

Our use of language: *the power of positive perspectives*

Stepping Stones with Children Facilitators' Webinar

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Alice Welbourn

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STEPPING STONES
WITH CHILDREN



A transformative training for children
affected by HIV and their caregivers

Gill Gordon



Salamander Trust

TRANSFORMING THE WAY WE THINK ABOUT HIV

We thought we would talk about our use of language today, as with *Stepping Stones with Children* we tried hard to think about how we use language.

Different ways in which we use language

STEPPING STONES WITH CHILDREN



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1 To describe people

2 To describe actions

3 To shape our thinking

4 To shape our current & future actions

5 To shape how we think & feel about
past, current & future actions

6 Further reading



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TRANSFORMING THE WAY WE THINK ABOUT HIV

There are at least 5 ways in which we use language.

We use language:

- to describe *people*,
- to describe *situations*,
- to shape our *thinking*,
- to *describe* our current and future *actions* and
- to shape *how we think and feel* about past, current and future events.

Perhaps you can think of others also?

We are going to go through these in turn.

1 To describe *people*



1 People with disabilities

“What matters most about language used in relation to work with women and disabilities and why?”

Betty Kwagala, TASO Uganda

“What matters most is to be sensitive and respectful to women with disabilities as human beings first, because negative language used in our day to day work creates negative attitudes towards women with disabilities. Below are some of the language commonly used which DEVALUE and DISRESPECT women with disabilities in the society.

- a disabled person
- the handicapped or the crippled or the lame
- wheelchair-bound or confined to a wheelchair
- birth defect or affliction
- victim of cerebral palsy
- suffers from polio, polio victims”



From ALIV[H]E webinar 2, October 2016

First to describe *people*.

Last October we ran a series of webinars with UNAIDS on a project called ALIV[H]E (<http://tinyurl.com/ALIVHEUNAIDS>).

We were talking about language in those webinars as well. Often we can inadvertently use language which other people can feel is inappropriate, or disrespectful.

This is what Betty Kwagala said. She is a woman living with HIV, who also has a disability, who works with (The AIDS support Organisation in Uganda). She talked about how she and her colleagues with disabilities feel about the use of language in relation to people with disabilities.

Those are just some ideas of how she felt language can be used **disrespectfully** and she came up with suggestions of preferred language (see next slide).

Language Around Disability

Negative	Positive
a disabled person	a person with a disability
the handicapped, the crippled or the lame	a person with a disability
wheelchair-bound or confined to a wheelchair	a wheelchair user or uses a wheelchair
birth defect or affliction	congenital disability or birth anomaly
a victim of cerebral palsy or other condition	has cerebral palsy
suffers from polio, afflicted with polio or post-polios	has had polio, experienced polio or has a disability due to polio

So instead of saying “a disabled person”, what is really important is to **put the person first**, and describe the *person* first - the woman or the man or child - rather than putting the disability first. So it is good if we think about the *person* foremost, rather than describing them as the disability.

Here are some examples which Betty gave in relation to this.

It was clear how she also feels the use of the word ‘victim’ or ‘sufferer’ is somehow disempowering as it is prejudging how we think somebody else should be thinking about their disability, or other issue they face, rather than enabling them to decide *for themselves* how to feel about their disability.

So what Betty was saying was to use neutral language as much as possible, rather than language which can feel negative or disempowering.

For example ‘has cerebral palsy’ is basically a neutral statement like ‘I am a *woman* who has cerebral palsy’ rather than ‘she is a victim of, or suffers from, cerebral palsy’.

To see a short film about children with disabilities, view: <https://www.youtube.com/watch?v=3SzazN2OrsQ>

1 People who use drugs

Negative

Drug abuser
Junkie
Addict
Etc.

Preferred language

Person who uses drugs



At the same ALIV[H]E webinar (<http://tinyurl.com/ALIVHEUNAIDS>), we also heard from Silvia, a woman who has used drugs. She was talking about a lot of the negative language which can be used around people who use drugs and drugs use and she gave some examples of this negative language.

Often when drug use is illegal, it enables people use negative language about the people involved, as if its illegality gives us permission to use negative language about someone who is engaging in that. Yet alcohol and tobacco are also drugs – although they are legal. And many people are addicted to them. But we don't talk about people who use these drugs in the same way.

