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Exploring Perceptions of Deaf Persons for Recommendations towards Effective HIV/AIDS Programming in Nairobi

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Deafness as a Difference in Human Experience: Cultural Recognition and Social Participation Support

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See table of contents

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Article abstract

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Conclusions: It is recommended that Deaf persons are empowered and involved in the development of learning materials to suit their unique needs, and create a sense of ownership of future education, treatment, care and support programs.

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Abstract

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Keywords : HIV and AIDS, Deaf, disability, Deaf VCT, Nairobi, Kenya, Africa

Résumé

But : Examiner les obstacles rencontrés, par exemple ceux reliés à la communication, par les personnes Sourdes habitant les agglomérations précaires entourant Nairobi dans leur quête de services liés à l'information et au traitement du VIH et du sida.

Méthodologie : À la suite d'une recension des écrits et de la tenue d'une rencontre de consultation avec *Deaf Empowerment Kenya*, deux groupes de discussion composés de membres des communautés Sourdes locales ont eu lieu. Un questionnaire quantitatif a ensuite été conçu et administré à 32 personnes Sourdes des quartiers de Dandora, Haruma et Kayole.

Résultats : Malgré le petit nombre de personnes Sourdes ayant répondu au questionnaire, les données récoltées permettent de mieux comprendre leurs perceptions du VIH et du sida. Elles ont mentionné que la programmation des activités de sensibilisation devrait se poursuivre en langue des signes kényane, première langue de cette communauté Sourde. Les personnes Sourdes ont proposé la tenue de séminaires avec interprétariat simultané ou conférenciers Sourds, la promotion de programmes de conseil et de dépistage volontaire offerts en langue des signes kényane et l'emploi de vidéos éducatives mettant en vedette des personnes Sourdes. Elles ont finalement indiqué que la documentation écrite devait compléter les apprentissages réalisés lors des séminaires et du visionnement des vidéos ainsi que comprendre des illustrations : l'information écrite ne leur apparaissait pas être suffisante.

Conclusions : Il est recommandé d'impliquer et de faire participer les personnes Sourdes dans le cadre de l'élaboration du matériel pédagogique produit à leur intention, et ce, afin qu'il réponde davantage à leurs besoins particuliers. Une telle collaboration les amène à développer un sentiment d'appartenance face aux programmes d'éducation, de traitements, de soins et de soutien leur étant proposés.

Mots-clés : VIH et SIDA, Sourd, déficience, programmes de conseil et dépistage volontaire pour les Sourds, Nairobi, Kenya, Afrique

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Introduction

According to the Kenya National Survey for Persons with Disabilities (NCAPD, 2008), about 4.6 percent of Kenyans experience some form of disability, and about 0.5 percent of Kenyans have some type of hearing impairment. This translates into approximately 195 000 deaf or hearing impaired Kenyans, given a general population of 39 million (CIA, 2009), and persons with hearing impairments make up 11 percent of the disabled population. These estimates are believed to be low, as the World Health Organization estimates persons with disabilities represent about 10 percent of the world's population, and of these 80 percent live in developing countries (Groce, 2004 : 3). Kenya's forthcoming national census results are expected to convey a more accurate figure as to how many persons with hearing impairment are living in Kenya. Acquired deafness in Kenya is largely due to preventable causes, such as childhood middle ear infections, malaria, meningitis and the use of autotoxic antibiotics (Taegtmeyer, 2008; WHO, 2009; Smith et al., 1996). Throughout Kenya, there are registered associations of the Deaf in all major cities and many municipalities, and there are 41 registered schools for the Deaf in Kenya.

