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## We need reproductive health services more than the rest- PWDs

**By Valerian Kkonde** PEARL NEWS SERVICE



Kasule Ronald - in wheelchair- the administrator of Access For Action Uganda, conducting computer lessons for the members at their premises in Bbamba-Kitebi, Wakiso district. Photo by Valerian Kkonde/PNS

"People with disabilities look to children as their best investment; they are the ones who will push them around in the wheel chair, as well as stand by them under all circumstances. This is how provision of sexual reproductive health services come into the picture. In fact, because we are disabled, we need these services more than any other person," observes Kasule Ronald.

Kasule Ronald is confined to his wheel chair. He is one of the living examples that render logic to the saying that disability is not inability; he is the administrator of Access for Action (ACFA) Uganda. This is a Wakiso district based NGO in Kiteezi, in the remote village of Bbamba, that strives to realize the aspirations of PWDs.

On September 25, 2008 Uganda ratified the UN Convention on Rights and Dignity of PWDs. The willingness and desire to enable PWDs lead their life to the best is clearly stated but walking the talk is conspicuously lacking.

"We appreciate the prevailing atmosphere geared toward our wellbeing, but more effort should be directed toward implementing the changes highlighted in policy." For society, PWDs are thought not to have sexual feelings. Worse still, some people wrongly believe that they possess curative remedies once engaged in sex. This not only reduces them to mere objects but exposes them to HIV/AIDS, unwanted pregnancies and STDs. Thus, they are denied an opportunity to make decisions as they struggle to share the joys of motherhood and fatherhood.

Dr. Wanyana, the Commissioner Health Reproduction- Ministry of Health- told PNS that every human being has a right to access health services when need arises. She added that what is lacking on the side of service providers is knowledge of how to effectively communicate with these people. And sign language is one of the challenges.

"Health care officials are supposed to provide services to all. Those who have a negative attitude toward PWDs simply have a problem with themselves," Wanyana observed.

"For expectant mothers with disabilities, and cannot deliver normally, we can assist them produce by applying caesarian. To ease the communication barrier, the programme is under way to teach medical officers the sign language so that they can communicate with confidence."

Dr. Wanyana pointed out that for the provision of reproductive health services to PWDs to be successful; it has to be a two-way endeavor.

"Some PWDs also have attitude problems; they have double meaning. They tend to think that they are being despised even when you are providing them with important information and services."

Bongole Rose, National Wheel Chair coordinator- Ministry of health- admits that providing reproductive health services to PWDs is a real challenge but that everything possible is being done to address this.

She revealed that it is now a hospital policy to have at least one adjustable delivery bed out of every ten in hospital.

As regards PWDs being stopped from having children, a PNS medical source said that this is often done to save the mother. The source cited cases like when the pregnancy is in the tube and could kill the mother, during instances of high blood pressure and mental disturbances.

"There are issues of human rights involved. And if the pregnancy poses no threat to the mother, then she should be free have the baby. Sometimes those caring for the PWDs look at the bringing up of the children once there is no doubt that the parents will not be in a position to meet their needs."

The source confirmed the plans to train medical officials in sign language but warned that a lot needs to be done. One reason for worry is the attitude in society, including parents, about PWDs. Many people care less about the education of PWDs.

On the issue of Braille, the source said that it is very expensive in terms of cost but that there are also many blind people who cannot read.

According to Dr. Sheila Ndyanabangi, Principal Medical Officer- Mental Health and Control of Substance Abuse- the present Health system only caters for those who come to health facilities.

"It is up to government to ensure that even the marginalized are catered for. The system does not care for those on the streets and those without any one to support them."

Doctor Ndyanabangi is however concerned at an equally dangerous situation faced by mothers, yet not taken seriously. Even medical officials do not often times realize it.

"When a mother delivers her baby, she is supposed to be happy. But trouble begins when maternity blues set in; the mother becomes unhappy, refuses to eat and to breast feed, cries and can commit suicide or kill the baby."

While post natal depression can be identified and treated, the doctor said that the work- habits of today deny us the opportunity to watch the mothers and help them before it is too late.

"Traditionally, when a mother delivered her baby, members of society would give her social support for a number of days while they also monitored her situation for any anomalies. Many people do not know about post natal depression but it is very common."