What we learn from scientists around the world and the challenges of drug use being illegal is that it is then virtually impossible for drugs to be controlled or quality checked or for education to take place around illegal drug use with children or adults. It is also then very hard for us to think about the *person* who is using drugs – what he or she is going through, why they have started using drugs in the first place, what challenges they may have faced in life which might have started their drug use; and how they could be supported to stop drug use, if they want to.

So some of the things she mentioned are there in the left hand column, which again are negative connotations. Silvia identified the same thing Betty was saying, which is 'let's talk first and foremost about the person', the *person* using drugs. So she is suggesting that we use instead a very neutral statement again rather than using words which can somehow be judgemental.

There is a great website about this: <http://supportdontpunish.org/>

1 People living with HIV

Negative

PWA

PLWHA

HIV-infected

AIDS victim

Other examples?

Preferred Language

Person living with HIV



And moving on to people living with HIV. So again there's a list here of negative descriptions of people living with HIV which are quite widely used. These examples are repeatedly found in journal articles and when people are talking. Again you can see the list on the left. The preferred language is focusing on the person foremost, 'the woman living with HIV' or 'the child living with HIV' rather than saying 'the HIV infected....'

There are some really useful documents to explain more. One is the UNAIDS terminology guidelines 2015. This explains more about the background of what I am trying to say quickly here. http://www.unaids.org/sites/default/files/media_asset/2015_terminology_guidelines_en.pdf

There was also an article to which I contributed, trying to explain how language can affect the way we think and feel in relation to women living with HIV. There is more background explanation there. <http://www.jiasociety.org/index.php/jias/article/view/17990/722>

2 To describe *situations* (a)

Negative

To infect

To be infected

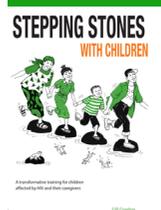
To have risky behaviour

Preferred Language

To transmit

To have acquired

To have vulnerable behaviour



(a) Next we can look at our use of language in relation to situations. The reason why, as people living with HIV, we are keen not to use the word 'infected', is that if you look in an ordinary dictionary, other words used to describe 'infect' are 'corrupt' 'tainted' 'dirty'. The way in which 'infect' is used in common language can then somehow influence the way we think of somebody whom we describe as 'infected'.

I appreciate that is the language health workers use. Yet health staff may often forget how the language they use can be used in everyday use as well. So we prefer not to use the word 'infect' but more neutral language.

Again the idea is to try to think about how we can use language in a neutral or more sensitive way. For instance, words like 'transmit' or 'acquire' have a more neutral feel to them than words like 'infect' can have. And when we talk about 'risky behaviour' sometimes there can be a sense of 'that teen was behaving in a risky way', or 'that woman's putting herself at risk'. But using the word 'risk' here can suggest that the individual has more choices than they may actually have.

(a) contd.) For instance if there's a young woman who is selling sex in return for support for homework, a question we can ask ourselves is: does she have other ways of getting support for homework? To what extent is it fair for anyone to judge her for that and call her a 'bad girl'? Or do we say 'those are really tough issues she is facing and let's find a way to support her to be less vulnerable'. Whatever someone is exposed to, if they don't have power to make safe decisions, is it fair just to label and blame them?

This is about power inequities: whether in relation to gender relations, or poverty, or because they are young and the other person is older, or a combination of these. It is these power inequities which we are trying to describe by using the word 'vulnerable' rather than 'risky'. This is why we have used that language in *Stepping Stones with Children*.

We can often alienate other people by the language we use about them or the issues they face.

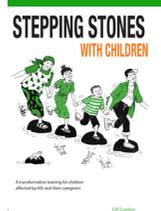
2 To describe *situations* (b)

Negative

To be lost to follow up
Defaulting

Preferred Language

To have not been retained in care
To have not been retained in care



(b) Next, we have been thinking a lot about the way health workers or policy makers talk about women in particular whom they describe 'as lost to follow-up', if they have started on ARVs during pregnancy, then the baby is born and the woman doesn't come back to the health centre. You can hear health workers – and even other people with HIV - complaining 'she's just lost to follow-up' or a 'defaulter'. But is this fair on the woman, particularly if she is experiencing violence from the health centre, which can often happen, or if she is experiencing violence from her partner or in the community? This may make her feel scared, so she doesn't want to come for treatment.

