From HIV to THRIVE:

To testing and treatment through *hope* and *rights*:

PCB, UNAIDS, Geneva, June 2012

Alice Welbourn PhD
Salamander Trust
www.salamandertrust.net

Salamander Trust
TRANSFORMING THE WAY WE THINK ABOUT HIV

20 June 1992…

Ladies and Gentlemen, Good morning. This month marks the 20th anniversary of my HIV diagnosis. I was tested in 1992 when I was expecting a baby and full of joy. Mine is just one of many stories of this experience in this room; and just one of 33 million experiences around the world. But I hope you will indulge me in this moment as I share it with you.

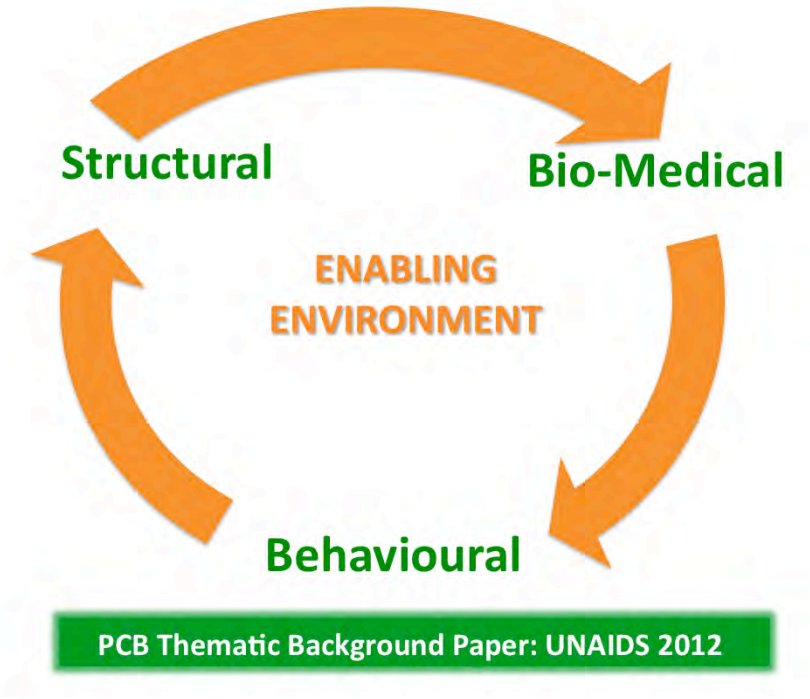
My journey….

- Test (1992)
- Devastation
- Fear
- Secrecy
- Depression & suicidal thoughts
- Care, Support, **Rights**……
- Treatment (2000) (CD4 <200)
- Adherence and total disclosure
- 2012 (CD4 = 850; VL = <20)

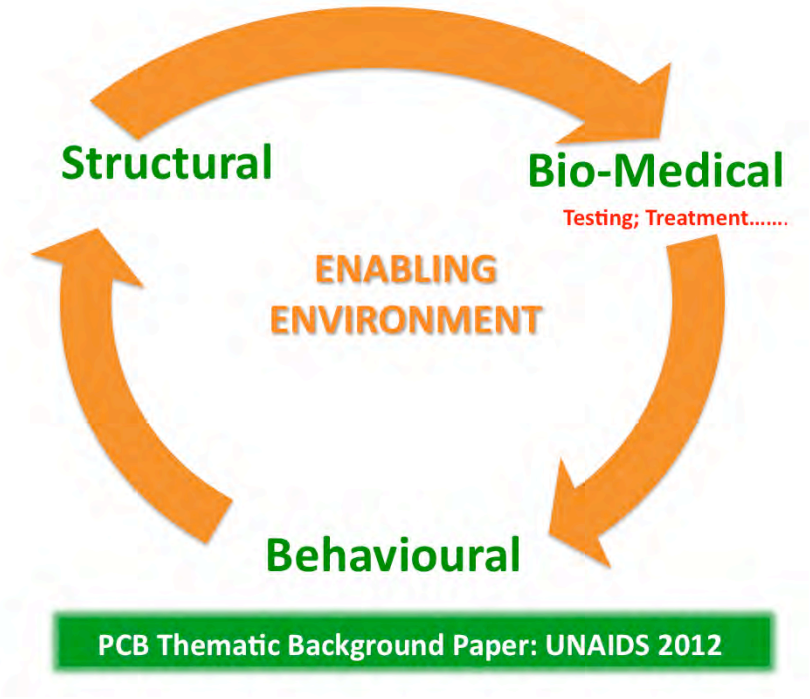
When I was tested, I was immediately filled with the feelings you see above. Because of the possible threat to my own health, which might have left my older children motherless, I was advised to have a medical termination.

