Our use of language: the power of positive perspectives

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This article was written by Laura Pulteney. It is drawn mainly from the transcript and presentation of the *Stepping Stones with Children* webinar of the same title, and the first ALIV[H]E webinar. Other sources include articles from JIAS, The Guardian and surveys and reviews undertaken by the Salamander Trust.

"Language shapes beliefs and may influence behaviours. Considered use of appropriate language has the power to strengthen the global response to the AIDS epidemic." (UNAIDS Terminology guidelines, 2015.)

Language is powerful. The words we use can change the way we see things, and although our words can unite, they can also alienate. We become accustomed to the vocabulary we use on a daily basis, which is often influenced by our social or professional environments. Sometimes we use language which others can find disrespectful and alienating. In this way, we might not realise that what we are saying inadvertently objectifies or stigmatises others. In the field of health and human rights, this can alienate the very people we want to include in health programmes and, in turn, make them more vulnerable. By thinking about and changing the language we use we can change attitudes and correct misinformation. In *Stepping Stones with Children*, we tried hard to think about how we use language. We came up with at least five ways in which we use language:

1) To describe people
2) To describe actions or situations
3) To shape our thinking
4) To shape our current & future actions
5) To shape how we think & feel about past, current & future actions.

By thinking about and examining our use of language, we can teach ourselves to use language in a more neutral and inclusive way. This can help to rectify misconceptions about HIV, reduce stigma, highlight where the power inequities lie and promote inclusion.

1. Describing People

How does the language we use to describe people shape our beliefs about each other? Language to describe people with disabilities, people living with HIV and people who use drugs can have negative connotations. The terms to be 'a disabled person' or a 'drug user' are problematic because the condition is emphasised over the individual. Instead we can use language which puts the person first, in what is known as 'people-first language'.

Language around disabilities

Betty Kwagala of The AIDS Support Organisation in Uganda (TASO), raised these points in a webinar with UNAIDS for the ALIV[H]E project. She spoke from her perspective as a woman living with HIV who also has a disability. She explained that what matters most about language used in relation to work with women and disabilities 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." She argued that it is important to put the person – the woman, man or child - first rather than the disability. In this way, we are thinking of the person in question as human first, instead of describing them as a disability. She explained how the words 'victim' or 'sufferer' can be can be disempowering.

To call someone a 'victim' is to say that they have no agency to change a situation they are faced with. It is prejudging how we think somebody else should be thinking about their disability, or other issue they face rather than deciding for themselves how to feel about their disability. Betty suggests that instead of using language which can feel negative and disempowering, we use more neutral language. For example, to say someone 'has cerebral palsy' is basically a neutral statement, such as 'I am a woman who has cerebral palsy' rather than 'she is a victim of, or suffers from, cerebral palsy'.

Negative	Preferred language
A disabled person the handicapped, the crippled or the lame	A person with a disability
Wheelchair-bound or confined to a wheelchair	A person who 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
Betty Kwagala, TASO, ALIV[H]E webinar 1, October 2016	

Language around HIV

Discourse around HIV policy is so often negative and militaristic; in the health field, language often focuses on eliminating disease and not on improving health. Language used to describe people living with HIV can be stigmatising. In the table are some examples of negative terms which are still widely used in literature today to describe people living with HIV, alongside language which it is preferable to use. The negative terms are problematic for several reasons.

Negative term	Preferred language
PWA PLWHA HIV-infected AIDS victim	*Person* living with HIV *Child* living with HIV

To say 'PWA' or 'PLWHIV' reduces people to an acronym, and we can forget that we are referring to human beings. As Alice Welbourn said in the same ALIV[H]E webinar, "As a woman living with HIV, I don't like being described as a PWA, a bunch of letters which makes me sound like an object… I prefer instead to be described as a *woman* living with HIV". In this way, the individual person as a human being is made paramount and the disability comes second.