The Deaf community in Kenya is comprised of shared residential school experiences, Deaf churches and social networks, based on a common language and shared values. Since most Deaf persons in Kenya are born into hearing families, they face many barriers in communicating with parents and siblings. Reading and writing in English is taught formally in schools for the Deaf, while Swahili and at least one other "mother-tongue" language is typically spoken at home, making it difficult to learn to lip-read more than a few basic words. As is common in other Deaf cultures around the world, the Deaf community in Kenya becomes a second family to Deaf people. The close-knit nature of the Deaf community, commonly referred to as the deaf 'grapevine' can make confidentiality, necessary to HIV testing, difficult to maintain (Gaskin : 1999, 76). Many Deaf persons experience feelings of distrust and dissatisfaction towards the health care system at large, and are consequently more reluctant than their hearing counterparts to seek testing and treatment services (Mallinson, 2004). According to the Kenya AIDS Indicator Survey (KAIS) (NASCP, 2007) there is an overall HIV prevalence rate of 7.4 percent in Kenya. Nairobi province has the second-highest prevalence rate, at nine percent, exceeded only by Nyanza province, at 15.3 percent. KAIS 2007 also revealed that as many as four out of five HIV-infected persons between the ages of 15-64 in Kenya do not know their status. Given that many Deaf persons are reluctant to go for testing, the number of Deaf persons who are HIV positive and are unaware could be the same or higher than the general population.

A combination of the aforementioned factors, along with lower literacy rates - since English is a second language for most Deaf Kenyans, after KSL- and a tendency of Deaf persons to have more than one sexual partner at a time (Nyang'aya, 1998) have coalesced to leave Deaf persons more vulnerable to HIV infection. Due to the close-knit and relatively small population, most Deaf adults in a particular town or region know one another. Research participants for this study were drawn from three urban slum communities, Dandora, Kayole and Huruma, outside of Nairobi centre, all of which are known to have a high concentration of Deaf persons. These communities are characterized by high rates of poverty and unemployment; low literacy rates and limited resources for primary school education; under-resourced medical clinics; polluted environments; contaminated water resources; poor sanitation; and a lack of accessible housing and transportation. Despite these conditions, it is common for Deaf persons in Kenya to migrate from rural areas to urban centers where there are known to be many other Deaf persons, out of a desire to connect with a community where they can use their own native language - KSL- and develop strong social support networks through shared experiences. Behavioural norms and values, unique to the Deaf community, develop as a result of these social settings. Deaf persons have lacked guidance from parents and teachers who do not communicate well in their

language, and consequently they have developed a lifestyle that allows for free sexual interactions. Many marriages are unofficial and short-lived and the divorcees soon get attached to other partners from within the community. This type of lifestyle greatly increases the risk of HIV infection among Deaf persons (Ibid, p. 20).

The objective of this research was to generate a baseline survey of Deaf Kenyans' awareness, attitudes and behaviours related to HIV transmission, and accessibility of treatment and care services. The specific objectives of the research were as follows :

- To assess barriers encountered by Deaf persons, such as language, in obtaining information and treatment services related to HIV and AIDS;
- To gain insight into the avenues by which the Deaf community in Kenya is learning about HIV, and their perception of the best means by which to do so;
- To explore sexual and high-risk behaviours within the Deaf community, thus assessing vulnerability to HIV infection;
- To investigate attitudes and knowledge about living positively;
- To inform the development of and enhancement of existing HIV and AIDS awareness, treatment, care and support programming targeted at Deaf populations in slum regions.

Prior to undertaking any research with human subjects, ethical clearance was obtained from the University of Ottawa's Social Science and Humanities Research Ethics Board (SSHREB). Informed consent was garnered from all participants, confidentiality of participants and anonymity of all responses was maintained at all times. Upon completion of all 32 questionnaires, participants were compensated with a complementary meal and social gathering on World AIDS Day.

