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Let's Talk: Sex and Sexuality Rights and Resources for Deaf Women in Africa

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Musimbi Kanyoro writes:

"In many ways, African women bear the brunt of AIDS. They are economically marginal. Those who develop AIDS are scapegoated and often thrown out of their family structures. As society's caregivers, women carry the social, psychological, and physical burden of AIDS."¹

According to Standing and Kisekka,

"[I]n situations of deepening economic crisis which disproportionately affect women as provider, no AIDS prevention programme can afford to ignore the socio-economic aspects of sexual behaviour or operate in isolation of the need for action on poverty and gender inequality."²

This perception is echoed by Vicci Tallis, who argues that "traditional human rights approaches are based on a male norm and women's rights are not always seen as human rights."³ Tallis further comments that "gender inequality is perhaps the main problem area impeding HIV/AIDS prevention."⁴ This is most clearly illustrated in the African context, where the prevalence of HIV/AIDS amongst younger women between the ages of 15 and 30 is indicative of "the strong patriarchal character of traditional African society in which young unmarried women have little defence against sexual advances from older, more powerful men."⁵ This lack of defence is related to the persistence in Africa of the belief that "AIDS does not affect young women or children, so older men, fearful of infection, seek out young girls as sexual partners."⁶ Myths such as that which suggests that an infected man can get rid of his HIV infection through sexual intercourse with a virgin are also responsible for the escalation of HIV infection amongst younger African women. More generally, the most significant factors contributing to the high rate of HIV infection among African women are:

- (1) the inferior role of women in African society,
 - (2) misconceptions concerning the use of condoms and an unwillingness by men in particular to use condoms in sexual intercourse,
 - (3) a tendency for several sexual partners, with polygamy still being a central part of African culture,
- and, above all,
- (4) a lack of understanding of what HIV/AIDS is and how the disease is spread.

¹ Kanyoro, p. 25

² Seidel, citing Stander & Kisekka, p. 178

³ Tallis, p. 59

⁴ Tallis, p. 59

⁵ Saayman (1992), p. 51

⁶ Kanyoro, p. 25

All of this is not only equally true for Deaf African women, but even more significantly so. Not only do they have to endure the same gender and sexual inequalities as hearing African women, but their inability to hear puts them at a distinct disadvantage in communicating their sexual and gender wants or needs. Given an unwillingness in the hearing community to engage in Sign Language or other communication skills that people with hearing loss will benefit from, Deaf African women invariably have limited access to knowledge concerning their sexual and gender rights. Deaf African women are especially marginalised, and it is incumbent on the hearing world to change their attitudes, and begin treating Deaf women with respect and dignity, as sexual and gender equals, with the right to equal access to information pertaining to HIV/AIDS, and the right to choose how they wish to engage, or not engage, in sex, and how they wish to project their own sexuality.

Cultural traditions and beliefs play a definitive role in any focus on issues related to HIV/AIDS and hence sexual behaviour. In traditional African culture, condom usage is viewed suspiciously, being "associated with casual sex," and insistence on it is usually "interpreted as a sign of mistrust."⁷ Encouraging condom usage is further believed to "advocate lower morals in young people and result in sexual promiscuity."⁸ In that African women are expected to assume passively submissive roles in sexual activity, having been "socialized to yield sexual decision-making to men,"⁹ and in that it is therefore considered taboo for an African woman to raise the issue of condom usage, even when she knows that her partner is having an affair or is infected with HIV, the fact that HIV is dominant particularly amongst African women is not surprising. Communication between partners is critical if errant sexual behaviour is to change. There has to be a willingness from both the Deaf and the hearing communities to find ways of enabling effective, accurate, and compassionate communication on issues of sex and sexuality, and sexual expression. In this regard, it needs to be understood that empowering women in Africa to protect themselves from HIV/AIDS depends on educating not only women - but, primarily, men. Giving Deaf Women in Africa a voice thus depends on enabling men to be open to hearing them.

