Family Planning and Reproductive Health for Persons with Disabilities (PWDs) in Uganda

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Uganda has made significant strides in improving reproductive health indicators among its youth, and is regarded as successful sub-Saharan African example of population-wide HIV prevalence reduction.

The Uganda demographic and health survey 2006 established what improvements had been made in the area of reproductive health in the previous five years:

- MMR from 505 down to 435/100,000 live birth;
- Teenage pregnancy from 31 to 25%;
- Use of family planning from 18.6 to 24.4%;
- Four and more ANC visits from 42 to 47%;
- Assistance by skilled providers during birth from 39 to 42%.

Strong government leadership, broad-based partnerships and effective public education campaigns all contributed to a decline in the number of people living with HIV & AIDS and sexual reproductive health complications.
Problem Statement

- Despite the scores, the SRH of PWDs has been overlooked by those working in this field in Uganda. This leaves PWDs among the most marginalized groups, yet they have greater needs for SRH education and due to their increased vulnerability to abuse.

- First is the frequent assumption that PWDs are not sexually active and therefore do not need SRH services.
  - Research shows however, PWDs are as sexually active (World Bank, 2004). Too often, their sexuality has been ignored and their reproductive rights denied.

- At best, most existing policies and programmes concentrate on the prevention of pregnancy but ignore the fact that many PWDs will eventually have children of their own.

- At worst, forced sterilization and forced abortion often have been imposed on persons with disabilities.

- SRH services are often inaccessible to PWDs for many reasons, including:
  - physical barriers,
  - lack of disability-related clinical services,
  - stigma and discrimination.
It is not only an issue of fundamental human rights, but a concern for the general population development:

“Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015”
James Wolfensohn, Former President of the World Bank, 2002

ACFA Uganda with support from IPPF and NGO Forum on Sexual Reproductive Health & Development, implemented a project to focus the Sexual Reproductive Health and Rights of PWDs in Uganda
Program intervention

Project focused on two main activities:

- Conducting a survey of the policy environment in Uganda in view of the sexual reproductive health of PWDs.
- Mobilizing and influencing key policy makers/stakeholders including community and local leaders to take action.
Methodology

- Study used a desk review to analyze legal documents and reports of government and Non-government actors in light of the SRH of PWDs.

- 42 key informants and 2 FGDs were conducted with participants from the line Ministries, NGOs dealing with SRH, PWDs, and others.

- Interviewees were identified predominantly through two methods:
  - through the local disabled representatives
  - through a nongovernmental organization and government departments providing sexual reproductive health or related services in the community.

- The analysis focused, among other things, on interpreting information, identifying gaps, and finally making recommendations as reported on later in this report.
Key Findings

- Uganda is fast moving away from policies and programmes that concentrated on pregnancy prevention or forced sterilization among WWDs; at the policy level at least.

- However, the most important challenge lies on the implementation: SRH services have not trickled down to the beneficiaries due to;
  - government’s laxity and lack of commitment to translate these policies into practice,
  - influence of the age-long attitudes that regard PWDs asexual.

- Major actors on SRH intentionally or unintentionally fail to appreciate PWDs as a unique community with distinctive issues and specific needs that require special interventions.

- Where PWDs were considered, some times they were given less priority.
There were stakeholders among government departments and the Civil Society that understood the SRH challenges faced by PWDs but lacked appropriate guidance and motivation into how to mainstream their needs.

A related study on Reproductive Health and HIV/AIDS by NUDIPU found that the exclusion of WWDs from reproductive health sensitization and awareness raising programmes had created a bottleneck in the national programs on HIV/AIDS (NUDIPU, 2003).

Study by World Bank and Yale University conducted in 2004 revealed that disabled people were at increased risk of acquiring sexual reproductive health complications including HIV/AIDS due to their susceptibility to physical abuse and the lack of intervention and appropriate preventive outreach.
Sexuality and disability are unconnected terrains: the reality is that PWDs are sexual beings with sexual fantasies, feelings and aspirations. They are unable to express their sexuality because of the restriction of their mobility, negative societal attitudes and the lack of educational, entertainment, social and health services and rights available to other people.

SRH programmes must involve the marginalized groups in decision making processes at all levels, and provide them with the opportunity to hold service providers and policy makers accountable for discriminatory practices, or poor quality services, in order to help redress inequalities in access to SRH services and ensure that they are acceptable and appropriate.

PWDs/DPOs are not consulted as much as mainstream health organisations. This is partly because, even within the forums for participation, they lack the skills, information or representation to have a voice amongst more powerful participants.

In order to improve the influence of marginalized groups on SRH services, legislation, policy and spending decisions at all levels; it is necessary to strengthen their capacity and of other civil society organisations concerned with SRH including women’s groups, health and human rights groups and elected representatives so they can better negotiate for their demands.
Implications/lessons Cont...

- Key terms in SRH service programme discourse are: dignity and respect, inclusion, participation, equalization of opportunities and empowerment; However, if the underlying negative attitudes and cultural representations of disability in society are not challenged through vigorous awareness-generation and attitudinal change strategies, such words will remain empty slogans.

- The provision of SRH services to PWDs has been historically slow because of an overwhelming and paralyzing misconception; outreach workers and organizers believe that the integration of PWDs into their programmes will be unattainably expensive.
Recommendations

- Health programmes must monitor and evaluate whether PWDs receive adequate and appropriate services through the establishments of indicators and benchmarks.

- Health professionals, partner organizations, and communities should undergo training or awareness-raising on how to address the SRH of PWDs.

- PWDs must enjoy their right to be treated with respect and dignity while using services.

- Improve accessibility of Health system, Facilities, and Services. Physical access to buildings and clinics as well as other indoor and outdoor facilities is crucial to PWDs.

- Budgets must be made for inclusion. Policies and programmes must be budgeted realistically if they are to make a difference.
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THANK YOU

ACFA Uganda Promotes Inclusive Policies and Practices