

## Disability, Rehabilitation and HIV.

A number of colleagues, from a variety of positions within organizations involved with disability and rehabilitation, have been asking about the work 'CCBRT' ([www.ccbirt.or.tz](http://www.ccbirt.or.tz)) is doing in the field of HIV/AIDS. The reasons why they ask were probably also different, from interested observers to people whom are frankly questioning why 'disability' organizations should be involved with HIV/AIDS 'at all': '**Aren't you an organization that wants to improve the lives of the blind and otherwise disabled**' ? My answer to this question is '**yes of course. That's why we need to address HIV/AIDS**'.

Intervention with disabled people (rehabilitation/integration) is no more possible without addressing specific HIV issues, like it is not possible without proper needs assessment of each disabled person, or without addressing his/her school issues, or later on problems of earning some income. **HIV is a part of the problems of disabled people and thus the problems caused by HIV/AIDS are to be taken into account in any rehabilitation program.**

So we urgently need to address this problem, however **with the means (funds, partners, systems) that we have**. In the following, I shall further clarify why, and how this can be done. Whilst trying to be short, as I wish to explain the different components from several points of view, my plea is likely to take some of your time. But it may be worthwhile.

### 1. HIV/AIDS in Africa.

1.1. We all know **the figures**. The rate of HIV in East, Central and Southern Africa is between 9-15 % of the **population**. However, how old and consequently how economically important are these 9-15 %?

The African population consists of:

- 50 % of children under 16
- 35 % people between 17-55,
- 15 % of people above 55.

Amongst the youngest and oldest, making 65% of the population, only a small minority has HIV.

95% of the HIV positive people, or between 8-14 % of the people infected with HIV, are amongst the 35% people in the age group 17-55. This represents the most productive sector of the society.

This means that from country to country, **AT LEAST between one adult in 3 and one adult in 5 has HIV. In Africa, also taking into account the increasing spread of the disease, this means that between 20 and 30 % of the adults may die in the coming 10-15 years.**

1.2. **Whom are** the people carrying the virus? They are in all groups of the society, but most of them are poor women, members of poor families and educated people. They are in particular mothers of large numbers of children (3-8), businesspeople, doctors, nurses, teachers, administrators, intellectuals, and other leaders.

This means that, speaking for CCBRT which is especially employing skilled and educated people, the percentage of HIV positive people amongst the African staff in our programs is likely to be higher than the respective national average as used in 1.1. . In Dar es Salaam, where we are testing thousands of people each month, and also from following the death registrations, we know that the prevalence of HIV in doctors, nurses,...., teachers, and the religious leaders who are often leading rehabilitation projects is not lower than in other groups of the society. We often notice the contrary.

### 1.3. HOPE

In this introduction to what HIV really means, it is important to mention that thanks to better and more affordable medications, there are new chances to assist AIDS patients having healthier and longer lives, so that **AIDS patients are able to educate their children before dying.**

Whilst up to 5 years ago, contracting HIV lead to a quick development of AIDS and a soon death, today these medicines provide **lots of opportunities for disease control and rehabilitation for the patient.** People carrying the HIV virus may today **still have a life expectancy of 10-15 years,** and in case they get a good diet and have access to the anti retroviral medicines probably even longer. This means that people who would normally have died when their children were just small kids between 0 and 10 years of age, are now able to remain healthy, and to raise and educate their children up to the age of adolescence or young adulthood. This makes a world of difference, and is a fantastic challenge for all people involved with health and rehabilitation.

## 2. The huge socio-economic consequences and impact of HIV/AIDS for African People.

**Virtually EACH FAMILY suffers** socio-economically because of HIV/AIDS:

- OR one or two parents died
- OR one or more sick people are taken care off at home or at a health center and cost money
- OR they take care of orphans from brothers/sisters/neighbors
- OR they contribute to others for taking care of orphans from brothers/sisters /neighbors
- OR people who were used to assist financially are no more doing so because they also got poorer, while they see the chance declining that their assistance will one day be returned
- AND in addition all people have to contribute to costs for funerals.

All these situations often lead to extreme poverty. Whilst without HIV, people were just able to cope, AIDS has for many become the drop that makes the circle of poverty a permanent feature. Whilst in the past the typical African solidarity amongst the poor was often an insurance in tougher times, people are now experiencing hardship through most of the year and are no more able to assist others. There can hardly be a more clear and meaningful illustration than the fact that in many African countries, whilst almost all children were attending and finishing at least primary school in the 80ies, in many African countries now up to 55 % of the children don't finish primary school. The main reason given is the increased poverty of many families due to AIDS, for whom the total cost of about 25 US\$ per year per child is too high.