In a big research study we conducted for WHO, we found that many women experience violence after their HIV diagnosis, including from intimate partners, from community members and it shoots up especially in healthcare settings. In other research for UNWomen, we found how GBV is very often a big barrier to treatment access for many women. You can read about these research studies on the Salamander Trust website, on the projects tab.

(b) contd.i) Who is supporting her not to be experiencing that violence, to feel welcomed in the health centre and invited and encouraged and supported to be taking ARVs? So we are saying that, instead of thinking the woman has done something bad, let's talk about how the health system has failed to retain those women in its care. This is thinking again about that power dynamic: who has the power? Is it the healthcare system, or the individual woman? If we start to talk about failure to retain the woman in care, then the responsibility lies with the health system, instead of with the individual woman.

When we have talked about this use of language with health managers or policy makers, they say 'that is interesting, we haven't thought about it like that before.'

So turning the language round helps policy makers and health managers really to think about where power dynamics lie for that woman.

For example, Martha Tholanah is a woman living with HIV from Zimbabwe (and a *Stepping Stones with Children* facilitator). She is very good at taking her ARVs and has taken them for years. But one time she went to clinic and said to the social worker, 'I do take these pills every day, but it's hard work having to go on doing so'. But the social worker, instead of empathising, got angry with her and said 'you've got to take your pills every day and it's really bad if you don't'. So Martha gave a talk, which she called 'Am I lost to follow up, or bullied out of care?', because she felt she was treated like a naughty child, rather than as the responsible adult she is. Everyone finds it hard to keep taking treatment, whatever condition they have. So we need to think carefully about what it is actually like for somebody on the receiving end of this type of negative language, and the effect this can have on their ability to keep going and on their spirits.

(b) contd ii) Yet in the end, even if healthcare providers are always polite and kind, and even if there is no violence at home or in the community, it is ultimately the individual right of all of us to decide if, when and for how long to do anything to our bodies. This is called our right to bodily autonomy and it is part of the Universal Declaration of Human Rights. So in the end, if someone does not want to take ARVs or other treatment, that is their right and we don't have the right to blame them or be angry with them.

It is often hard for health workers too because they have been told they have a job to do, which is to get women to start on treatment as soon as they have tested positive; and to get them to 'disclose' to their partners. Both of these can put the women in danger of violence. So the healthworkers fear that if the women don't do these things, that they themselves will get blamed for not doing their jobs properly. So they can bully the women to 'behave', as the social worker did with Martha, without realising that this very attitude can drive women away.

But healthworkers haven't been trained in human rights. This is something that we are working on. We have also been trying to do this with the human rights component in relation to children and all of us, in *Stepping Stones with Children* and its version for adolescents and adults, *Stepping Stones & Stepping Stones Plus*.

(And of course, we also need to remember that many healthworkers also may have HIV or be affected by HIV or looking after people with HIV in their own families. They too are scared about what people might think of them and that they may lose their jobs, so they may use harsh language about people with HIV, to cover up their own fears. So healthworkers too need support, to make sure they don't fear their own job loss.)

2 To describe *situations* (c)

Negative

To drop out of school
Other examples?

Preferred Language

To have not been retained in school



(c) Finally for now, when we talk about children/teenagers not going to school any more, do we call them dropouts? Or do we say, 'that child can't go to school any more because the parents can't afford school fees or the girls is expected to stay at home and look after the other children or people who are sick'.

Again if we ask ourselves, 'where does the power lie?', it helps us to see it from the child's perspective. Maybe it is the school's fault, the system of the school that isn't enabling the child to come in at a different time of day or supporting a girl with sanitary towels during her periods, or with uniform or other challenges. Or do the parents need support to understand the rights of the child and the long-term benefit of the child going to school?

If we want to place the blame anywhere, we should place the blame on the system which is failing the individual children or individuals who are not able to come and get more medication or schooling, rather than blaming the individual children. How can we all work together to improve the system?

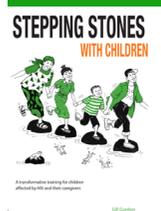
3 To shape our *thinking* (a)

Negative

To end GBV
HIV/AIDS

Preferred Language

To achieve safety
Just 'HIV' or 'HIV *and* AIDS'



(a) Moving on to how we shape our *thinking* in regards to language. In *Stepping Stones With Children* we talked about safety a lot, rather than 'ending GBV' because 'ending GBV' is a double negative: to end something is a negative and GBV is a negative.