Thankfully because I have – for the most part - always had care, support and **rights** on my side, I am still here with you today and am fit and well. This care came from my partner, who I am thankful to say, remains HIV negative, from close family and friends and from amazing women with HIV whom I met then and who have continued to be an extraordinary support group for me ever since.

I have learnt some lessons over the past 20 years, both personally and professionally. I would like to share some of them with you today.



Today, in examining Combination Prevention, we are reminded in the PCB Thematic Background Paper for today of 3 key elements to “Combination Prevention”. These are the bio-medical drivers, which of course are critical; the behavioural drivers and then also the structural drivers.



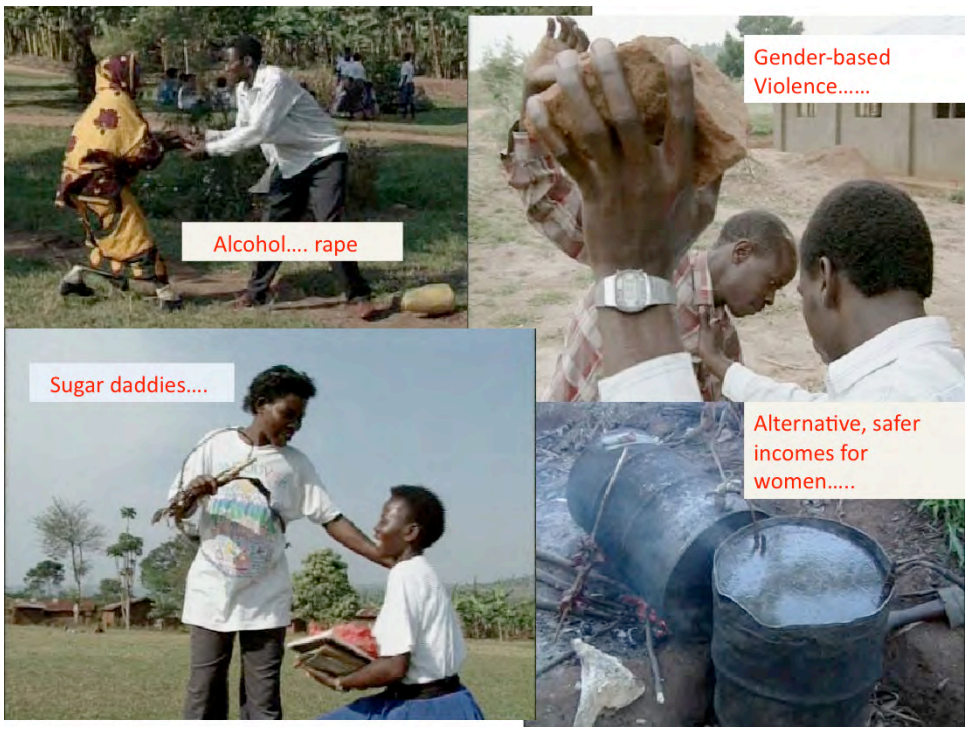
We all know that we want **to increase testing and increase treatment** – but how do we do this in a way which is ***voluntary, rights-based and ethical*** rather than just forcing people into something which is currently full of **FEAR**?

This is where the behavioural and structural drivers come in – so that people know ***why*** they behave as they do and can ***support*** one **another** to change.

Medical science just **cannot** do this by itself, no matter how much it tries.

So that's why I created the Stepping Stones programme. I developed this in 1993-5 with many supportive colleagues. It's a programme that specifically speaks to the **behavioural** and **structural** elements of the response: including **gender, gender, equity and rights – and especially respect, support for and solidarity with everyone living with HIV – and everyone who is somehow marginalised by societies around the world.** It is designed for use in communities with "ordinary" people, who may have no literacy skills but who of course have the potential for huge insight into their lives – though few sadly recognise this.