### **Women, the caretakers of the disabled children, suffer in particular.**

65% of HIV positive people in Africa are women. In most African Countries, women get married into the family of their husband and will for the rest of their lives depend on that family. Whenever women are victim of misuse, or when the marriage breaks up (which in a situation of poverty is more likely to happen), then women can't go back to their own family. In case the husband dies of AIDS or if she gets sick, then she is accused by the family of being the one who has first contracted the disease. They are chased away, loose the right to stay in the house of their husbands' family and consequently they have to cater for their children by themselves. Often un-educated, having no money, their only stable currency being their sexuality, they partly rely on men who pay the bills for sustaining their own and their children's primary needs. This makes them vulnerable of getting HIV, whilst their only crime is having to take care of their children's survival. In Dar es Salaam e.g., we are trying to assist hundreds of women who are today still HIV negative, but who come for testing once every three months because they know one day they'll be HIV positive. They are unable to raise the issue of sexuality and HIV to the men who pay the bills for their children.

Their problem: poverty. Not a lack of ethics, as some people in Western countries suggest.

## 3. Disabled People, Rehabilitation, HIV/AIDS, and organizations involved with disability.

**'Disability' organizations should be concerned with HIV/AIDS, at least for 4 reasons:**

**3.1. ... because HIV/AIDS affects our Project staff.**

In Dar es Salaam, 27% of our CBR Community Workers have already died. Others are sick. A large number of hospital and other staff are on anti-retroviral medicines.

The long term planning for Africa should be done under the assumption that we shall loose between 20 and 30 % of all our trained staff. Therefore we should:

(Action 1)

- a. Write to our disability projects that we are very concerned about this issue.
- b. Encourage all disability projects to provide to their staff training on HIV/AIDS issues such as prevention, to get tested and to provide information where services are available in case they are positive.
- c. Invest more in training. E.g. Africa is losing more doctors, AMOOs, and nurses to HIV/AIDS than the number of new ones that are being trained. Without properly reacting to this HIV challenge, the numbers of surgeries will go down.
- d. Disability projects should have a policy if yes or no we pay anti-retroviral medicines to our staff, so that they can continue living in good health, take care of their children, and make use of the past investments in training etc... by longer being able to provide quality services. The price for these medicines in Africa will soon be getting under 1 US\$ per day.

**3.2. ... because our target group, the disabled people, are severely affected.**

First. Because they are poor, especially disabled children, disabled girls and women are more often sexually misused and are at great risk of getting HIV.

Secondly. HIV in Africa, just like Disability in Africa, is to a large extent poverty related. That is why women and poor families are more affected. **Therefore we find both conditions often in the same families.** Poor women don't have a proper diet, have no access to health care, pre-maternal care is lacking, they deliver at home or in a far away dispensary, they have no access to good child care and therefore have very high rates of disabled children. They don't have money, and in times of poverty, depend on male persons for their survival, and thereby are a high risk group for HIV infection. **Within 3-5 years, one disabled child in three will be a full or a half orphan.** Already for this reason (others are following), it is not a choice if, yes or no, we want to be 'involved with HIV'. **Of course we are involved.** HIV positive people and AIDS patients are our eye patients, our families receiving CBR services, they are the parents of our children in the schools for the blind or deaf. They often got infected with HIV through the same reason why their child got disabled: poverty.

For the moment, most of our programs just deny that many disabled children will become orphans, that their family may loose their meager income, that their house may be sold, that they will be even more discriminated, that they will need to take care of their parents, that they may become street children and get into prostitution or crime. By providing opportunities for early HIV testing, a lot can be avoided, and proper guidance and preparations can be foreseen. Instead of black misery: legal aid, proper counseling and integrated family care can provide them with fair chances. In Dar es Salaam our HIV programs have proven that it is possible. Soon, these services will be completely integrated within our CBR Program.