However, the perceived need to empower Deaf African women, both individually and as a group, needs to be weighed against respect for the deep-rooted significance of traditional cultural beliefs and practices, and the reverence in which these are held. It is therefore imperative that those involved in HIV/AIDS prevention in a multicultural context approach their task with sensitivity to issues of cultural pluralism and respect for specific cultural norms, with it being important in this regard to remember that cultural traditions and practices "are only indirectly responsible for the transmission of the virus." 'Social-engineering' in the form of attempting to alter, or even eradicate, those cultural beliefs and practices which to the outsider appear to be contributory factors in the spread of HIV, can at best be seen as "unethical". In order to facilitate co-operation by tradition-bound communities, the emphasis in HIV/AIDS prevention strategies should thus be on attempting "to make cultural practices safer, rather than to eradicate them".¹⁰

In order to start addressing these issues, the National Institute for the Deaf in Worcester, South Africa, hosted an international HIV/AIDS training conference in October 2005,

⁷ Gausset, p. 514

⁸ Kanyoro, p. 24

⁹ Schoofs, p. 6

¹⁰ Gausset, p. 517

as one of many pre-conferences to the 3rd Mental Health and Deafness World Congress that was held in Worcester that year. At this pre-conference, Sign Language was emphasised as needing to be an integral part of HIV/AIDS education for Deaf people. Access to information was noted as an especially crucial area that needed attention. The conference recommended establishing an HIV/AIDS resource centre. Members of the conference called on education, health and social services to "work closely together to ensure equitability, accessibility, appropriateness and availability of HIV/AIDS education, prevention, counselling and treatment programmes."¹¹ Programmes that empowered "parents and families with knowledge and skills to equip their children with life skills, norms, values, inner security and information regarding sexuality and sexual behaviour in order to maintain a healthy lifestyle and cope with peer pressure"¹² were encouraged.

All of these recommendations point to the very real need for a Special Interest Group on HIV/AIDS to be established. The purpose of such a group would be to explore practical ways of conducting research into concerns around HIV/AIDS amongst Deaf women in Africa, and educating Deaf women in Africa on all manner of issues pertaining to HIV/AIDS and the associated issues of sex and sexuality. Perhaps there should be several such Interest Groups, catering for the full spectrum of socio-cultural, political and religious needs. If this is to be the way forward, then I would like to propose that the faith communities should be approached and included as a vital resource for destigmatising HIV/AIDS, and assisting Deaf women in Africa to become educated and empowered within their communities with respect to the HIV/AIDS pandemic.

While it is imperative that they rise to this challenge, research illustrates the enormity of the challenge that the church and other faith communities face.

Geeta Rao Gupta, speaking at a plenary session on *HIV/Aids in Africa: What Works* (2003), lists the following statistics on the prevalence of HIV/AIDS in Africa:

29.4 million people live with HIV/AIDS, of which more than half are women;
 10 million are young people between the ages of 15 and 24;
 almost 3 million are children under 15;
 in 2001, of all young women aged 15 to 24, an estimated 6 to 11 percent were living with HIV/AIDS, compared to 3 to 6 percent of young men;
 AIDS has orphaned 13.4 million children;
 the prevalence of HIV is 38% in Botswana, and 33% in Zimbabwe and Swaziland.

While statistics are not always accurate, the health profession nevertheless places a strong emphasis on them, with most of what is known in both the medical and the public domain about the severity of the HIV/AIDS pandemic derived from an analysis of the available statistics. Given their shock value, statistics can also have a far greater impact on attitudes and in terms of affecting social behaviour than any number of discussions and workshops. While statistics thus need to be faced, Anglican Archbishop Njongonkulu Ndungane argues that the church is called on

¹¹ NID Report, p. 1

¹² NID Report, p. 1

"to measure HIV/AIDS in human terms rather than only in statistics. ... until and unless we begin to measure the pandemic in terms of broken hearts, orphans, fear, loneliness, pain and grief, we will not adequately respond to a disease which is impacting on all humanity."¹³