The programme has spread now, through the efforts of many civil society organisations and individuals, across 100 countries around the world. The IMPLEMENTATION GUIDELINES on the www.steppingstonesfeedback.org website guide organisations in their own adaptation of the material, thus allowing it to feel fresh and personal and immediately relevant to each new community that makes use of it.



In the programme, four peer groups divided by age and gender are able to discuss, act through and reflect safely in their own groups upon challenging issues in their lives, such as the problems of young **men**, excess drinking and rape, ***older*** men & partner violence, younger ***women*** & the temptations – and consequences - of sugar-daddies; and for *all* women, the issues of sustainable incomes which are safe for them as well as safe for others….. (For instance, where women have to pay taxes, in many places they take the initiative to start beer and (illegal) spirits brewing. This can result in excess alcohol consumption amongst men especially – which in turn leads to unsafe sex. Then women can get blamed for the brewing – without an appreciation of why they have started this practice in the first place.)

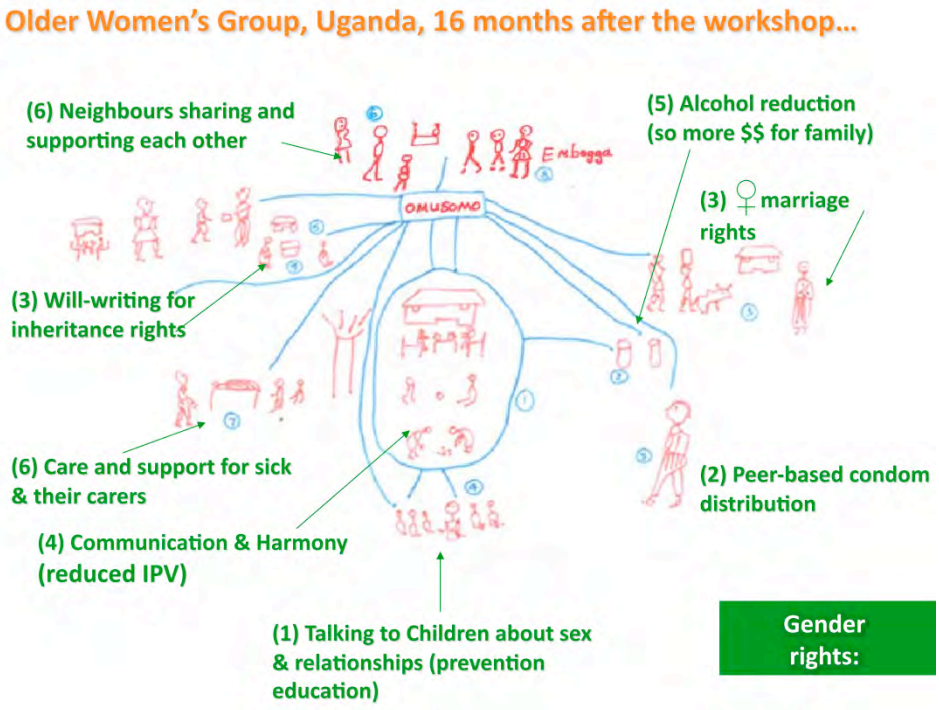
Thus the whole process is designed to build an ***enabling environment*** to ***address*** these **structural** and **behavioural** factors which act as barriers to safer practices, for men and women, older and younger alike.

"Through the workshop I have plucked up the courage to face the elders. Before, I couldn't even mention the word "condom" in front of them – but all the time now we are using the word "condom" in front of the elders"

Julius, young man - Stepping Stones workshop, Uganda, 1994

Generational rights:

We have seen huge improvements **in INTER GENERATIONAL mutual respect and understanding**, through these workshop - bridging the gender gap and the inter-generational gap alike. And key issues like condom use have also become much more acceptable across the board, to older and younger, men and women alike.