A review of literature was conducted prior to the development of the questionnaire. Drawing on the aforementioned surveys and questionnaires administered to Deaf populations in Kenya and elsewhere, and the difficulties associated with administering questionnaires in Sign Language, a new questionnaire was developed, ensuring a more comprehensive understanding of the awareness of HIV and AIDS among Deaf persons, and the accessibility of related educational, treatment and care services. The questionnaire covered nine themes, including demographic information; education; involvement with the Deaf community; access to and perceptions of health services; education on reproductive health, sexually transmitted infections (STIs) and HIV; knowledge of HIV transmission; attitudes and knowledge about persons living with HIV and AIDS (PLWHAs); sexual and high-risk behaviours; and access to HIV testing and anti-retrovirals (ARVs).

Prior to conducting focus-group discussions, a draft of the questionnaire was reviewed with a Kenyan Sign Language interpreter, with over five years of interpreting experience, trained in confidentiality, and a Deaf person, who's native language is American Sign Language (ASL), but is also fluent in English and KSL.[1] Some questions were adapted to suit the Kenyan cultural context, ordering of words and terminology were adjusted for ease of translation.

Subsequent to the review, two focus group discussions were conducted in Dandora, one with a group of four Deaf women, and another with three Deaf men. Participants were drawn from a snow-ball sampling, utilizing social networks based out of Deaf Empowerment Kenya. The participants were asked not to answer the questions personally, but to articulate their comprehension of the question, possible answers, and perceived difficulties other Deaf persons may have in answering the questions. In some instances, questions were added or

[1] The questionnaire was written in English (For a complete list of questions, see **Appendix 1**). It should be emphasized that KSL cannot be directly translated into English and vice-versa. Therefore, the interviews were administered by the author with a KSL interpreter, and the spirit of the questions was maintained at all times, with further illustrative examples offered to facilitate understanding of the question.

clarified, and possible responses for closed-ended questions were modified or added.

The questionnaire was revised based on the input of the two focus groups, and two pilot interviews were conducted, one with a woman and the other with a man. Based on the answers from the pilot interviews and any difficulties encountered with Kenyan Sign Language interpretation, the questionnaires were revised and finalized. The questionnaire consisted of 55 closed and open-ended questions, and participants were allowed to decline answering any questions if they so wished.

Early on in the one-on-one administration of the questionnaire, it became apparent that some of the questions were provoking a sense of hostility from the participants towards the researcher and the interpreter. For example, question 20, "If you have sex with someone who has HIV and AIDS, without using a condom, can you get HIV and AIDS?" was understood by participants in an accusatory manner, as if to imply that the participant would do such a thing, instead of as a hypothetical question, as it was intended. The interpreter and the researcher agreed to modify how the question was asked, to illustrate a hypothetical story, rather than super-impose the interview participant into the scenario. To 'gloss' (write) how the question was asked in KSL, Interpreter: IMAGINE ONLY, TRUE STORY: NO. IMAGINE (References Left : interviewer) *J-Sign Name* HIV POSITIVE. (References Self) *D – Sign Name* HIV NEGATIVE. IMAGINE THESE TWO HAVE SEX. CONDOM, NOTHING, SKIN TO SKIN. POSSIBLE *D-Sign Name* BECOME HIV POSITIVE? Upon making these changes to how the question was asked, while maintaining the spirit of the question, it was obvious the Deaf participants understood what was being asked of them, and they were able to articulate their answers with more confidence and clarity. Another challenge posed to the interview process was determining the age of some of the younger participants. With most of the participants, it was clear they were 18 years of age or older, and most knew their year of birth. However, there were several participants who were unsure. In these cases the interpreter would try to determine when the participant started school, or graduated, and calculate their approximate age from these milestones. There was one recruited Deaf woman that was not able to participate, as the information she provided suggested she was not yet 18 years old, the age of consent granted for participants by the SSHREB. So as not to make her feel excluded, the researcher asked the woman a few basic questions about herself, such as place of residence and when she started school, and invited her to the "thank you" gathering on World AIDS Day, but did not include her questionnaire in the tabulated results.

