

## HIV/AIDS Policy Document

### Link to Dark & Lights mission and vision

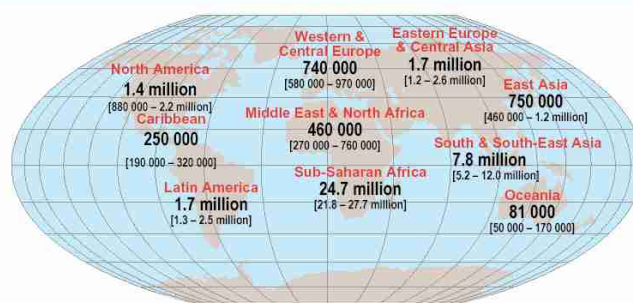
There are many reasons why Dark & Light should formulate a HIV/AIDS policy:

- HIV/AIDS is a global epidemic and an important cause of death in developing countries.
- The deadly virus is leaving a trace of social and economic devastation. Also resulting in loss of personnel and capacity.
- Disabled people are more vulnerable to get infected with HIV.
- Prevention of HIV/AIDS infection during medical/ surgery work is important for our eye care programme.
- HIV/AIDS is also a cause of blindness and disability in general.

### Context: General information on HIV/AIDS

Worldwide an estimated number of 39,5 million adults and children are living with HIV<sup>1</sup>. The highest infection rates are in Sub Sahara Africa. Every 15 seconds someone dies as a result of AIDS<sup>2</sup>. The disease also has a major social impact. Families become incomplete or children become orphans (15 million orphans worldwide). Since HIV/AIDS is making most victims amongst young people, there is also a serious decrease of labour force, resulting in more poverty.

#### Adults and children estimated to be living with HIV, 2006



**Total: 39.5 (34.1 – 47.1) million**

The following table shows the HIV/AIDS Infection rate (% of infected adults >15 years) in Dark & Light programme countries<sup>3</sup>. The infection rate in the African programme countries is higher than in the Asian countries. The infection rate in the Dark & Light programme countries is low when compared to some Sub Saharan countries with an infection rate of more than 20%! This is however not a reason to neglect the HIV/AIDS topic. Prevention activities deserve serious attention in countries with a low infection rate. Of course countries with a high infection rate need other measures than countries with a low infection rate. Therefore, Dark & Light will make a differentiation in this policy document between countries with an infection rate above 1% and under 1%.

<sup>1</sup> Source: UNAIDS global summary 2006

<sup>2</sup> Source: Stop Aids Now

<sup>3</sup> Source: Website Stop Aids Now: [http://www.stopaidsnow.nl/worldmap\\_landendata.html](http://www.stopaidsnow.nl/worldmap_landendata.html) - UNAIDS

Country	Infection rate
Ethiopia	4,4 %
Kenya	6,5%
Nigeria	3,9%
Sudan	1,6%
Tanzania	6,5%
Afghanistan	< 0,1%
Bangladesh	0,1%
Cambodia	1,6%
Indonesia	0,1% <sup>4</sup>
Laos	no data/ low infection rate
Nepal	0,5%
Pakistan	0,1%
Philippines	no data/ low infection rate
Netherlands	0,2%

### Vulnerability of disabled people for HIV/AIDS

People with disabilities are part of every social group - class, caste, ethnicity, gender, religion, sexual orientation. And in the context of HIV, they are also found within every key group at higher risk such as sex workers and their clients, injecting drug users, men having sex with men, but also orphans, prisoners, etc. People with disabilities are therefore exposed to the same risk factors for HIV as the non-disabled general or key populations at higher risk. Moreover, people with disabilities are at greater risk of HIV-infection. There are several social and economic causes that make people with disabilities more vulnerable to contracting HIV than the non-disabled populations<sup>5</sup>:

There are many myths around people with disabilities:

- People with disabilities do not feel the desire to have sex.
- People with disabilities can not get HIV.
- People with disabilities are no victims of (sexual) violence
- People with disabilities do not use drugs or alcohol

<sup>4</sup> Highest incidence rates in: East and West Java, Mid Sumatra, Papua

<sup>5</sup> Sources:

1) World Bank (2004), Disability and HIV/AIDS at a glance - 2) World Bank (2004), Capturing hidden voices – 3) Save the Children (2004), Double burden: *a situation analysis of HIV/AIDS and young people with disabilities in Rwanda and Uganda* – 4) VSO (2003), *HIV&AIDS and disability: National Conference Report*. Namibia.

