class and other intersectionalities. The commodification of women's body positions the body as something that is used (for labour, for pleasure, for the procreation of life) something that is desired, and something that is either paradoxically exploited or protected. According to Irigary[21], female sexuality has always been conceptualised on the basis of masculine parameters. She concurred that women have a use-value for men: as a commodity that has an exchange value.

> *…Woman is never anything but the locus of a more or less competitive exchange between two men.*[22]

…the normative authority of man over woman…

According to Mohanty[23] there is an assumption of universality: issues are viewed from a western perspective which represents a composite singular '*third world*' women and experience:

> *…concepts such as reproduction, the sexual division of labour, the family, marriage household, patriarchy etc are often used without their specific local cultural and historic contexts.*[24]

Correa and Petchsky[25] challenged the argument that sexual and reproductive rights are a western concept – and not applicable to women in different contexts and cultures. They argued that democracy movements are not seen as imposed so why should women's rights be questioned.

Different feminisms are challenging the notion of universality of experience and meaning: yet whilst meanings and discourse may differ, many feminists argue that the oppression of women is fundamental across context.

Women and reproduction

Women's reproductive capabilities '*marks women as mysterious, taboo or dangerous*'[26]. In many (and one could argue most) societies and cultures women are defined by their role as a '*mother*' and their ability to give birth. In her analysis of women's oppression De Beauvoir saw women's reproductive role as fundamental.

> *…Woman has ovaries, a uterus: these peculiarities imprison her in subjectivity, circumscribe her within the limits of her own nature*.[27]

She further asserted that '*women **is** womb*'. Davis[28] noted that the commodification of motherhood complicates and deepens power relations based on class and race. For Correa and Petchsky[29] reproductive and sexual rights remains a contested domain – with religious fundamentalists leading the pack: advocates for fertility reduction don't care about women's health or empowerment but rather have their own agenda that is not necessarily in the best interests of women.

Davies noted historical construction of women's reproductive role is synonymous with historical failure to acknowledge the possibility of women; and that the discourse is littered with racist and misogynist assumptions. Within the politics of reproduction there was, and continues to be, a growing intervention of technology into the most intimate of spaces, and whilst technology is not inherently oppressive, there exists in theory and in implementation the danger of women loosing more control over their bodies. The modification of body is fundamental to women's bodies as a site of struggle. Haraway[30] posited that biotechnologies are the critical tools used to re-craft women's bodies and obviously are central to the control of women's reproduction. As Davis noted:

…do not see themselves as agents of oppression…

> *…the socio-economic conditions within which reproductive technologies are being developed, applied and rendered accessible or inaccessible manoeuvre them in directions that most often maintain or deepen misogynist anti-working class and racist marginalisation*.[31]

In interrogating technologies as inherently affirmative or violative of women's rights it is more important to address the context of technology – and look at profits, politics and control.[32]

Davis highlighted the need to reconceptualise

reproductive issues highlighting that it is no longer acceptable to ground an analysis of the politics of reproduction in a conceptual construction of women as sex. Furthermore, it is not enough to assume that female beings, whose bodies are distinguished by biological features related to reproduction, should be able to claim rights to exercise control, over the process of their organs for example, in reproductive choices, accessing abortion and challenging sterilisation. Davis noted that

> *…the social/economic/political circumstances that oppress and marginalise women of various racial, ethnic and class backgrounds, and thus alter the impact of ideological conceptions of motherhood, cannot be ignored without affirming the same structures of domination that have led to such different – but related – politics of reproduction in the first place*.[33]

With this in mind she highlighted the elements of a reconceived agenda of reproductive rights in which economic accessibility is important, but that it is equally important to look at economic and ideological considerations that lead women to certain choices, thus denying them the possibility of bearing and rearing children in numbers they themselves choose. She asserted that the point of departure should be – reconceptualisation of family

and reproduction rights from private to public and from individual to social.