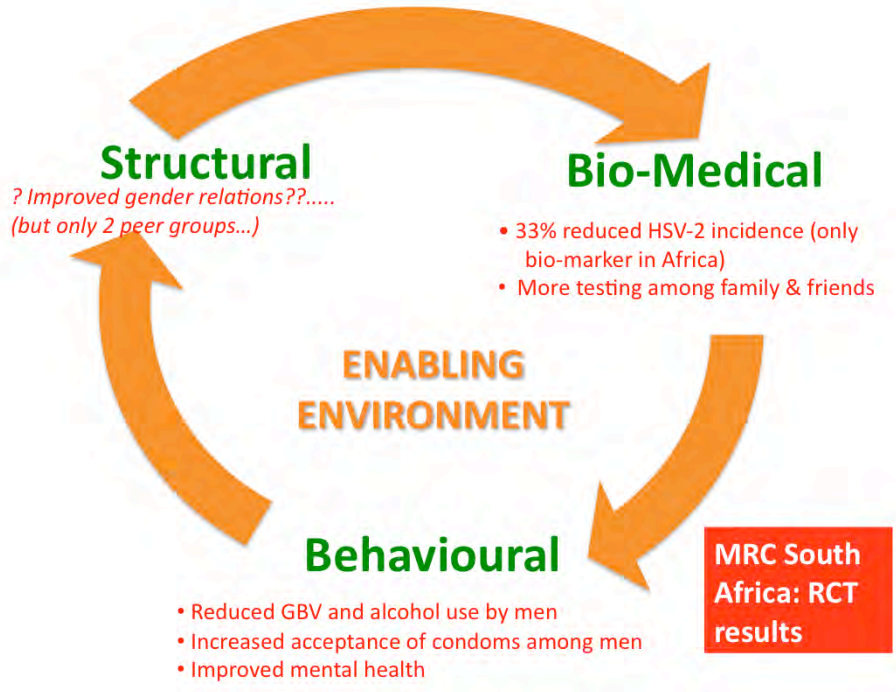
WE HAVE ALSO SEEN HUGE IMPROVEMENTS IN GENDER RELATIONS, including reductions in gender violence. Here we can see in this diagram what the issues were which the older women in one community in Uganda said had changed, in their view, since the workshop 16 months previously: prevention education; condom distribution; property and inheritance rights; a reduction in gender violence and greater harmony in the household; reduction in alcohol consumption (ie less expenditure also); and, critically, greater care and support for people with HIV and their carers.

You can see at the bottom how the women had taken the initiative after the workshop to use the communication skills (which included assertiveness training and "I" statements) which they had learnt, to talk with their children about sex and relationships for the first time. **We have heard of similar changes and the creation of this ENABLING ENVIRONMENT from around the world.**

(THRIV)E = THE EVIDENCE BASE: Medical Research Council, South Africa

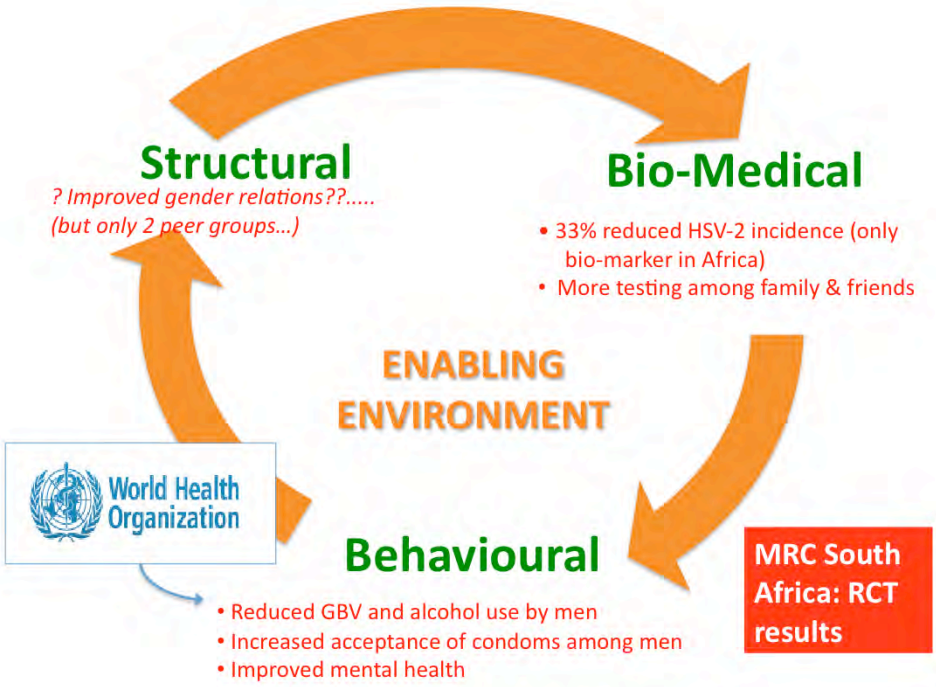
- Stepping Stones adaptation (*only 2 peer groups*)
- **RCT**
- **Reduced HSV-2 (only RCT with a bio-marker in Africa)**
- **Reduced GBV**
- **Improved mental health of participants**
- **More testing**
- **More condom acceptability for young men**

