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 impairments. This means approximately 3.5 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 at low risk of violence and rape than their non-disabled peers.

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.

Furthermore studies reveal problems with 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

No discrimination could be observed between health workers and disabled clients in this study. Instead it was observed that persons with disabilities did not attend HIV/AIDS clinics.

Problems with access and confidence are often reported as important issues regarding attendance at HIV/AIDS services for disabled persons. Those obstacles are there, but according to this fieldwork those 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 value" including the need to be loved as anybody else. They may engage in more informal relationships, 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 being labeled 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 shame, which combined with the feelings of being looked upon as less worthy and less acceptable as disabled, intensify "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 when they attend HIV/AIDS services.

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.

4. Perspectives

The real challenge seems to be how to target the normative expectations which produce stigma in the first place and pattern the behavior of PWDs when they "choose" to cover up their serum-status instead of coming forward to be tested or treated. TASO Kampala can be seen as a good example of meeting this challenge. They employed a disabled counsellor who as a plugin actively convinced PWDs in the communities that care and treatment could prolong their lives and maintain or improve their quality of life. TASO Kampala was the only clinic in this study which had disabled clients.

This study suggests that interventions must focus on the social value of PWDs and their ability to participate in processes of reciprocal exchange in areas such as education, employment, marriage etc. These issues have to be addressed all the way from policy level to community level. This may be a way of meeting some of the underlying functions of stigma and challenge the boundaries that society creates between "normals" and "outsiders".

However, these may be seen as long-term interventions. If one seriously wants PWDs to be included in HIV/AIDS efforts, the "barrier-system" has to create a link to PWDs, their families and the rest of the community by using outreach efforts, because this study shows that fear of stigma prevents PWDs from attending HIV/AIDS services by themselves even if they know that they might be HIV positive.

It seems important to train HIV/AIDS educators, outreach workers, clinic and social staff on disability and stigma issues.