In describing someone as 'HIV-infected' the emphasis is on the virus and that is what we think about first. When this expression is used, the impression created in our minds is that having HIV is central to who the person is and overlooks the fact that we are referring to

somebody who has thoughts and feelings. Then, if you look up the word 'infect' in the dictionary, synonyms include 'corrupt', 'taint', 'pollute'. [1] In terms of how this shapes our beliefs, the negative connotations of this vocabulary can adversely influence how we think about someone who is described as 'infected'.

In contrast, the preferred language puts the person first, reminding us that we should always talk about other individuals as we would like ourselves or our children to be talked about. When we describe someone as a 'person living with HIV' the image brought to mind is that of a person living their life, who happens to have HIV. This term implies that it is possible to be healthy and live well with HIV, as indeed it is; it is possible to strive to achieve goals, to pursue education, to work, to have a family and enjoy life despite its many ups and downs. This language is more empowering for all of us.
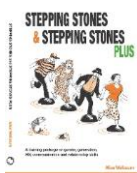
Language around drug use

At the same ALIV[H]E webinar we also heard from Silvia Petretti, a woman who has used drugs. She talked about the negative language which is used around drug use and people who use drugs. One thing she highlighted is that often when drug use is illegal, it enables people to use negative language about the people involved, as if its illegality gives us permission to use negative language about someone who is using drugs. 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.

Negative	Preferred terminology
Drug abuser Junkie Addict Etc	*Person* who uses drugs

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.

An example of what can happen when drugs are legalised and language around drug use changes is Portugal. In 2001 the possession and consumption of illicit substances was decriminalised after the country went through a period of opioid crisis. One in ten people across Portuguese society were using heroin, there were high rates of overdose, death and HIV. These rates eventually reduced and this has been attributed not only to the law change, but also a transformation in how drugs and addiction were viewed. People who use drugs began to be seen as people who need support as opposed to lawbreakers or criminals. The language around drug use also changed, as "those who had been referred to sneeringly as *drogados* (junkies) became known more broadly and sympathetically and

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more accurately as "people who use drugs". Like Betty, Silvia suggested we 'talk first and foremost about the person', the person using drugs. She proposed that we use instead a very neutral statement again rather than using words which can somehow be judgmental. (There is a great website about this called 'Support, don't punish'. Legalisation of drugs where we live might not happen anytime soon. But we can provide support in other ways by changing the language we use in relation to people who use drugs. This could help with harm-reduction measures.

2.1 Language to describe actions or situations

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'. This is often used to describe a woman who has 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

Negative	Preferred language
To be lost to follow up	To have not been retained in care
Defaulting	

just lost to follow-up' or she's 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 this increases especially in healthcare settings. In other research for UN Women, we found how gender-based violence is very often a big barrier to treatment access for many women.

For the woman who has not returned to the medical facility, 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? 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 once she went to clinic and said to the social worker, 'I do take these pills every day, but it is 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
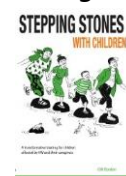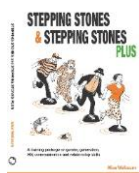
a [talk](#), which she called 'Am I lost to follow up, or bullied out of care?', because she felt she was treated like a naughty child, rather than as the responsible adult she is. Everyone finds it hard to keep taking treatment, whatever condition they have. So we need to think carefully about what 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.

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. The healthworkers can 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 may be 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.

2.2 Language to describe actions or situations

When we talk about children or teenagers not going to school any more, do we call them dropouts? Or do we say, 'that child can't go to school anymore because their parents can't afford school fees or the girl is expected to say at home and look after the other children or people who are sick'.

Negative	Preferred terminology
To drop out of school	To have not been retained in school

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?

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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?

3.1 To shape our thinking: Achieving safety

In *Stepping Stones with Children* we talk 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.

Alice was in a meeting in West Africa and she 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 Alice 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 she 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.'