Ndungane goes on to emphasise the need for the church to "reach out with compassion to those with HIV/AIDS" and for "the inter-faith community to join forces in the exercise of our caring ministry". In this regard, he points to the fact that "caring involves a broad spectrum of activities ranging from public pressure for affordable drugs to simply welcoming people who live with HIV/AIDS into our lives."¹⁴

Gill Seidel argues that "Respect for human rights and the dignity of persons with HIV or AIDS is an essential condition for effective AIDS intervention."¹⁵ Welcoming HIV-positive people into our communities, and treating such people with respect for their dignity, is perhaps not only the most appropriate, but possibly also the most effective, method of combating HIV/AIDS, in that it enables the afflicted to "come forward for information, counselling and treatment." In contrast, as Seidel points out, "discrimination hampers ... efforts to implement effective prevention and care programmes."¹⁶ The Christian community has the example of Jesus Christ, whose response to those suffering from leprosy exemplifies the way in which those infected with HIV ought to be treated. Willem Saayman argues that Jesus's response to lepers was contrary "to all the established social, religious and cultural norms of his day." In the same way, then, "we will have to reach out and *physically* comfort those suffering from this terrible sexually transmitted disease."¹⁷ The Church has already begun to take this initiative through its rendering of "a variety of humanitarian services ranging from counselling and home based care to responding to the needs of children orphaned as a result of HIV/AIDS."¹⁸

The Church nevertheless needs to respond to the HIV/AIDS pandemic "not just as a health problem but as a social force which devastates families, increases poverty and threatens our economy." As such it is challenged to grasp "the opportunity in this terrible epidemic ... to reinfuse society with a spirit of social integrity, ... to rebuild a sense of community where people demonstrate that they really do care for each other in a real and practical way."¹⁹ Inherent in this challenge is a call for the church to promote "an inclusive understanding of human rights"²⁰ which acknowledges the interdependence between respect for the values of human dignity, equality and freedom and the promotion of socio-economic rights. After all, as Tinyiko Maluleke says, "while we in the Church may *not* all be *infected*, we all *can* be infected and ... we certainly are all *affected*!"²¹

Given that ill health may be related to social problems such as the lack of sufficient or suitable sanitation, unhygienic living conditions, general poverty especially in the rural areas, and insufficient access to basic health necessities such as food, water, clothing

¹³ Ndungane, p. 11

¹⁴ Ndungane, pp.11-13

¹⁵ Seidel, p. 182

¹⁶ Seidel, p. 182

¹⁷ Saayman (1999), p. 218

¹⁸ Germond, p. 4

¹⁹ Commin, quoting Bishop Philip Rubin, p. 2

²⁰ Villa-Vicencio, p. 12

²¹ Maluleke, p. 91

and shelter - and in that inequality in such regards is a reality affecting the vast majority of South Africans, whose health problems may be directly attributable to the preferential treatment accorded certain racial groups over others under the apartheid regime - it becomes clear that "health" is indeed a critical human right's issue, and that measures ought to be taken to allow for greater equality regarding access to health care, and thus to promote the attainment of total health for all. The aim of those involved in health care should always remain to provide the highest possible standard of health care for all people at all times, irrespective of a person's social circumstances, disabilities, or nature and degree of illness.

For Deaf women in Africa, this so-called human rights ethic remains elusive. Young adolescent girls in Africa are often forced into sexual relationships with older men, who expect them to behave in ways that negate, if not destroy, their own innate sense of sexuality and sexual freedoms. Women and girls are under threat of being seen as promiscuous if they know about sex, and it is regarded as taboo for women to speak openly about sexual matters.

Contraception and female circumcision are two controversial issues in the discourse on African female sexuality. Ifi Amadiume engages with these issues in her paper entitled *Sexuality, African Religio-Cultural Traditions and Modernity: Expanding the Lens*. She writes that:

"Some might argue that instead of instilling fear of sex in young girls, [African society] should have developed the use of contraceptives. ... [T]he health problems associated with contraceptive use suggest that modernity has not treated women's bodies any better. Certainly, some use contraceptives by choice, but women are also forced to use contraception for population control."²²

The ramifications for Deaf women in Africa are obvious.