A total of 32 individual interviews were conducted over a period of 15 days. All participants were between the ages of 18 and 50, comprised of 15 men and 17 women, from communities in Dandora, Kayole and Huruma. Participants were recruited on a voluntary basis, through the snow-balling technique, drawing on existing social networks from Deaf Empowerment Kenya. The results of the interviews were transcribed into Minitab, a data analysis software program, to generate queries across more than one category of question. For example, Minitab enabled the comparison of responses about HIV transmission between various groupings of participants, such as gender and different residential communities.

The results of the interviews are meant to inform the development and enhancement of existing HIV and AIDS awareness, treatment, care and support programming targeted at Deaf populations in slum regions. The results are presented below, and include analysis and recommendations for future programming, based on the sample data.

Demographics of Participant Group

Most of the Deaf interviewees were from hearing families, and most relied on speaking and lip reading, and/or the use of the local language to communicate with their hearing family members. The majority of Deaf persons' families do not know KSL, meaning important socialization on issues such as sexuality and high

risk behavior can be lost when only communicated in an oral language, leaving Deaf persons more vulnerable than their hearing siblings.

Only one-quarter of the Deaf population interviewed have work in the formal sector, while the remainder are either employed informally, looking for work, unemployed or volunteering. While this survey did not collect information on net-household income, it is reasonable to expect that the majority of those interviewed are from low-income households. HIV-infection would therefore put a significant strain on household resources, as it could lead to increased medical bills and reduced financial contributions, even through informal means, due to illness.

Seven participants were between the ages of 18 and 28 (22%); 16 were between 29 and 39 (50%); and nine were between 40 and 50 (28%). All of the participants' parents are hearing, and only three have other family members who are Deaf (9%). 21 (65%) of the participants indicated they have children, all of whom are hearing, and 11 (35%) were child-less.

Speaking and lip reading (6; 18%) was the means most commonly used by the participants to communicate with their families. The second most common means of communication was a combination of speaking and lip reading and the local language (5; 16%). The third most common means was gestures (Four; 13%), tied with a combination of speaking and lip reading and some KSL (4; 13%). Only two participants (6%) indicated KSL as their exclusive means of communication, and interestingly, neither indicated they had other Deaf family members (those with other Deaf family members indicated they use KSL, in combination with lip reading or gestures). Four (13%) participants indicated communicating at home via KSL, in combination with speaking and lip reading, local language and/or gestures. The remaining seven (22%) participants relied on some combination of gestures, writing, and/or speaking and lip reading and/or a communication system developed by the family. This suggests that the majority of Deaf persons' families does not know KSL, and therefore are not able to communicate complex messages with their children. This can have very important implications for providing guidance on issues related to sexual and high-risk behavior, as Deaf persons often miss out on the passing down of familial and socio-cultural values that are not communicated in a language they fully understand.

Fourteen (44%) of the participants are employed in the informal sector, or self-employed, for example, selling fruits, washing clothes, tailoring, or carrying water. Eight (25%) participants are working in the formal sector, for example working as a butcher, hotel services, or at a local company. Six (18%) are unemployed; three (9%) are looking for work; while one (3%) is volunteering. All participants were recruited within the Nairobi suburbs, with four men and six women from Dandora; one man from Bab'dogo; one woman from Nyeri; five men and five women from Kayole; and five men and five women from Huruma.

Education

The majority of the Deaf persons interviewed had basic education, and some technical skills intended to help them find employment. Given their educational background, highly sophisticated and technical language cannot be applied by most Deaf persons in a professional context. It is appropriate for HIV program interventions targeting Deaf populations to be delivered via school campuses and technical training centers, as most Deaf people attend these institutions. The intervention would therefore reach a wider audience.