But what of the **EVIDENCE BASE for this work?** In South Africa the MRC there trialled an adapted version of the programme as an RCT, with only the two younger peer groups, because RCTs are so expensive. Despite only involving the two younger peer groups there were still some marked changes amongst the participants, including improved mental health status, increased rates of testing amongst friends and family, increased acceptance of condoms by young men and reduced gender-based violence.



So we can see that the MRC RCT achieved medical results, and achieved behavioural results, especially reduced GBV and alcohol use by men, increased condom acceptance and improved mental health.

There seemed to be less effect on gender relations. However, there is clear feedback from many ***other Stepping Stones*** programmes both that gender relations have improved *and* that attitudes towards people with HIV have improved hugely after Stepping Stones workshops. However, here **older** men and women were **not in the trial** and since younger women mainly date ***older*** men, I suggest this adaptation was hampered by the exclusion of the older peer groups.



Nonetheless, because of the great work of Garcia-Moreno, Watts and others demonstrating that gender-based violence is a driver to increase women's vulnerability to HIV around the world, WHO has now recommended the Stepping Stones programme **as a key community-based tool for HIV prevention.**

"After being found HIV-positive, my husband left me. But after attending the Stepping Stones training, my husband decided to go for HIV testing and counselling, a thing that he vehemently refused to do in the past. His results revealed that he was HIV-positive. The training helped him to rediscover himself and he apologized for leaving me. My husband and I are now back together and happily married again with no incidents of violence because we are able to communicate better as a couple and respect each other's rights"

Enita Jailosi, Umodzi, Malawi (COWLHA)

We have also heard from organisations working with women with HIV what a big difference the programme has made to their lives. Now of course, if couples are happy, they are more likely to stay together and their children are far more likely to be happy, well cared for and more able to cope with HIV also. So this is a win-win situation for everyone.

However, beyond RCTs, it is still really hard to evaluate, in ways which are acceptable to donors and other policy makers, other issues which we also know to be important. These include VALUES, such as…. compassion: learning, sharing, caring and changing attitudes and practices as a result of that.... breaking down labels and stereotypes and building up communication and relationship skills between genders, generations, people of different religions, people without HIV and people with HIV etc... it is about hope, trust, and upholding one another's **rights** sustained through a strong sense of community-based **ownership**.

Scale up: 1995 - 2011

- **120** countries: Africa, S & E Asia, L America, Pacific, E Europe
- 28,000 manuals to over **5,000** organisations
- 20 languages and adaptations for 17 different contexts
- Contexts include: marginalised & stigmatised groups, ***key populations***, schools, health services, military, people in conflict zones
- Community of Practice: >1,000 organisations

"Almost certainly the most widely used intervention of its kind in the world" **Dr Rachel Jewkes, MRC South Africa**

So what about scale-up? Well the numbers above give some indication of the spread and growth of the use of the manual since its launch in 1995.

The key challenge has been that, because of the drive only to fund the "evidence base", (ie results from medical bio-markers), several large programmes have faced closure as funds have dried up.

