Access to HIV/AIDS services for disabled persons in Uganda - problems of stigma and discrimination?

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Persons with disabilities are a large and largely overlooked population in the fight against HIV/AIDS.

1. Background

The UN has estimated that 10% of the world’s population experience some form of disability or impairment. This means approximately 2.5 million disabled persons in Uganda.

Few HIV/AIDS interventions have directly targeted individuals with disability. They have gone unnoticed in HIV/AIDS outreach efforts, because it is commonly and incorrectly assumed that disabled persons are sexually inactive, unlikely to use drugs and alcohol and are less at risk of violence and rape than their non-disabled peers.

Furthermore, studies reveal problems of health workers having discriminatory attitudes towards disabled persons and turning them away from HIV/AIDS services.

The latter could not be verified in this study. However, it was observed that only few disabled persons seemed to attend HIV/AIDS services and the question thus arises, why this is so? What keeps disabled persons from coming forward to be tested and treated?

2. Methodology

This study is based on five week’s ethnographically inspired fieldwork in May 2006 in the Republic of Uganda in which the interaction between health workers and disabled persons was explored with a focus on HIV/AIDS.

Uganda was chosen because of contacts to The Danish Council of Organizations of Disabled Persons and their umbrella partner in Uganda, the National Union of Disabled Persons of Uganda. However, these organizations have no political or financial interests in the project.

This study is built upon:
1. Participant observation at five HIV/AIDS clinics.
2. Formal interviews with ten disabled persons and eight health workers.
3. Informal interviews with a representative from UNAIDS and with representatives from four disability organizations.

The theoretical and analytical framework is inspired by sociologist Richard Jenkins’ theory about social identity, and sociologist Erving Goffman’s theory about stigma.

3. Results

Stigma, marginalization, poverty and illiteracy, unemployment and the lower probability that a disabled person will be considered an eligible marriage partner, significantly diminish the ability for many to negotiate safer sex.

What keeps disabled persons from coming forward to be tested and treated?

Problems with access and confidence are often reported as important issues regarding attendance at HIV/AIDS services for disabled persons. These obstacles are there, but according to this fieldwork these physical barriers in the “healthcare-system” do not seem to be as important as barriers outside the “system”.

Looking at the stigma PWDs have to face related to HIV/AIDS, the challenge seems to be related to normative expectations in society. Especially roles and rules related to the “expected wife” and the “supporting husband” seem to be determinants when disabled persons are not considered eligible marriage partners, and thus are not expected to be asked to participate in the reciprocal exchanges inherent to such relationships.

However, persons with disabilities have the same desire for “wholeness” and “social alness” including the need to be loved as anybody else. They may engage in more informal relation- ships, which may be looked upon as “improper”. In addition, being diagnosed HIV positive reveals that one has somehow behaved “immorally”. Especially disabled women seem to fear having labelling as prostitutes, but disabled men also have the feeling that sex is not looked upon by society as being ok for them.

Being HIV positive evokes feelings of guilt and blame, which combined with the feelings of being looked upon as less worthy and less acceptable as disabled, intensely HIV stigma. The fear of stigma and its consequences such as social exclusion seems to pattern their behavior, when Persons with disabilities “choose” to cover up their serum-status.

This study points to the fact that this internalized stigmatization leading to a kind of self-regulated exclusion seems to be a central reason why persons with disabilities do not attend HIV/AIDS services. However, self-regulated exclusion should be seen as dictated by circumstances and not necessary as a “chosen” behavior.

A Triple Burden

Disabled—HIV positive—prostitute

Especially disabled women seem to be frightened of HIV testing, because a HIV diagnosis may suggest that they have behaved immorally, for which reason they will be labelled as prostitutes.

If it is commonly assumed that disabled persons are not sexually active or considered eligible marriage partners, then these assumptions result in disabled women being looked upon as prostitutes or as persons who have behaved immorally if they are diagnosed HIV positive.

I would like to thank MDDPU (The National Union of Disabled Persons of Uganda) for permission to use the photos in this paper.

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