I was in a meeting in West Africa and I asked 'what are you going to do when we end GBV?'. These were UN, NGO and government staff. They looked puzzled and said 'we'll be out of a job' - and then they laughed and I asked 'do you want to be out of a job?' They said 'no, because we have our rent to pay, and school fees to pay'. So I said, 'isn't that a problem then? Don't we need to think about how to describe the work we do as something positive, which is creating something positive? Of course you don't want to finish your jobs, because you need income. That's why it is good for us to think and talk about doing something positive, and talk about positive outcomes in the future.'

Next, many people still talk about 'HIVAIDS', as if it was one word and one thing. We think it is important *not* to do this, so that more people realise that if people with HIV are able to access and take treatment, we can lead long fully productive lives, without developing AIDS. This too could help to take the fear out of HIV.

3 To shape our *thinking* (b)

Negative

PMTCT / eMTCT

Treatment naïve patients

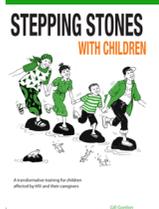
To *use* people

Preferred Language

Peri-natal care

People new to treatment

To seek people's engagement



(b) Then if we talk about PMCT (Prevention of Mother-to-Child Transmission) or EMCT (Elimination of Mother-to-Child Transmission), these are again negative things, about prevention, elimination and really focusing on the transmission of HIV from a woman during childbirth or pregnancy to her child.

This focus on the woman in this way which can feel very blaming.

(b) So again we're suggesting we could talk instead about 'peri-natal *care*, and *support*' and we could call that "HIV-related peri-natal care" – which is both positive and supporting and putting the *woman* first, instead of negative and potentially blaming and thinking more of her child or partner than of the woman's own needs.

Peri means around and *natal* means birth so together that means 'everything around birth' so that could be conception, pregnancy, childbirth, breastfeeding stage and this is a much more neutral way of describing it.

Often you hear workers saying 'treatment naïve patients'. Naïve is a French word originally. If in English you say an adult is naïve, it's as if they're childish or immature. Again it seems somehow a negative way of talking about people, so you can say 'people new to treatment' which is the same number of syllables but more gentle and neutral.

Next, you often hear about *using* people, 'we can *use* the midwives to do this' or '*using* the community'. Can you not 'seek peoples' engagement' rather than *using* somebody? It seems again a derogatory way of talking about people, to talk about *using* them, rather than engaging with them respectfully and thoughtfully.

So those are some other phrases we have talked about and in *Stepping Stones with Children* we have tried to as much as we can to shape the language in the sessions in a much more neutral way.

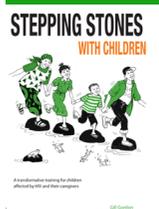
3 To shape our *thinking* (c)

Negative

To *disclose*

Preferred Language

To share one's HIV status



(c) Finally, we much prefer talking about 'sharing one's status', instead of 'disclosing' it. There is a lot of emphasis from health staff and in policy documents on the need for 'disclosure'. However, especially, given the high levels of violence and fear experienced by women living with HIV and others around HIV, we consider instead that they should be supported to *share* this information with someone they trust, only when they feel ready to do so.

This is very much the approach we have taken in *Stepping Stones with Children*, in relation to caregivers talking about HIV with the children in their care. This is why 'disclosure' is *not* an indicator for the programme, because we didn't want to put caregivers or facilitators under any pressure to make this happen.

As we expected, it turned out that almost all the caregivers, once they felt understood and supported, *did* decide to talk to the children about why their parent(s) had died, or the child's own HIV status, and felt very relieved and happy to have done so. The children too said how happy they felt. So our supportive approach was successful.

So this is why we prefer the phrases 'share' or 'talk to', which seem to us much more gentle and kindly, instead of 'disclose', which sounds much more formal, official and obligatory.

GLOBAL PLAN TOWARDS THE ELIMINATION OF NEW HIV INFECTIONS AMONG CHILDREN BY 2015 AND KEEPING THEIR MOTHERS ALIVE

or:

4M
EXECUTIVE SUMMARY

4M:
My health,
My choice,
My child,
My life

Developing a national network of Mentor Mothers to support women living with HIV through pregnancy

Which would *YOU* choose?

(d) 4M is a project that some colleagues in Salamander Trust, Angelina, Ellen and Nell, have been running. They have recently held workshops in Uganda and Kenya with UNYPA and PIPE respectively and here it has been called 4M+. It is a peer mentoring project run by and for women living with HIV going through the pregnancy journey.