### Poverty

People with disabilities face poverty, stigma and discrimination. They often belong to the poorest and most marginalized communities, which is a significant risk factor in vulnerability to HIV.

### Poor access to information on sexual and reproductive health and HIV&AIDS

The global literacy rate for adults with disabilities is as low as 3 percent. Only 1 percent of women with disabilities are literate<sup>6</sup>. Low literacy rates as well as poor access to mass-media messages for people with hearing and visual impairments (the billboards do not reach the blind, radio spots do not reach the deaf) present real challenges to dissemination of information outreach. People with disabilities attending school have lower knowledge about HIV/AIDS compared with their non-disabled peers. However, only 2 % of children with disabilities attends school and so most of them are unable to access HIV information via the education system<sup>7</sup>.

### Poor access to health care, including HIV&AIDS services

Access to sexual and reproductive health services, HIV-testing, care, medication and support is limited. Health clinics are often difficult to access for people with physical disabilities. There is a lack of counsellors who are able to use sign language. This means that deaf people do not have any privacy when they receive counselling. Health staff is sometimes prejudiced and might believe that people with disabilities do not have sex. So people with a disability are being sent away when they come to a clinic for a HIV test, because they do “not need” a test.

### Sexual abuse and exploitation

People With Disabilities are put at increased risk of infection due to sexual exploitation and misconceptions about their sexuality and rights. Being a woman with a disability is an additional risk factor for HIV<sup>8</sup>. They experience high incidence of sexual abuse and exploitation. They receive no or only limited legal support when they want to report rape or sexual abuse and the perpetrators often easily get away with it.

Multiple partners: The stigma experienced by persons with disabilities means that they are less likely to marry and that they are three times more likely to have a series of unstable relationships. In addition, people with disabilities are often situated / living among the poorest groups in society and therefore they sometimes use sex as a way to meet their economic needs.

People with disabilities are left out of HIV&AIDS policies and programming. Governments and policy makers rarely consider disability issues when formulating their HIV&AIDS strategic plans, despite the growing international attention for the rights of people with disabilities and the adoption of the United Nations Convention on the Rights of People with Disabilities in 2006. This Convention obliges states to provide access to sexual and reproductive health including HIV information and services for people with disabilities. However, initial steps to achieve inclusion are being taken, mainly by the disability movement. Disabled People’s Organisations in different countries in Africa and Asia are becoming more and more involved in the HIV arena to mainstream disability into AIDS organizations. In order to reach universal access to HIV prevention, treatment, care and support by 2010 and the Millennium Development Goals in 2015, it is necessary to make HIV&AIDS policies and

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<sup>6</sup> Source: Save the Children (2004), Double burden: a situation analysis of HIV/AIDS and young people with disabilities in Rwanda and Uganda

<sup>7</sup> Source: same as above

<sup>8</sup> Source: same as above

programmes inclusive for people with disabilities. The UN, donors, AIDS service organizations, non-governmental organizations, the private sector and disabled people's organizations: all play a role in making policies and programmes inclusive for persons with disabilities.

#### HIV&AIDS as a cause of disability

In some programme countries cases are reported of people living with HIV/AIDS (PLWHA) who became disabled because of infection with the virus. There are some HIV/AIDS related eye diseases leading to blindness if not treated well. Herpes Zoster Ophthalmicus (HZO) and Cytomegalovirus Retinitis (CMVR) are most often mentioned in relation with HIV/AIDS. However, the number of cases is still relatively low. With the increased availability of anti-retrovirals the number of people with HIV/AIDS related eye diseases will probably increase. People live longer with HIV/AIDS, so the chance of developing HIV/AIDS related eye diseases also becomes bigger. More information about HIV/AIDS and eye care can be found in the HIV/AIDS special of the Community Eye Health Journal:

<http://www.cehjournal.org/download/ceh47.pdf>

Some PLWHA become disabled because hospitals refuse to provide necessary medical treatment because of the HIV infection of the patient. Cases are being reported of PLWHA not getting necessary operation after an accident, resulting in disability.

*Being a woman with a disability is an additional risk factor*

Disabled women face unique challenges in preventing HIV infection, due to: a high risk of gender-based violence, the lack of access to reproductive health care services and low awareness of mother-to-child HIV transmission. Compared to non-disabled women and to disabled men, women with disability are more likely to be illiterate and unemployed. Because of prejudice and stigma, they are more likely to live in a series of unstable relationships. These social and economic factors make women with disability harder to reach with HIV messages and reduce their ability to negotiate safer sex.