Involvement with the Deaf Community

Approximately one third of those interviewed were members of a Deaf community group. However when asked how they communicate with other Deaf persons when not face-to-face, nearly half of all participants stated they do not communicate when separated by distance. Given these two trends, it is worth noting there are several structured or semi-structured avenues, outside of educational institutions,

through which Deaf persons can be reached, such as churches, social groups and sports teams. It should be emphasized that Deaf persons seldom rely on text-based modes of communication (short message service [SMS, also known as text messaging], letter, email), and prefer to communicate face-to-face. Therefore during any Deaf community engagement activity, written materials should only be supplementary to live, visual-gestural communication, whether through a facilitator skilled in KSL or an interpreter.

Access to and Perceptions of Health Care Services

Nearly all of those interviewed reported using the hospital when sick, and approximately one-third indicated they use the support of a friend or family member to assist them with communication at the hospital. Very few (2; 6%) reported that their health care provider understands some KSL. Without receiving health care information in KSL, there is greater potential for misunderstanding. Also a dependency on others to communicate may leave some Deaf persons feeling uncomfortable about HIV testing, for fear of having their confidentiality compromised. While most of the Deaf interviewees gave a fair or good evaluation to health care services in Kenya, communication barriers and fear of having confidentiality broken or distrust of medical staff were the concerns most often expressed.

More than one third (7; 38%) of the Deaf interviewees indicated that when sick, they prefer to go to a hospital, buy medicine from a pharmacist, and pray to God to get better. Six participants (19%) stated they only go to hospital and buy medicine; four (13%) indicated they used a combination of herbal/traditional medicine, hospital care, medicine from a pharmacist and prayer. Two participants (6%) indicated they exclusively go to hospital when sick; three (8%) prefer going to the hospital and prayer; while one (3%) goes to the hospital and uses one other means, and four persons (13%) indicated using some other combination of health care interventions.

Nearly half (15; 47%) of those interviewed give a fair evaluation to medical services in Kenya. 13 (41%) saw medical services as good; while two (6%) said health services are poor, and another two participants had no opinion, having never or seldom used such services. Participants were asked to elaborate on their answer to explain their rationale for their evaluation of medical services; the three most common concerns were: difficulties receiving necessary treatment and medicines (12); communication barriers (10); and fear of having confidentiality broken or distrust of medical staff (4). The frequency of reporting concern about difficulties communicating and distrust of medical personnel provides a strong indication of how Deaf persons feel towards seeking medical help, as they anticipate encountering difficulties and fear their confidentiality will be compromised.

Education on Reproductive Health STIs, and HIV

Seminars and workshops were both the most common means by which the Deaf interviewees had learned about HIV, STIs and reproductive health, and the preferred method for learning about such topics. Those surveyed indicated a preference for face-to-face, personal interactions when learning about such topics, and saw potential for a video with KSL and/or Deaf actors as a useful tool for learning about HIV. This suggests that future programming of the Deaf community should focus on delivering messages in a medium Deaf persons can understand- KSL, either in person, through lectures, workshops, or counseling, or through media such as films in sign language.

When asked how they learned about HIV and AIDS, STIs and sexual and reproductive health issues[2], a significant majority (29) of the Deaf interviewed cited public seminars and workshops.[3] Eight reported learning about these

[2] Participants were asked to select all means by which they learned about these topics. Therefore percentage values are not given, as many gave multiple responses.

[3] Seminars and workshops are a common means of communicating public awareness messages to civil society in Kenya. HIV & AIDS seminars are typically funded by a host organization (usually an international

topics in school or from teachers; five had been for one-on-one counseling or to a Deaf voluntary counselling and testing (VCT)[4] centre; three said they had learned from television; another three said they learned from friends. The following means were only mentioned once : puppet shows, newspapers, hospital, posters, and social discussion groups. One person had never learned about these topics, and two people mentioned other means. Workshops were the most commonly reported avenue for learning about HIV, but it is important to note that the other most common avenues where also face-to-face, personal interactions, either with teachers, counselors or friends. Deaf persons can understand and retain information when it is delivered in their language and in a personal way. Very few (2; 6%) reported learning about these topics from written materials.