Negative	Preferred terminology
To end GBV	To achieve safety
HIV/AIDS	Just 'HIV' or HIV *and* AIDS depending on the appropriate context

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. As explained in this article, 'HIV is a virus and AIDS is a clinical syndrome'. Furthermore, the UNAIDS Terminology Guidelines 2015 state that 'the expression HIV/AIDS should be avoided…Most people with HIV do not have AIDS…It is preferable to use the term that is most specific and appropriate in the context.'

3.2 To shape our thinking: Peri-natal care and seeking people's engagement

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 can feel very blaming.

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

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birth so together that means 'everything around birth' so that could be conception, pregnancy, childbirth, and the 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.

Negative	Preferred Language
PMTCT eMTCT	Peri-natal care
Treatment naïve patients	People new to treatment
To *use* people	To seek people's engagement

Next, you often hear about using people, for example 'we can use the midwives to do this' or 'using the community'. Wouldn't it be better to say 'let's seek peoples' engagement' rather than 'let's use somebody'? It seems again a derogatory way of talking about people, to talk about using them, rather than engaging with them respectfully and thoughtfully. In *Stepping Stones with Children* we have tried as much as we can to shape the language in the sessions in a much more neutral way.

3.3 To shape our thinking: Sharing one's status

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

Negative	Preferred language
To *disclose*	To share one's status

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.

4M: A peer mentoring project

4M is a project that some colleagues in Salamander Trust, Angelina Namiba, Ellen Bajenja and Nell Osborne, 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.
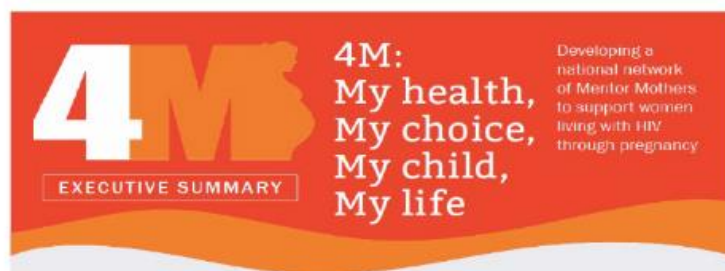
At the top of the image here you can see the title of the so-called 'elimination plan' as people called it, the Global Plan, which many will be familiar with. A number of women living with HIV said that this Global Plan is just so negative. Some Ministry of Health people in different countries were saying '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. This is 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

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*. In the second session, participants learn about the old brains at the base of our necks, and how we have the auto-responses of flight and fright and freeze and appease built into our old brains. So it is really good for us to think

Negative	Preferred Language
Needs assessment	Visioning exercise
Problem solving	Solution seeking / dreaming Ability spotting Virtues Building our resilience
Target group	Priority Group
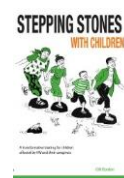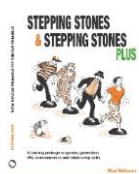
Fight, struggle, end	Vision, dream, nurture, growth
Ending stigma & discrimination	Promoting respect & rights

positively and openly and in much more creative ways, and not to have problem-oriented and negative threat-oriented, defensive, militaristic thoughts and language.

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 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

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.

Negative	Preferred Language
Blaming others	Using mind-sight to understand
Blaming self	Using SIFT & ability spotting to understand ourselves Staying on our hubs Dreaming our futures Using virtues

Instead, participants of *Stepping Stones with Children* can think about the exercises used in the programme. These include mindsight to understand where other people are coming from; an 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 also the ongoing process of virtues, which we all possess and which are universal and timeless, such as generosity, thoughtfulness and courage.

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'!

We have seen that we can adapt the language we use to create more positive perspectives. We can promote respect around disabilities, HIV and drug use through the adoption of people-first language. Changing our terminology allows us to identify power dynamics - often the power lies with the health or educational institutions, not the individuals who use them. This awareness could help remove barriers to treatment access for women. And, instead of focusing on threats, using language positively allows us to build supportive environments, where we can seek people's engagement to help us all achieve safety. Together we can harness the power of positive perspectives!

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