#### Strategy Dark & Light on HIV/AIDS

The strategy of Dark & Light on HIV/AIDS will cover three areas:

- Awareness of local partner organisations – work place policy
- HIV/AIDS and eye care
- HIV/AIDS and people with disabilities

#### Awareness of local partner organisations – work place policy

In HIV endemic countries, like South Africa, Botswana and Zimbabwe, the disease has a severe impact on the people of working age, 15 till 40 years. One of the main reasons for this impact is that this age group consists of mostly sexually active persons, who are in great danger to contract the HIV-virus. As a result of this impact, the working place will have, one way or another, to deal with this disease. The impact in a low endemic country will be less than in a high endemic country. Still the problem of HIV in the workplace can exist.

Four reasons why an organisation should deal with HIV and AIDS in the workplace<sup>9</sup>:

<sup>9</sup>Source: Stop Aids Now - Document on Good Donorship Guidelines (page 8 - 10)

- When HIV is highly stigmatized in the workplace, stigma can make employees reluctant to find out their HIV status and to seek treatment and support.
- Secondly, HIV infection is concentrated among people of working age.
- Thirdly, the consequences of HIV for the workplace can be high by all affected employees. Absenteeism or low-energy levels of staff can have their effect on the workplace. Also when illness or even death occurs among staff, knowledge is lost and new workers have to be trained.
- Fourth, the special attention to HIV in the workplace can help to be “living examples” for the rest of the community.

The best way to deal with HIV and AIDS in the workplace is by developing a workplace policy on HIV/AIDS. Dark & Light will ask all partner organisations in programme countries with an infection rate higher than 1% to develop a workplace policy on HIV/AIDS (if not yet available). The partner organisations in countries with an infection rate less than 1% are encouraged to do so, but it is not obligatory. To give a good example, Dark & Light will start by including HIV/AIDS in their own workplace policy documents.

There are many ways to develop a workplace policy on this topic. Dark & Light will give its partner organisations some guidelines and tools to develop a workplace policy. More information can be found in the following document:

[..\..\..\Projecten\Algemeen\Informatie\HIV AIDS\Overview Workplace policy HIV-AIDS.doc](#) written by Prisma in 2008. Dark & Light will not develop a stringent format for a workplace policy because we think it is important that the partner organisations will formulate their own policy. However, the workplace policy should at least cover the following topics:

- Risk reduction and prevention information for staff.
- Addressing knowledge and attitude levels of staff to actively reduce stigma.
- Assistance for staff in terms of care and support for themselves (and others close to them)

#### HIV/AIDS and eye care

To prevent the spread of HIV/AIDS during eye care work it is important to apply stringent hygiene measures. Dark & Light will ask all eye care programmes to adopt the prevention measures that were developed by the Community Eye Health Journal: [http://www.cehjournal.org/download/ceh\\_16\\_47\\_040.pdf](http://www.cehjournal.org/download/ceh_16_47_040.pdf) and [http://www.cehjournal.org/0953-6833/16/jceh\\_16\\_47\\_040.html](http://www.cehjournal.org/0953-6833/16/jceh_16_47_040.html)

Since Dark & Light is not working in high endemic HIV/AIDS countries, Dark & Light will not develop any special programmes with regard to the prevention of HIV/AIDS related eye diseases. Only in high endemic countries, setting up a referral service with HIV/AIDS organisations could be worthwhile. In the countries Dark & Light is working, the few cases that will occur can be treated within the existing eye care structures. To make sure the partner organisations are well informed, Dark & Light will provide all eye care programmes in countries with an infection rate above 1% with the information provided by the <http://www.cehjournal.org/download/ceh47.pdf>.

## HIV/AIDS and people with disabilities

In order to reach Universal Access to HIV prevention, treatment, care and support by 2010 and the Millennium Development Goals in 2015, it is necessary to make HIV&AIDS policies and programmes inclusive for people with disabilities. The UN, donors, AIDS service organizations, non-governmental organizations, the private sector and disabled people's organizations: all play a role in making policies and programmes inclusive for persons with disabilities. The following steps should be taken to include people with disabilities in HIV&AIDS policies and programming<sup>10</sup>:

### Access to information on sexual and reproductive health and rights and to HIV&AIDS information

Sexual reproductive health and HIV&AIDS prevention information must be accessible for people with hearing and visual impairments like materials in Braille, audio and video materials. Materials should also be available in a format that is accessible for illiterates, such as cartoons and drama.