The respondents were also asked what they thought was the best way for them to learn about HIV and AIDS and sexual health. They were permitted to provide as many means as they wanted. Seminars were cited 17 times; one-on-one counseling 10 times; video with sign language and/or Deaf actors (KSL) was cited nine times; discussions with friends was mentioned six times; Deaf VCT five times; brochures four times; newspapers twice; videos, posters, and Persons living with HIV and AIDS (PLWHA) support groups were each cited once. The preferred modes of learning also indicate a strong preference for face-to-face interaction. Most said they probably preferred seminars and counseling because this was how they had learned about HIV in the past. However, one means that was mentioned that had not been cited in the previous question, video with Deaf actors, indicates there is an alternative means of educating the Deaf community that has yet to be employed. A video could reduce the expense of training counselors in KSL, or the time restraints for coordinating seminars, which may conflict with other obligations, such as operating a small business or caring for children. Although the questionnaire did not ask a follow-up question to those participants who had never learned about HIV, several of the participants supplemented their answers to indicate that they did not have time to attend seminars due to such obligations.

Knowledge of HIV Transmission

When asked, “What is the best way for you to avoid getting HIV and AIDS?” the most common response was use condoms (15, 47%), with six people from Dandora and five from Haruma citing this as their primary response. Four participants (12.5%) said being faithful was the best protective measure. Two participants cited a combination of condom usage and being faithful, two cited abstinence, while another two participants did not know the best way to protect themselves (one was from Kayole, the other from Haruma). Two participants suggested there is medicine to protect one from becoming infected with HIV. Going to the VCT was mentioned by five participants, but in combination with other methods. Perhaps the most interesting response what that two HIV-positive persons could have sex with each other, as long as an HIV-negative person does not have sex with someone who is positive. From these results, it is evident the “ABCs”[5] and “know your status” messaging is gaining some traction in the Deaf community, but there is still confusion about the availability of medicine as a protective measure, and an incorrect assumption that two HIV-positive persons can have sex without protection.

When asked if they thought it was possible to get HIV from having sex without a condom, 29 (91%) participants answered correctly, that one

NGO), and either facilitated by the host development agencies or by a facilitator contracted by the host. The seminars can be as short as half a day or as long as two weeks, and involve of range of activities, such as capacity-building, leadership skills, and peer-education. Seminars attended by Deaf persons either have Deaf facilitators or a hearing lecturer with KSL interpreter.

[4] Deaf VCT (voluntary counseling and testing) refers to a VCT clinic that offers specialized services for Deaf persons. Medical and administrative staff are trained in KSL, and sometimes Deaf counselors are hired, and a trained KSL interpreter is on staff.

[5] ABCs refers to a three-pronged approach to HIV prevention: Abstain from sexual intercourse, Be faithful to one partner; and use Condoms.

can contract HIV; two (6%) answered "no," incorrectly, and one (3%) did not know. When asked if proper condom usage could reduce the chances of HIV transmission, 23 (72%) answered, "Yes" correctly; seven (22%) answered, "No" incorrectly, and two (6%) said, "I do not know". The three communities had a fairly even understanding of protective advantages of condom usage, with nine participants from both Haruma and Dandora answering correctly, and eight from Kayole. Only one person from Kayole did not know the answer, and one person from each community answered incorrectly. Thus further demonstrating awareness of the effectiveness of condom use is well understood in the Deaf communities interviewed.

Participants were asked if it was possible to become infected with HIV from kissing on the mouth. 20 (63%) participants answered correctly, "No"; seven (22%) responded, "Yes"; three (9%) said, "Yes, if there are cuts on the mouth"; and two (6%) said they did not know. A follow-up question was asked regarding deep-kissing (exchange of saliva), since the distinction was raised in the focus-group discussion. One third of participants (11; 34%) said you could get HIV from deep kissing, and nine (28%) said you could not get HIV from deep kissing. Seven (22%) believed that you could get HIV from deep kissing if there were cuts on the month, and three (10%) did not know. The results demonstrate there is a strong misconception about HIV being spread by kissing, which concurs with Groce, et al.'s (2006; 2007) findings. Redressing this myth can have important implications for reducing stigma towards persons living with HIV and AIDS (PLWHA).