Regarding female genital circumcision, Amadiume writes:

"Any form of touching or cutting women's private parts with the knife as we now know is harmful and unnecessary. In modern times many women undergo episiotomy for childbirth and are sewn up again. This practice whereby women are cut by male gynaecologists has raised a lot of political questions just like the cutting practices of traditional midwives. At all times and in all cultures there has been a lot of meddling with and fighting over women's sexual and reproductive organs. The advance of capitalism has also seen the intensification of strategies and efforts to control woman herself in both body and mind."²³

This all points, again, to the need for Deaf women in Africa to be empowered, through being equipped with knowledge concerning their basic human rights and the facts about HIV/AIDS. The United Nations published a Declaration in June 2001 that speaks of optimism and hope. A UN General Assembly Special Session on HIV/AIDS adopted a

²² Amadiume, p. 4

²³ Amadiume, p. 6

*Declaration of Commitment on HIV/Aids.*²⁴ This Declaration says, in Article 53, that the UN must, and I quote:

"By 2005, ensure that at least 90 per cent, and by 2010 at least 95 per cent of young men and women aged 15 to 24 have access to the information, education, including peer education and youth-specific HIV education, and services necessary to develop the life skills required to reduce their vulnerability to HIV infection, in full partnership with young persons, parents, families, educators and health-care providers."

Article 60 of the UN Declaration states that, by 2005, the UN must

"implement measures to increase capacities of women and adolescent girls to protect themselves from the risk of HIV infection, principally through the provision of health care and health services, including for sexual and reproductive health, and through prevention education that promotes gender equality within a culturally and gender-sensitive framework."

While these ideals and hopes are indeed admirable, the stark reality for Deaf women in Africa suggests that the ideals of the UN may be over-optimistic. For example, Deaf women in Africa are afraid to be tested for HIV. The consequences of taking an HIV test are often severe. Apart from fear and anxiety in the face of impending illness and ultimate death, the infected Deaf woman suffers the risk of having her support structures, in the form of career, family and friends, collapsing, which in many ways is often more devastating than the knowledge that one is infected. In this regard, the Church too is at fault, in so far as it has not only largely failed to "assure people with HIV/AIDS that they are welcome in their congregation," but has tended to purvey a judgmental stance towards extra-marital sexuality and related issues. Consequently, many people feel that "it is better *not* to know and *not* to be tested."²⁵ For many it is thus not merely a question of whether it is necessary to take the HIV test, but rather whether the possible social consequences of a positive result are worth the benefits of knowing one's serostatus.

In some countries, the stigma attached to an HIV-positive serostatus is such that, because there is usually nothing that can be done to treat the disease, doctors avoid informing their patients of positive results in HIV tests.²⁶ Assuming that the doctor has, in fact, informed the Deaf woman of her positive serostatus, unless steps were taken to counter communication challenges, one cannot assume that the Deaf woman will have accurately understood what she was being told. If the communication is not considerate of the needs of the Deaf woman, the doctor takes the risk that the infected Deaf woman may persist in unsafe sexual practises, which not only puts her at risk of having her HIV infection convert more rapidly to full-blown AIDS, but also puts others at risk of contracting the HIVirus.

The church and other faith communities can play a pivotal role in helping to overcome the particular vulnerability of Deaf women in Africa in relation to HIV/AIDS and promote their well-being. The notion of the localised congregation gives sense and

²⁴ UNAIDS Inter-Agency Task Team on Gender and HIV/AIDS, p. 2

²⁵ Memela & Cochrane, p. 7

²⁶ Panos Dossier, p. 46

structure to the element of spirituality as an essential component of total health. Gary Gunderson has outlined eight "strengths" of the congregation which he regards as underlining the crucial role of the religious community in enhancing health:

- * the strength to *accompany*, to be present in the lives of other people;
- * the strength to *convene* ... interests ... around specific problems or opportunities;
- * the strength to *connect* people to resources;
- * the power to *frame*, providing a framework of meaning around experience and data;
- * the power of *sanctuary*, providing a safe place to gather;
- * the power to *bless*, to sanction ... ;
- * the power to *pray*, to find meaning between the holy and the human;
- * [the capacity to] *persist* - they have a long time span, memory, and hope.²⁷