…the site in which gender is constructed, inscribed and performed…

A useful framework developed by Correa and Petchsky[34] positions the grounds for reproductive and sexual rights on four ethical principles: bodily integrity, personhood, equality and diversity. They noted that each principle could be violated through acts of '*invasion or abuse*'[35] and that this is evident at the hands of government officials, healthcare providers, male partners, family and institutions. Such violation can happen through

omission, neglect, disregard and violence. At the core is the right to bodily integrity, that is the right of all women to security in and control of the body, and yet this is the very aspect that patriarchy is most effective in undermining.

Correa and Petchsky asserted that the affirmation of rights to control and ownership of one's body does not mean that the body is seen as separate from self, rather that body is an integral part of self – and health, wellbeing and sexual pleasure are a necessary basis for active participation in all aspects of living. Personhood refers to respecting the person as a whole being: for example, personal respect at a clinic level which embodies trust and that healthcare workers take seriously women's experiences, desires, wants and needs – understanding that women know their own bodies and listening to them about side effects. Equality in relation to sexual and reproductive rights is multi-levelled and goes beyond gender relationships between men and women to include the relationship between women, as well as looking at equal risks and benefits; current contraceptive policy and practices clearly do not adhere to the principle of equality. Finally diversity should be taken into account and there is a need to respect difference, for example, gender identity, values, culture, religious norms, sexual orientation and HIV status.

According to Sanger[36], the world can only be free if women are free and given that birth control is seen as women's problem it should therefore be women's issue. Correa and Petchsky noted that who controls methods carries both the risk and benefits – and that this must be fair; in this way public policy should put greater emphasis on male responsibility. This point is contested across feminist scholarship however, with some women arguing that they want total control and others wanting greater male involvement.

…the oppression of women is fundamental across context…

HISTORY OF CONTRACEPTIVES IN SOUTH AFRICA: POLITICS OF DIFFERENCE

Contraceptive policy and practice in the Apartheid

> *Apartheid impacted on services most noticeably in the difference between private and public sector services as well as whether women were offered a broader range of services or not.*[37]

During the Apartheid regime the experiences of women in South Africa differed on the basis of race:

> *…different experiences of urbanisation, of domestic relationships and different positions in the hierarchy of the proletariat, all of which are connected in complex ways with domestic struggle, have a bearing on their place in urban South Africa, and on the resulting*

forms of consciousness which they have developed.[38]

Family planning policy was no different. The family planning programme was implemented in 1974 by the white minority government: which demonstrated that '*stronger efforts were made to reduce the birth rate among blacks than among whites*'.[39] The South African family planning programme became a focal point of racial political contestation.[40] The key elements of the population programme was to limit women's fertility, change the human mortality rates and control immigration. The policy was to integrate family planning into all health services and the number of clinics offering contraceptives increased twentyfold, out-numbering health clinics in less than ten years.[41]

In 1984 the government launched the updated Population and Development Programme – which was framed as a way to increase social and economic development to '*underdeveloped groups*' in the population.

The purpose was to:

- ensure parity in economic opportunities
- promote basic health
- improve the quality of life for all
- promote development of rural areas
- 'orderly' geographic distribution of the population
- maintain a population size
- reduce family size to an average of two children

...historical failure to acknowledge the possibility of women...

According to Moultrie[42], the new family planning paradigm was based on the reduction of fertility through family planning services, offering a way to deliver '*rapid fertility decline among Africans*'.[43] In reality, the new programme increased provision of contraceptives but had no real power to reduce social and economic inequalities[44]; and one can argue that

reducing inequalities was not the primary goal of the Nationalist government anyway.