Here is **how the scale-up has happened.** It has been very much a hand to hand process rather than a top-down campaign process. Much as we would have liked to roll it out more strategically there was never the funding available to do that…

CHALLENGES:

RCTs vs "Combination Evaluation":

"A combination of qualitative and quantitative mixed methods with nested designs and triangulation of different data sources… will most likely provide more complete information of HIV prevention effectiveness than applying *one method as a definitive gold standard.*"
UNAIDS 2010

Despite many examples of similar findings from around the world, providing a "convergence of evidence", RCTs and bio-markers are still considered the evidence base. So today we call on UNAIDS to **promote and disseminate** its important document shown here, recognising the power and importance of **"Combination Evaluation" in creating a holistic evidence base – and "evidence-*informed* action" - which promotes and respects combination prevention:** and which respects that bio-markers and bio-medical "test and treat" interventions alone just won't adequately overcome the ***fear*** of the world. We need interventions which uphold **human rights** and the means to measure those interventions, to show the changes we wish to see in the ***real*** world of ***humans*** rather than the test tube world of the research laboratory.

THRIVE through Combination Prevention:

- **TESTING & TREATMENT: (Tx as Prevention is critical but will never work if people are fearful of disclosure)**
- **HUMANE & HOPE: remember that bio-markers aren't enough**
- **RIGHTS to overcome fear: use combination prevention strategies, including behavioural & structural strategies**
- **INVOLVEMENT: include people with HIV in all you do – and support *all* marginalised groups in your work**
- **VOLUNTARY CHANGE is permanent and sustained because people believe they own it themselves**
- **EVIDENCE BASE which is *inclusive:* values & numbers**

So in conclusion, I would like to offer some personal thoughts about how we can all move forward. I don't like to think of myself as "suffering from HIV". I like to think of myself as **thriving.** And that should be the same for *all* of us with HIV.

So here above I have some thoughts for how we can move from HIV to THRIVE.

In relation to *voluntary change:* this is with specific reference to testing. None of us likes to be coerced into anything. And people being coerced into being tested are no different. If people can be given the safe spaces to discuss these issues for themselves and understand the benefits for them of learning about their HIV status – and can feel safe in the knowledge that their rights will be upheld and that they will be cared for, respected and loved, even if they test HIV positive, then they will be very likely to test, as we saw from the results from S Africa.

Then if someone does something on a voluntary basis and has a good experience, they are far more likely to promote it amongst others. This is the real way to sustainable change across populations, *not* coercion.

Support to NSPs….. Stepping Stones:

- Engages Men and Boys
- Promotes:
  - * Gender Equity
  - * Solidarity with & involvement of people with HIV
  - * SRH&R of people with HIV
  - * Community engagement & action
  - * *Safety* for women and girls

There is some great work that has been conducted by colleagues at ATHENA and HEARD around a Gender Equity Framework for Combination Prevention in relation to National Strategic Plans. Happily Stepping Stones ticks most of the boxes in this framework and is recommended as one key resource.

Stepping Stones Plus – combines:

"Positive Health, Dignity & Prevention" + "The Global Plan"

Includes sessions on MMC, Tx Adherence, peri-natal care & support also

We also now have "Stepping Stones Plus", which is a **supplement** to the original manual. This brings us up to date in terms of ARVs access and sexual and reproductive rights of people living with HIV. It covers all the key aspects of what is known as "positive health dignity and prevention" and "the Global Plan" for an HIV-free generation. **Bio-medical interventions alone again will not touch upon these issues.** It also includes other aspects of combination prevention, including MMC and support for people with HIV in treatment adherence which, as we all now know, also enhances prevention measures. We have this now in English, Spanish and French.