Dr. Ndyanabangi also revealed that false pregnancy is another noteworthy issue as far as reproductive healthy is concerned. She said that false pregnancy is a case faced by women with fertility problems, emphasizing that the mind and body are one but it is us human beings who try to separate them.

"These women think so much about pregnancy that they come to believe they are pregnant. They get all the signs and pains of someone who is really pregnant. Even the stomach swells and feels the "baby" turning in the stomach!"

The doctor narrated a recent case which involved operating upon a woman with a false pregnancy. She said that the doctor who was attending to the "pregnant" woman left and another took over. The doctor did not establish the status of the woman and simply kept dealing with her as one who is pregnant.

"When time for "delivery" approached, the woman was operated upon! Trouble arose as the relatives started claiming that the doctor had stolen the baby."

Ndyanabangi however said that this situation can be over come by using the Ultra Sound Scan. She said that these machines are readily available country wide, even in Health Centers IV.

"But even without the Ultra Sound it is still possible to determine whether the pregnancy is for real or false. But most important it is always safer to refer pregnancies to referral hospitals."

The demographic health survey, 2006, indicated that 41% of all women in the reproductive age group do not have access to family planning. Reasons for this include: the negative attitude, limited supplies, lack of trained providers, long distances to health facilities and inaccurate information about the available methods.

On the provision of mobility to persons with movement challenges, Bongole Rose said that a wheelchair is vital in equalization of opportunities because it promotes personal mobility, which is an essential requirement to participating in many areas of social life.

"Without wheelchairs, these individuals are unable to participate in those mainstream developmental initiatives like education, employment and strategies that are targeting the poor. They cannot even go to hospital."

It is estimated that 1.5 million people in Uganda need wheelchairs. The number of wheelchair users in Uganda is increasing due to increase in number of road accidents. However the number of children with disabilities who need wheelchairs is usually underestimated because some parents hide them away.

Pointing out that inappropriate wheelchairs cause secondary disabilities, Bongole said that "an appropriate wheelchair has to meet the user's needs and environmental conditions, provides proper fit and postural support, is safe and durable.

Bongole said that this comes about because they were not assessed.

"In Uganda, only 1% of people who need wheelchairs own or have access to one. This is caused by the high cost of production of the wheelchairs, the raw materials are usually imported and the production equipment is expensive. The majority of people who need wheelchairs are poor thus cannot afford them, they lack the purchasing power."

A number of associations come up, and many more are cropping up, claiming to be championing the cause of PWDs. Their relevance in terms of promoting the interests of the members leaves much to be desired.

Were leaders of these associations for the PWDs to be well intentioned, there would be mobile clinics for them and many would be leading far more dignified lives than they do. PWDs would also be at the fore front of helping their colleagues, but even the associations have failed to put to use these talents.

When PNS contacted the National Union of Disabled Persons of Uganda- Program Officer HIV/AIDS, Babu- he refused to divulge any information and terminated the call. It was the same story with Kayemba Richard the Program officer, National Union of Women with Disabilities in Uganda.

Kasule reasons that it makes no sense for government to claim to be concerned about PWDs but does not empower them to access the services and programs.

"All this proves the deplorable state of the practical experience. We have a very rich policy environment right from the constitution, the National Council of Disability, the Act on Disability and the UN Convention on Rights and Dignity of PWDs. But if development is skewed towards a few, then our philosophy of development for all is empty."

He goes on to argue that once the agent of change is considered as foreigner or outsider, then nothing is bound to change.

"We need to change the mindset of doctors and the society to appreciate the fact that PWDs too have sexual desires. PWDs are not asexual. That is why they need the reproductive health services so that they can properly plan their families."

To the PWDs, Kasule advises that it is the time to take the initiative and be open so as to bring about the desired change. This involves being presentable, the urge to learn and the readiness to take on the challenges that come one's way without seeking favours. And Uganda being a free market economy, PWDs should just put to use the policy environment in place, dust their talents and make use of every opportunity that avails itself.

Admitting that it is an uphill task to change the mindset of society, Kasule says that it is quite possible, looking at the challenges he encounters as the administrator at Access for Action Uganda. Without personal and reliable means of transport, he is able to leave the remote Bbamba village- home of ACFA Uganda and champion the cause of the PWDs and non disabled alike.

"This is no one man's role; civil society, government, development partners, individuals and PWDs themselves must join hands to fight the negative attitude. We definitely need to collaborate," Kasule emphasizes.