Patterns of contraceptive use was associated with education, wealth and urban or rural residence. Other factors included homeland policy, the labour migration system and suspicion by black people of government policies. The racial residential segregation, the cornerstone of apartheid policy, influenced the availability and quality of family planning services – administered separately by health services specific to each racial group or by the homeland administration. Across the homelands there were great disparities in access and quality of services[45]; yet by 1990 estimates of 58% of women aged between 15 to 49 were practicing some kind of contraceptive.[46] There was an overwhelming dominance of injectable contraceptive use with black women.[47]

…the very aspect that patriarchy is most effective in undermining…

In the Kaufman study[48], 60% of women were using an injectable contraceptive: the injectable contraceptive was promoted and pushed by the family planning programme, as it was easy and cost-effective to administer. Why did women seemingly '*choose*' injectable contraceptives, primarily Depo Provera? First and foremost, women may not have been given any other options: African women were seldom provided with information on contraceptives and alternative choices.

> *…The policies of the family planning programmes under apartheid may have constrained their choice of method more than the choices of women in other racial groups*.[49]

Poor women, who were dependent on erratic, and experienced poorly stocked and incomplete, services, most likely did not know about other contraceptive methods. There are however other reasons for the '*choice*' or at least for the continued usage that link to women's agency and control of their own fertility – for example, Burgard noted that

> *…sexual relationships conducted under conditions of forced or unwanted sex may make 'invisible' methods of fertility regulation, such as injectable contraceptives, highly desirable*.[50]

South Africa was not the only country that promoted Depo Provera. An example of the complexities of contraception, and especially injectables, which on the one hand are forced upon women, but at the same time can be seen as women taking control and agency, was evident in Zimbabwe. During the 60's and 70's Depo Provera was constructed by black Zimbabweans as a form of medical colonialism of African women's bodies, and because of

…a need to respect difference…

its centrality to the white regime's population control strategies, as a weapon for reducing the population. At the same time Depo Provera was associated with 'subversive' conduct by women as it enabled women to regulate their own fertility without the permission or knowledge of their husbands and was increasingly popular amongst women in 70's. Depo Provera was banned by the democratically elected government in 1981, viewed as a tool of the oppressor only to be re-legalised in 1992 for contraceptive use:

> *…by this time the control of African's reproductive abilities was no longer a site of unresolved conflict between men.*[51]

Depo Provera had advantages that outweighed its association with coercion and racism, and women's attachment had remained strong during the banning; thus there was an acknowledgment that the range of contraceptives offered was not sufficient.[52]

Bozzoli[53] noted that in almost every sphere of their lives African women remained more heavily controlled by the state than men. However, despite living under a repressive patriarchal political regime, women enjoyed some agency: due to the migrant labour system there was a large proportion of female-headed households, especially in the rural area and this gave women increasingly more control over socio-economic decision making, which included decisions about reproduction and more agency to make choices about fertility.[54]

> *…Suspicion may have been widespread at the community level among local leaders or headsmen but the circumstances of a particular women's life may have led her to use contraceptives regardless of that suspicion; the politicization of family planning may have not deterred use at the ground level.*[55]

Post-Apartheid policy and practice

In a study by Gready et al,[56] service providers exerted a lot of control over which contraceptive methods women use. Of concern was the fact that

> *…the vast majority of the women attending public sector family planning clinics were consistently offered injectables as their first option.*[57]

Regardless of whether women were accessing services at a public or private setting women had very little information about side effects and contra-indications of the methods they were using, resulting in many women not realising problems should they occur. Gready et al noted that

> *…the vulnerability that a client feels can either be reduced by a sensitive, information-sharing manner or it can be amplified through abusive exchanges.*[58]

In the study, women expressed a desire for information on how the method works, what the side effects are and what are the instructions for use. Indicators of appropriate and acceptable contraceptive services included privacy, confidentiality, sufficient time with the healthcare provider and reduced waiting times.[59]

In an effort to amend the racist population control policies of the past, the post- apartheid policy framework has included:

- National Contraceptive Policy located within a Reproductive Health Framework (2001)
- National Contraceptive Service Delivery Guidelines (2003)

The current policy framework includes the National Contraception and Fertility Planning Policy and Service Delivery Guidelines; a companion to the National Contraception Clinical Guidelines. The philosophy underpinning the current policy is that

…presents an equally insidious problem…

…enabling women to make choices about their fertility is empowering and offers women better economic and social opportunities.[60]

Contraception is seen as important to human development, gender empowerment, HIV and sexual and reproductive health. Adopting the WHO PMTCT programme, that locates contraception provision as an important component, the MOH policy asserts that contraception and family planning contributes to the reduction of HIV, the prevention of pregnancy and is included in the planning of health programmes.