(Action 2)

- a) People living with Disabilities and family members should receive information and counseling on HIV/AIDS issues esp. on prevention.
- b) Those PWDs who are at high risk or who are already sick should be assisted in receiving proper counseling, testing and care.
- c) The problem of disabled children who will become orphans needs to be examined, and addressed.
- d) In case specialist HIV and integrated orphan programs are available in the respective area of our projects, then these should be utilized rather than recruiting 'own' HIV specialist staff.

**3.3. Our rehabilitation programs for disabled people need to recognize and incorporate the specific challenges imposed by HIV/AIDS, otherwise they cannot achieve the objective of 'rehabilitation'.**

Rehabilitation has everything to do with creating an environment that is conducive for the disabled person to get chances in life, whilst normally the environment is discriminating if not hostile. That is the biggest advantage of CBR compared to institutions: in the home environment, it is possible to work with the people whom are at the origin of the attitudes that cause stereotype thinking about disabled people: the disabled people themselves, their families, the people around. As the disabled person becomes more and more active, some of the attitudes of the people around get adjusted and they are willing to get engaged in contributing to giving it a chance. In case of a disabled child, parents receive some training by a community worker, they do exercises with the child e.g. to increase muscle strength, they involve the child into day to day activities and may even manage to get the child at school. In case of adult disabled people, family members get involved in teaching self care skills, to enhance mobility and to learn skills to gain some income.

All of this is only possible because the people living around the disabled person want it, find it worthwhile and are able and willing to put the necessary effort, financial investments and time in it.

**But now, from country to country and increasingly in almost all families, this situation has changed.** Poverty has increased so much, the family care takers get poor themselves, many need care and the problem of the disabled person is no longer amongst the priorities for investment or action.

**It is quite impossible to continue providing services as we did before. It is simply not possible to focus on rehabilitation, in other words to be people-focused, and at the same time to ignore the specific problems caused by AIDS such as increased poverty, lack of food, disease, social misery, discrimination, abuse, and the prospect of dying and the children becoming orphans.**

In the sector of service delivery to disabled people, in **Western countries**, one can afford just to concentrate on one specialist discipline, without taking into account any other of the problems the disabled person or her/his family members are facing. Other specialists will take care of the other problems. But in **Africa**, when you enter a poor family, people turn their full hope towards you. If you tell a starving family at their home that you want to help their disabled child, they will accept that in the hope that one day you will *really* help them. One cannot preach an empty stomach about children's rights, about equal opportunity. In poor societies, any effective assistance that will rely on what the people can do for themselves, necessarily needs to focus on a holistic approach. Without 'holding hands', but be open to empower them on those issues which are most important to them. Otherwise your fragmented approach will have to go all the way by itself, without the collaboration of the people themselves. Which means of course that you will fail from start to end. In poor societies, and esp. in community based approaches, we need to support the strongest, before we can speak about the rights of the weakest.

Virtually ALL our CBR program colleagues will tell us that they are the only people with a health concern entering the homes of people in their community. Most other 'community health programs' hardly ever leave their health centers. **And increasingly our CBR programs feel that they are no more up to their duty, because of HIV.**

Lots of the folders and PR materials which our funding agencies are sending to their donors no longer fully represent the true situation. Yes we cured the leg but the child cannot thrive because mother is already dead, and father is dying from AIDS. Or the family's meager resources have to be shared with many AIDS orphaned relatives which has increased the poverty they are suffering. They don't know how to cope. A lot of 'rehabilitation' which we may claim on our folders means in fact 'integration into poverty'. Is that a satisfying result? Of course not.

**This does not mean that we should start specific HIV programs.** Rather, we need to empower our CBR programs to contribute to preventing the spread of HIV, and to find ways to fight poverty in the families of disabled children.

Our community programs will need to diversify their activities, towards addressing these problems of the disabled people and their families. They should not only provide information about transmission and prevention, but also transfer for treatment, suggest legal aid, and prepare the future of the orphaned disabled and non disabled children.

(Action 3)

Our rehabilitation programs should be informed about this situation, as they are trained in the consequences of HIV/AIDS on the lives of disabled people and their families...

- a) ... and on how to address it by providing in all families of disabled children formal training on HIV/AIDS issues such as prevention, HIV testing (and where it is available), legal aid, orphan preparation and orphan care.
- b) In case specialist HIV programs are available in their area, then these should be used rather than recruiting own HIV staff.
- c) Our health programs (eye centers etc...) should study how they can contribute to preventing HIV through their centers.
- d) Right now there is research going on in collaboration with CCBRT, which will provide in-depth information and analysis on the experience of providing CBR services in an environment highly affected with HIV.