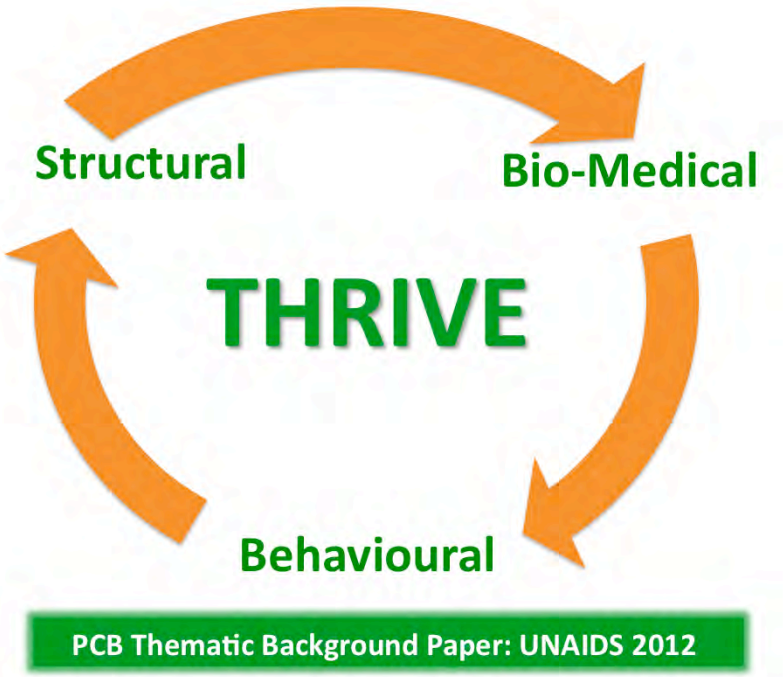
Just starting now:

"Stepping Stones With Children" from 5-14 years – .....*and their guardians....>*

Women in Uganda, India: "we are using what we have learnt to ***talk*** *with our children also about sex & relationships..."*

Salamander Trust

Finally we are also just starting to adapt Stepping Stones for use with children aged 5-14 and their guardians, to address the many and complex issues, such as secrecy, grief and disclosure which I touched on earlier. **Bio-medical interventions alone again will not touch upon these issues.**



So here we are again, back to where we began. Bio-medical interventions are of course important – but we don't live in a test tube. We live in a real messy world of people, laws and culture. Putting the Hope, Rights and Involvement back into HIV, by ensuring that we address behavioural and structural drivers also, is critical if we are going to beat this virus. We don't want to just *survive* HIV, we want to THRIVE – to work with you to overcome HIV for good and to create a new sustainable future - where we *all* thrive together and where HIV is consigned to history. Thank you!

PCB NGO DELEGATION KEY POINTS
June 2012

These can be found in the notes below this slide

PCB NGO Delegation June 2012 - Combination Prevention Thematic Messaging

Key Messages
Combination Prevention is not limited to biomedical approaches
Combination Prevention should be inclusive of an array of interventions providing comprehensive bio-medical and behavioral components that address and provide legal services, education and financing along HIV prevention, treatment care and support.
Combination Prevention requires, to be successful in the long run, speedy development of effective and affordable new preventive technologies such as PrEP, PEP, HIV vaccines and microbicides.
Prevention methods promoted in combination prevention must be those best suited for *all* populations, not just one specific population, i.e. an intervention aimed at one population must be considered as well in terms of its impact on other populations, such as male circumcision and its impact on women, among others.
Combination Prevention requires a more cohesive policy framework that stops false dichotomy of treatment VS prevention.
Program design and resource allocation should be holistic and inclusive of both treatment and prevention.
Policy framework needs to recognize, support and reinforce Combination Prevention intervention programming that reaches the whole population, while also meeting the diverse variation of community/context specific prevention needs (ie. Women and Girls, Migrants, Sex workers, People who Use Drugs, Men who have Sex with Men, Young People, Transgender persons, etc...)
No single prescription or standard package will apply universally
There need to be responsive interventions to address epidemic hotspots.

Human Rights Issues
Human Rights must be considered for all people within effective Combination Prevention Interventions.
Upholding all people's Sexual and Reproductive Health and Rights as Human Rights (inclusive of abortion, comprehensive sexuality education) and help services that support overall health is an imperative component of effective Combination Prevention.
Effective Combination Prevention interventions and policies must acknowledge and respond to the specific social/political/cultural/environmental conditions that make people vulnerable to HIV and AIDS.
Promotion of equitable access and non-discrimination are key Human Rights elements of effective Prevention Interventions that can expand access and positive health impact for MSM, Transgender, Sex workers, People who Use Drugs, Women and Girls and young people as well as People Living With HIV.
Addressing parental consent barriers to Combination Prevention access for young people to access HIV prevention, treatment, care services
A recognition that political, legal and economic factors require the changing of legal environments with the elimination of punitive laws and policies as well as stigma and discrimination as these undermine the HIV response. Many criminal laws act as barriers to HIV prevention, care, treatment and support. Reforming laws can involve a range of actions including de-penalization, decriminalization, regulation or legalization. (UNAIDS/PCB(30)12.5 paragraphs 4&6).