The new policy offers, according to the MOH,

…broad forward looking contraception and fertility planning programme, with our emphasis on improved access as well as expanded contraceptive choice.[61]

The need to update the policy was prompted by changes in contraceptive technologies, high prevalence of HIV in South Africa and the need to ensure linkages and alignments with other related national and international policies and frameworks – and the MOH wanted to expand the definition of family planning (context of '*fertility management*' holistic framework: wider choice and method mix. [62] The policy proposed to address the

…continuum of both pregnancy prevention and planning for conception, and address the implications there of for people living with HIV.[63]

The policy promotes key revisions to address the needs of women living with HIV '*either on or off ARVs* by:

- Increase access to copper intrauterine device (CU IUD)
- Introduce single rod progesterone implant
- Introduce levonorgestrel interuterine system (LNG-IUS)
- Introduce combined oestrogen and progesterone injectables
- Increased access to female condoms

Despite a reframing and re-organisation of the South African healthcare system, the apartheid framework has influenced contraceptive use beyond apartheid. The reliance on injectable contraceptives among black women has persisted[64] and presents an equally insidious problem currently.

According to Cooper et al[65], South African policy makers have focused on policies, guidelines and services to integrate HIV with sexual and reproductive health (SRH), including STI management and treatment, as well as TB. Cooper et al found divergent views amongst policy makers on tailoring SRH services to meet the diverse needs of women living with HIV: some viewed the issues of women living with HIV to be unique whilst others saw them as similar. Despite the difference in opinion, there is still significant support for policy on the integration of SRH and HIV, including contraception, pregnancy, maternal

health, cervical screening. Currently, the contraceptive methods available are sterilisation (may or may not be forced or coerced), injectables (often promoted as the best possible option for poor black women), IUD's and oral contraceptives. Access points for contraceptives include government family planning clinics, general clinics, gynaecologists, private doctors, pharmacy, churches, hospitals and private clinics.

HORMONAL CONTRACEPTIVES: AUTONOMY, RIGHTS AND SAFETY ISSUES FOR WOMEN

Hormonal contraceptives are used widely, particularly in the developing world and South Africa is no exception.[66] There has been growing concern over the years as to whether there is a possible negative link between hormonal contraceptive injections and HIV: firstly, does the use of hormonal contraceptives increase the risk of HIV transmission, and secondly how do hormonal contraceptives interact with ARV's or impact on women living with HIV. Although there is some preliminary evidence that injectable contraceptives may increase a women's risk of HIV infection, the expert group, consisting of scientists, researchers and public health specialists argue that there is insufficient data at this point to recommend that these forms of contraceptives be withdrawn.[67] Activists and women's rights advocates on the other hand feel strongly that there is sufficient evidence of the increased risk to HIV infection posed by the continued use of injectable, hormonal contraceptives to immediately stop their usage and to provide safer options for women. Whilst scientists argue that the consequences of withdrawing the contraceptives outweigh the benefits, as it will result in more unplanned pregnancies and potentially greater maternal mortality, the on-going promotion of contraceptives that place women at risk of HIV infection is a violation of their rights.

…to immediately stop their usage and to provide safer options for women…

Medical evidence suggests that hormonal contraceptives have many negative indications for women living with HIV: for example, different side effects as well as actively causing other health problems and diseases. For example, hormonal contraceptives may increase women's risks to sexually transmitted infections, as well as being responsible for high rates of cervical cancer given their association with low cervical immunity. Furthermore, contraceptives, may also be responsible for high incidence and morbidity related to diabetes in South Africa given their hormonal nature and weight gain that goes with it. Apart from all these challenges, Depo Provera is still being widely used in South Africa and elsewhere.