### **3.4. AIDS patients have become a new group of disabled people, however with an enormous potential.**

This will be way out of what most people in **organizations funding disability work** are willing to consider. But even if they wouldn't consider supporting it, as I explained above, the local disability/rehabilitation projects will sooner or later have to consider it anyhow. Simply because it concerns the disabled people they are working for.

The prior mandate of **organizations funding disability work** is to prevent disability, and to provide rehabilitation. Disability is not the eye that does not see, or the leg that doesn't walk. Disability is the fact that because of not seeing or not walking, the child does not get a chance for education, the adolescent doesn't develop skills and self reliance, the disabled adult isn't able to start a family life or to take care of his/her family. That is what disability is all about. It's attitudes of others that disable, not just the physical restrictions. Somehow we are all disabled, maybe temporally able bodied, but we all have limitations, genuine restrictions while the society accepts what we are able to accomplish. But the same society finds restrictions due to physical impairments disturbing, strange, they don't know what to do with it and those attitudes are the core reason why people with disabilities are discriminated. Not because of the leg, the eye, the hearing that doesn't function. But because of their own environments' inability to deal with it, to be

creative, to see the richness of each individual human being ALSO in that different person. Human history is filled with prejudice. That it be against women, disabled people, black people or ethnic minorities. AIDS patients are the latest victim of human inability to love those who don't fit into our ideal-typical dreams. This sclerosis of the heart leads to prejudice and stigmatization whilst the society seems to legitimize these attitudes by e.g. isolating disabled people in centers, confirming and strengthening the impression that they need special treatment by experts.

In a similar context, AIDS patients are discriminated. In the issue of AIDS these negative attitudes have lead to a stigma which hampers preventive efforts, as well as service delivery to those in need.

That is the big challenge for CBR (Community Based Rehabilitation): integration because of human rights: it is the right of people to get equal opportunities.

There to, many **organizations funding disability work** have adopted the strategy of CBR. It is not a miracle strategy. But it first of all has the great merit of not isolating disabled people from their families and make them dependent from charity. CBR tries not to do big miracles for a few, but to provide opportunities to the many. CBR first collaborates with medical centers, such as eye or orthopedic units, and send them those people whose problem can be cured (e.g. many cases of epilepsy, or some orthopedic problems), whose functions can be restored (e.g. cataract surgery), or whose abilities/independency can be increased (e.g. orthopedic surgery/orthopedic prosthesis). Once the medical and paramedical avenues have been considered, for those whose abilities could not be increased up to the level of self reliancy, the CBR workers will provide services that will increase the activities of the person in his/her given social setting, focussing on integration within the family and community activities. This is often a life long process, as every new phase in life brings up new challenges (a blind adult faces other limitations than a blind child). This is why the CBR strategy is the only reasonable strategy: it takes into account that integration of disabled people (rehabilitation) requires empowerment at each stage of life, there where the negative attitudes towards the disabled person happen.

That is also what makes CBR work the perfect basis for assisting people living with HIV/AIDS. CBR programs are often the only available, but also potentially the best providers of services to AIDS patients.

This would technically not be too much of a jump. CBR Workers already collaborate day to day with local health services, as mediators for change.

(Action 4.)

- a) In CBR Programs where HIV/AIDS is seen as a major problem in their families, CBR Community Rehabilitation Workers should be taught about HIV/AIDS issues in particular prevention, counseling and testing, and HBC (Home Based Care) work with AIDS patients. They should give priority to disabled people and their families living with AIDS, and if possible open up to others (this would fit perfectly into the WHO/UNAIDS strategy of training 'family care takers' through available community health workers).
- b) CBR Programs would NOT need to be involved with any medical assistance. The CBR Workers should be mediators between the clinician at the local health center or dispensary, and the patient. Also this fits into WHO/UNAIDS policies.
- c) The CBR Workers would be in a good position to be trained in assisting the family to prepare the future of the disabled and other children (as orphans).

It is my sincere hope that organizations involved with rehabilitation will come to understand that the direct impact of HIV/AIDS on the lives of disabled people and their families is of more disabling effect than the traditional 'impairments'.

Not addressing HIV/AIDS is a barrier towards achieving poverty alleviation in disabled people.

If we don't want our work to become of cosmetic importance only, then these are times for change.

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