Young People
Young people have to be prioritized in any prevention effort and must be included from design through implementation and M&E of all prevention efforts.
Need to recognize the diversity of young people as they constitute sub-populations of all key populations (young Lesbian Gay Bisexual Transgender and Inter-sex populations, sex workers, People who Use Drugs) and all of the human right issues facing these populations when it comes to young "Knowledge, Attitudes and Practices" surveys.
Need to scale up funding/direct investments in community mobilization and community-based prevention programs for MOST-AT-RISK young people, especially those run by young people.
Finance programs developed by young people for young people.
Programs for most-at-risk must adapt their service delivery to take into account the specific needs of young most-at-risk, such as young people who inject drugs, must have access to prevention and harm reduction.
Focus on scaling-up all young people's access to comprehensive sexuality education, but also focus on and specially promote adaptation of CSE to be oriented toward most-at-risk young people including young people living with HIV.
Recognize the need to introduce structural interventions such as changing policies and legislation that restrict access to services for young people from most at risk population such as young people who use drugs, Lesbian Gay Bisexual Transgender and Inter-sex populations, sex workers and others.
Need to address the specific needs of young people living with HIV, including the right to live free of violence and stigma and discrimination.
Need to guarantee culturally relevant youth friendly sexual and reproductive health and HIV service organization and service providers to promote youth access to health facilities, commodities and treatment.

People Who Use Drugs
Technical and biomedical responses within the harm reduction lexicon that have transformed HIV prevention and drug treatment need to be embraced in effective Combination Prevention
Fear of judgment remains an overwhelming barrier to service access and retention acting as a major barrier to scale up. Importantly the quality of the relationship between the drugs practitioner and the drug user remains and has been shown time and again to be the most influential factor in fostering positive progress in drug treatment and the achievement of wider health gains. Biomedical approaches need human connection and community mobilization to optimize their effective implementation and positive impact.
As UNODC and others focus the purpose of OST drug abstinence; HIV prevention must be integrally incorporated
Drugs policy remains very volatile and the legal environment often restricts the range of technologies that could be used to promote harm reduction and HIV prevention with people who use drugs. It also drives underground the experiences and insights of drug user activists and groups who are often have a catalytic effect in the identification, development and dissemination of peer-driven harm reduction responses to new drug trends or risk behaviors. Community voices and experiences are key to developing effective and culturally relevant Combination Prevention policies and interventions.

Filling the GAPS Around Combination Prevention
More research on the impacts of the array of prevention methods on women and on women-controlled prevention methods.
Expanded research that includes* people living with HIV (ie. HTPN 052)
Expanded global access to female condoms
Increased funding for research in new both bio-medical interventions such as microbicides and a vaccine against HIV
Increased funding for diverse arrays of community-driven and structural interventions
Increased research on maternal and child health (impact of breast feeding, mother's health, etc)
Expanded access to HIV ARV's for people living with HIV to provided dual benefit for primary health and reduction of HIV transmission
Increased funding streams to programmes targeting risk environments (gender inequalities, sexual cultures, poverty and access to services) often not accounted in many HIV/AIDS programming with separate monitoring process)
Increased funding and technical support for CS Lead Combination Prevention Interventions?
We need funded research designed to evaluate combination approaches: which combination of interventions are most cost effective, over what period of time, with which target populations?
Structural level interventions are under-funded and understudied.
Operations research is needed to understand the barriers and facilitators to implementation of prevention programs, from a provider perspective.
We need to begin preparations for task shifting/cross training of community-based, civil society organization staff – to better prepare civil society to implement comprehensive prevention programs (HIV testing, PrEP, PEP, treatment, behavioral, community-level, and structural interventions).
We need to work to reframe HIV prevention in a broader sexual health and wellness framework – one that combines HIV with other STIs, mental health, and other sexual and reproductive health services.
We should move beyond conceptualizations of sexual health as the absence of disease.