These eight "basic strengths of congregations" individually and collectively demonstrate the capacity of the church and other faith communities to "build community"²⁸ of an inclusive kind by integrating the role and experience of the infected Deaf woman with the overall continuity and life of the community as a whole. In their emphasis on the interdependence of the well-being of the individual and that of the whole, these "congregational strengths" exemplify the ethos of a human rights culture in action. Along with empowering Deaf women in Africa infected with the HIVirus both to continue contributing to the life of their communities and to be socially and spiritually sustained by them, community support gives concrete expression to the principle that "No-one should care alone and no-one should die alone."²⁹

Once diagnosed as HIV-positive, Deaf women will require, along with emotional and spiritual support, a substantial amount of health care and medical attention. HIV/AIDS Clinics provide access to counselling and medication, but financial constraints have largely limited access to hospital facilities, especially access to in-patient facilities such as beds and constant supervision from qualified health professionals. As such, the family unit has had to assume a critical role in health care, providing those infected with ongoing emotional support, physical care and treatment supervision throughout the duration of the illness and, in the case of HIV/AIDS patients, right up until the point of death.

The family physician has the capacity to influence the quality of health care that the Deaf HIV-positive woman receives from her family as the primary caregivers. By interacting with the family, the family physician is able to determine what the factors are that will influence the quality of health care given to the Deaf infected woman, and whether certain outside influences ought to be considered and possibly addressed when determining the correct course of action for treating her. While it is of unquestionable importance for the health professional to be certain of the biomedical aspects of the HIV-positive woman's physical condition, in order to prescribe the correct medication and suggest the most suitable health interventions, the benefits of the biomedical approach will be largely diminished if cognisance is not taken of the equally relevant "fears and feelings" of the infected woman. For Deaf women this will, of course, pose a

²⁷ Gunderson (1999), p. 8 & Gunderson (2001), p. 223

²⁸ Giljam, quoting Karpf, p. 6

²⁹ Giljam, quoting Karpf, p. 6

significant dilemma. The vast majority of medical practitioners have no understanding of Sign Language, and have limited exposure to Deaf people. Unless the physician is trained in Sign Language, or has a qualified interpreter present, the physician will not be in a position to accurately "hear" what the Deaf woman is saying. Furthermore, the physician will be unable to appropriately advise the family or other such caregiver, nor will he or she be in a position to assist the Deaf HIV-positive woman to sustain the highest possible level of total health. The need for an interpreter to mediate between doctor and patient also, of course, not only compromises the ethics of confidentiality and privacy, and the patient's rights in this regard, but may inhibit disclosure on her part of necessary information, and as such compromise appropriate intervention.

Perhaps the greater challenge is to attempt to eradicate the stigma attached to being HIV-positive. Both hearing and Deaf women in Africa living with HIV and AIDS should be reminded that their seropositivity does not signify an end to their productive lives, but rather a new beginning. They can, and should, continue playing active roles within their communities. Their communities should make it possible for them to do so. Those who are not infected with HIV need to be educated about the disease, as having the correct information will contribute significantly to removing the stigma of HIV and AIDS. Misinformation, largely in the form of myths concerning the ways in which the HIVirus can be contracted, need to be dispelled, as such myths contribute to such inhumane suggestions as that calling for all HIV-positive people to be placed in "isolation or quarantine."³⁰

Deaf HIV-positive women in Africa have an especially heavy burden to bear. Part of destigmatising HIV/AIDS is, however, to remember that, while acknowledging the enormous challenges faced every day by Deaf women in Africa, the fact is that HIV/AIDS affects all people, and does not differentiate. It is thus incumbent upon us all, in demonstrating care, to echo the words of the World Council of Churches, to "share the sufferings of those living with HIV/AIDS, opening ourselves in this encounter to our own vulnerability and mortality."³¹

³⁰ Seidel, p. 182

³¹ WCC Report, p. 35

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