When asked if it is possible to become infected with HIV if one only has sex with people he or she knows well, 18 (56%) respondents answered, "Yes" correctly; while 11 (34%) said, "No" and three (9%) said they did not know. It is worth noting that the misperception was concentrated with the participants from Haruma ("No" - four) and Kayole ("No" - six), and only two participants from Dandora answered incorrectly. Perhaps the misperception has been more successfully addressed through Deaf Empowerment Kenya's outreach activities in Dandora, where most of its work has been concentrated. This question indicates there is a false sense of security among Deaf persons with regards to having sex with people to whom they are close. It should be emphasized that no matter how well one knows a person, the only way to know if he or she is HIV positive is through an HIV test.

Twenty-one (66%) respondents indicated correctly that married people can get HIV. Ten (31%) believed married people could not be infected with HIV and one (3%) did not know. Even though most participants were correct, future educational training should emphasize that marriage is not a good way to protect oneself from HIV. Eighteen (56%) of the respondents said you still need to worry about HIV, if you always have sex with the same partner; while 14 (44%) said there was no need to worry. Again, it should be reinforced in training that the only way to be sure about the partner's HIV status is through HIV testing and fidelity.

The majority of those interviewed (25; 78%) indicated correctly that they could not tell who is HIV positive only by looking; while five (16%) believed they could identify a person who is HIV positive, only by looking and two (6%) said they did not know. This is an encouraging statistic, but more work still needs to be done to dispel the belief that one can tell who is positive only by looking at a person.

More than two-thirds of the participants (26; 82%) knew that HIV could be transmitted via shared needles, whereas four (12%) thought that HIV could not be spread this way, and two (6%) did not know the answer. This indicates there is a strong understanding that HIV is spread through infected blood, but more could be done to reinforce this information, especially in those Deaf communities known to use needles for injection drug use in Kenya.

Attitudes and Knowledge about PLWHA

Half of all Deaf interviewees were of the belief that, "You don't need to worry about HIV because there is treatment." It is therefore im-

portant that future programs address this misconception, and emphasize that anti-retroviral (ARV) drugs are not a cure. Nearly two thirds of participants know someone who is HIV positive, many of whom are Deaf. For that reason, it is imperative that programs also address coping strategies for those with a friend or family member who is HIV positive.

The views of the participants on whether or not they continue to worry about HIV, since there is treatment, are nearly split down the middle. 16 (50%) of the participants agreed with the statement, "You do not need to worry about HIV because there is treatment;" while 15 (47%) disagreed because they continue to worry about HIV. Only one person (3%) did not know whether to agree or disagree with the statement. It is interesting that six Dandora participants agree with this statement, and three disagree, and one does not know, while sentiments are nearly reversed in Haruma (three agree, and seven disagree). In Kayole, opinions were split down the middle, with five persons agreeing and five disagreeing with the statement. When asked about their perceptions about other Deaf persons' concerns in regards to HIV, in general, more than one-third (12; 38%) of participants said they believed other Deaf persons are worried about HIV. An equal number (9, 28%) felt that other Deaf persons were not worried, as those who believed some are worried, and some are not worried. Only two persons (6%) said they did not know. The perception that HIV treatment makes HIV less of a concern could mean two things. Either the Deaf interviewees no longer see HIV as a death sentence, because they are aware of ARVs and other medications to treat opportunistic infections, and therefore see no reason to worry, or they mistakenly believe HIV is curable. Either way, future programming for the Deaf community should make it clear that HIV is still a life-threatening disease, and that taking medication for the rest of one's life is by no means a cure. Emphasis should be placed on the importance of awareness and taking precautions to protect oneself from HIV infection.