At the top of the slide, you can see the title, of The so-called 'elimination plan' as people called it, the Global Plan which I am sure you are all familiar with. A number of us of women living with HIV said that this Global Plan is just so negative. Some Ministry of Health people in different countries were saying 'these women are terrible, they keep having babies and we have to eliminate this' which just felt and sounded awful.

So we created our 4M programme with a very different title. The 4Ms stand for 'my health, my choice, my child, my life'. And you can see the focus is on the *woman* herself and her own autonomy and gives her power to decide what choices she wants to make during her pregnancy and the childbirth and beyond. It is a much more women's rights-focused approach.

Just using empowering language in the title of a programme, from its start sets a different scene for the whole programme. I just wanted to share this with you as a way of describing the impact language can have on the way we think, feel and act around women living with HIV and their babies.

4 To shape our current and future *actions*

Preferred language – positive (not negative); creative (not militaristic)

Negative

Needs assessment

Problem solving

Target group

Fight, struggle, end

Ending stigma & discrimination

Preferred Language

Visioning exercise

Solution seeking / dreaming

Ability spotting

Virtues

Building our resilience

Priority Group

Vision, dream, nurture, growth

Promoting respect & rights



We can also use language to shape both our current and our future *actions*. So much of project language is around *needs* assessment and *problem* solving. It is also very militaristic. With formal research also we start with a research *problem* and we are hard wired from our ancestry as animals to think in *threat-oriented, negative* and defensive ways, as we learnt in earlier sessions of *Stepping Stones with Children*. Do you remember the old brains at the base of our necks, and how we have flight and fright and freeze and appease built into our old brains?

So it is really good for us to think positively and openly and in much more creative ways, and not to have *problem-oriented* and negative *threat-oriented, defensive, militaristic* thoughts and language.

Instead we can have a visionary exercise in the community instead of a needs assessment, and have *solution-seeking* and dreaming exercises instead of *problem* solving. And exercises like ability-spotting and virtues, and as we used all the way through *Stepping Stones with Children*. These build our own and our children's resilience. The exercises were all about finding those virtues inside us which we all have, but which are so often hidden. Through these exercises, we can remind ourselves they are there, and then build on them.

5 To shape *how we think & feel about* past, current & future actions

Negative

Blaming others
Blaming self

Preferred Language

Using mind-sight to understand
Using SIFT & ability spotting to
understand ourselves
Staying on our hubs
Dreaming our futures
Using virtues
What else?

Martin Luther King said: *“I have a dream”*
(not *“I have a nightmare”*....)



It is also helpful to think about how language helps us to shape *how we think and feel about* past and current actions and how we can move away from blaming others, which our use of negative language often does - and also often blaming *ourselves*.

Instead, we can think about the exercises we have learnt about and used in the *Stepping Stones with Children* programme. These include mindsight to understand where other people are coming from; the exercise about our sensations, images, feelings, and thoughts (SIFT) about how we are feeling in our bodies about dealing with different experiences; ability spotting, to understand our selves and others; staying on our hubs so we don't get overwhelmed with anxiety; then dreaming about our futures which enables us to tap into our deepest creative ideas inside us; and of course using our virtues.

Finally, it is important to remember that negative language affects us not only psychologically, but also physically. Negative language increases the cortisol in our bodies, which promotes stress and suppresses our immune system. By contrast, if we use positive language, this increases oxytocin in our bodies which promotes a sense of well-being and boosts our immune system, which can keep illness at bay. The more science tells us about the links between language, our minds and our bodies, the more we learn how much it is a good thing for us in so many ways.

As Martin Luther King said '*I have a dream*' – not '*I have a nightmare*'!

6 Further reading

ALIV[H]E Project

Webinar on Language [here](#)

UNAIDS 2015

Terminology Guide [here](#)

Welbourn 2015

Language and the Blame Game [here](#)

Welbourn 2013

Pillars and Possibilities [here](#)

Dilmitis et al 2012

Language, Identity & HIV [here](#)

Kansas Coalition 2005

Asking Powerful Questions [here](#)



THANKYOU!

Thankyou so much to all of you who took part in the call, and especially to Ellen, Martin, Olga, Sam, Sue, Gill and Angelina for helpful comments on this presentation during the webinar and afterwards; and to Laura for writing up all the notes from the call.