### Access to sex education

It is often not acknowledged that (young) people with disabilities also have sexual feelings, needs, and desires. As a result, many young people who live with disabilities do not receive sex education, either in school or at home. Young people with disabilities should also be included in sex education so that they can protect themselves from risky sexual behavior, acquire negotiating and refusal skills and build up their self-esteem.

### Access to sexual and reproductive health and HIV&AIDS services

Health centers should be accessible for people with physical disabilities, for example by placing ramps. Health centers should be able to provide comprehensive information and confidential counseling to persons with intellectual and sensory disabilities.

### Prevention of sexual violence

Measures should be taken to prevent sexual violence and abuse of people with disabilities, such as training for people with disabilities on sexual negotiation skills and assertiveness; and changing attitudes in communities regarding disability through public education. Prevention of abuse in institutes/schools for disabled deserves special attention as well.

### Participation of people with disabilities

Guarantee that people with disabilities participate in the design, implementation and evaluation of sexual and reproductive health and rights and HIV&AIDS policies and programmes.

### Integrate HIV&AIDS in disability work

Disabled People's Organizations should raise awareness among persons with disabilities and build HIV&AIDS into their regular programmes. They can also make human resources/disability experts available to provide support in the HIV response.

### Include disability in monitoring mechanisms

Ensure that global and national monitoring mechanisms track the involvement of persons with disabilities as planners, implementers as well as beneficiaries of HIV&AIDS programmes.

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<sup>10</sup> Source: HIV/AIDS and disability flyer – DCDD 2008

### Twin track approach

Dark & Light will adopt a twin track approach on HIV/AIDS and people with disabilities. We will focus at:

- mainstreaming of HIV/AIDS in our disability programmes
- mainstreaming of disability in HIV/AIDS programmes

### Mainstreaming of HIV/AIDS in our disability programmes

#### Education programmes :

- All partner organisations are asked to include HIV/AIDS prevention and sex education in the regular school curriculum. The lessons must be suitable and accessible for children with disabilities.
- Partner organisations are encouraged to develop (or use already existing) accessible education materials (e.g. tactile and audio materials for the blind).
- The quality of the HIV/AIDS prevention lessons will be monitored by Dark & Light and where needed partner organisations will receive advice for further development and improvement.

#### Rehabilitation/vocational training programmes:

- The partner organisations are asked to include HIV/AIDS prevention and sex education in the regular training curriculum. There should be special attention for the vulnerable position of the disabled.
- Partner organisations are encouraged to develop (or use already existing) accessible education materials (e.g. tactile or audio materials for the blind).
- The quality of the HIV/AIDS prevention lessons will be monitored by Dark & Light and where needed partner organisations will receive advice for further development and improvement.

### Mainstreaming of disability in HIV/AIDS programmes

- Dark & Light will lobby for inclusion of disability in HIV/AIDS programmes by active participation in the HIV/AIDS & disability workgroup of DCDD. This workgroup lobbies for inclusion of disabled in HIV/AIDS programmes of Dutch Development Organisations. There is also an active lobby towards the Dutch Government. Apart from Lobby and Advocacy the workgroup is collecting data, best practices, educational materials etc.
- Dark & Light will also lobby for inclusion of disabled in HIV/AIDS programmes within our existing network (ICCO-alliance, PRISMA, EU-Cord)
- Dark & Light will encourage the disability partner organisations to start working together with local HIV/AIDS organisations and to promote inclusion of disabled.

### Capacity building:

- Dark & Light will set up a pilot project on HIV/AIDS & disability in cooperation with one or more (new) partner organisations. The aim of the pilot is:
  - to build up knowledge and experience
  - to develop a model for inclusion/curricula & special education materials for visually impaired (and other disabled)
  - To build up training capacity on HIV/AIDS & disability mainstreaming
- Dark & Light will organise a training session on HIV/AIDS & disability during the next partner seminar (with focus on the practical implementation).

- Set up a regional training programme (Africa & Asia) for HIV/AIDS & disability mainstreaming. Preferably in cooperation with other organisations: for example LftW, DCDD, ICDD etc.

#### Future programme development

When Dark & Light has developed expertise on HIV/AIDS & disability we can develop bigger programmes with our partner organisations. These programmes are very suitable for institutional donors.

Would you like more information? Please contact Paulien Bruijn:  
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