WHO have been discussing medical eligibility criteria for contraceptives annually since 2012, which in itself suggests that they themselves see that there are potential risks hence

the need to constantly assess. In March 2014, the WHO convened a meeting to develop a set of guidelines (edition four) that provided recommendations concerning the use of hormonal contraceptive methods. Under discussion were four critical questions[68]:

1. Does the use of a particular method of hormonal contraception directly increase the risk of HIV acquisition?
2. Does the use of hormonal contraceptives accelerate HIV disease progression in women living with HIV?
3. Does the use of various hormonal contraceptive methods increase the risk of female to male HIV sexual transmission
4. Are there any possible interactions between hormonal contraceptive methods and antiretroviral medications

The guidelines suggest the following:

For women living with HIV or at high risk of HIV the following recommendations have been developed

- No restriction on the use of combined (contain estrogen and progestogen) hormonal contraceptives (including combined oral, patches, vaginal rings or injectibles)
- No restrictions on the use of progestogen only injectables, pills and implants. WHO points to inconclusive and contradictory study findings with regard to progestogen-only injectable contraception but have concluded that this should be carefully monitored but at this stage does not warrant a change in policy and practice – and if there is a change it should be based on local contexts. They concede that women at high risk (it is not clear how this is determined – would this for example be all women in a particular high prevalence country or at the discretion of the health care provider) should be informed about risk and have access to preventive measures, such as male and female condoms.

…human rights issues are evident that cannot be ignored…

- Women at high risk '*may generally use*' levonorgestrel-releasing intrauterine device (LNG-IUD). Women living with HIV who are asymptomatic or display '*mild*' HIV clinical disease may '*generally use*' LNG-IUD, but women who have severe or advanced HIV clinical disease should generally not use LNG-IUD.

For women living with severe or advanced clinical disease (WHO stage 3 or 4) use of LNG-IUD should not be initiated. Recommendations regarding hormonal contraception and ART interactions are very sketchy and do not suggest any changes: it would seem that research in this area is not a priority, leaving further gaps in knowledge for women living with HIV.

CONCLUSION

The right to the highest attainable standard of health can be used as a framework in which to locate the right to safe, accessible, affordable, available and appropriate contraceptive choices. The emerging evidence increasingly suggests the negative effects of hormonal contraceptives and HIV, both in terms of HIV prevention and treatment issues for women. Within this context, clear human rights issues are evident that cannot be ignored. Urgent discussion and debate is needed around the following:

- Does South Africa have an adequate legal and policy framework to address the contraceptive needs of women living with HIV? If not, what are key concerns that should be addressed?
- Is there sufficient evidence to call on the government to immediately withdraw all stocks of Depo Provera from all clinics and to ensure that alternative contraceptives are provided? Should it be withdrawn for all women? Should it only be withdrawn for women living with HIV? Or should it not be withdrawn at all but rather offered with a full and detailed explanation of its advantages and disadvantages?
- What needs to be done as activists to ensure that the evidence is collected speedily without the violation of further rights?
- How do we ensure that all women who have used Depo Provera are provided with up to date and accurate advice on how the drug may have affected their risk of acquiring HIV?
- What needs to be done to begin discussions on whether the users of Depo Provera who acquired HIV are entitled to compensation for the risk that they were exposed to whilst using the drug. How do we start to collect evidence that could be used to assist women who are living with HIV to begin to explore the possibility of claiming compensation from Phizer?
- How do we identify the specific indications for women living with HIV and ensuring women are immediately offered the choice of other methods?

Butler called for a re-articulation of what qualifies as bodies that matter including– lives worth protecting, lives worth saving, lives worth grieving.[69] This is pertinent in the current context of contraceptives and HIV as it is evident in both the policy and the practice that women do not matter. Organisations of women living with HIV find themselves, once more at the forefront of a struggle to make women living with HIV matter in the face of profits and politics.

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