More than one third (13, 41%) of participants stated they do not know anyone who is HIV positive. Ten (31%) said they have a Deaf friend who is positive; four (13%) have both hearing and Deaf friends who are positive; two (6%) have a hearing friend who is positive; one (3%) has a hearing family member who is positive; one (3%) has Deaf friends, hearing friends and family who are positive, and one person (3%) only knows of a hearing friend who is positive. These results suggest the Deaf interviewees are more aware of HIV within the Deaf community than outside of it. They are also likely close to the people who are HIV positive, so the reality of the disease can be very apparent to them. It would be appropriate to include in future training for the Deaf community on how to cope with a friend or family member who is HIV positive.

Sexual and High Risk Behaviour

There was a strong sentiment among the Deaf interviewees that someone who is HIV positive should not be public about his or her status. This opinion was often justified due to fear of gossip, discrimination and stigmatization. Future programming interventions of the Deaf community must work towards counter-acting these beliefs. Another area of concern was the self-reported instances of sexual assault, both perpetrated (12) and survived (9) by members of the Deaf community. Programming should also re-enforce what is inappropriate and illegal, and that Deaf persons have the right to report any incidence of sexual assault.

Nearly all of those who were interviewed (29; 91%) were of the opinion that someone who is HIV positive should be private about his or her status and not disclose to others. Only two (6%) people said someone who is positive should go public, and one (3%) person said they did not know which was right. When asked a follow-up question to explain their rationale, a wide variety of responses were garnered. Of those who thought it was good to be public about one's status, one (3 %) said one should tell one's family, so they can care for the person, and two (6%) said telling others would prevent one from feeling stressed and isolated.

The most off-cited reason (14; 44%) one should not be public about his or her status, was a fear of others' gossiping, discriminating against, stigmatizing and hating the HIV positive person. The second most common response (4; 14%) was if one were to tell others, one would become stressed. Two people (6%) said one will die faster if one were to tell others, while another two (6%) said one would be breaking the law of confidentiality and the hospital instructs patients not to disclose to others. Two participants (6%) said they did not know either way if it was better to tell others or keep one's status private. The following sentiments were each expressed only once, but are nonetheless revealing of the stigma surrounding HIV; "People will see you as a bad person"; "You will commit suicide"; "People will not have sex with you, and you will be alone"; "The Deaf will abuse you when they find out"; "It is a shame because you are disabled". The overwhelmingly negative sentiment towards being openly positive reveals that the Deaf interviewees have either witnessed the hostility experienced by persons who are openly positive, or they have internalized some of the fears and negative attitudes associated with being HIV-positive. Future programming interventions of the Deaf community must seriously address these attitudes, and work at counter-acting them, by instilling a sense of solidarity, compassion, empathy, acceptance and understanding within the Deaf community.

Nearly all of the Deaf persons (29, 91%) interviewed reported having been shown how to use a condom correctly, with only three (9%) stating they had never been shown. This was a very encouraging statistic, which again demonstrates that awareness about condoms is high in the Deaf community.

When asked whether the participant had ever been sexually assaulted, 23 (72%) reported no incident; while nine stated they had been assaulted or did not want to disclose. Of those who reported assault, three had been forced to take off their clothes; four had been touched inappropriately without permission; six had been forced to have sex; and four had been raped and one participant declined to answer. The distinction between forced sex and rape was made because they are two different signs in KSL. The former represents coercive sexual intercourse, typically when "No" is not taken for an answer, and the assaulted party concedes against his or her will. The latter refers to violent sexual intercourse, in which case the assaulted party is physically forced into submission. While it is difficult to determine whether this distinction is universally understood in the Deaf community in Nairobi, or in Kenya in general, focus group discussions and the final responses suggest that Deaf persons do make the distinction in how they communicate instances of sexual assault. Only one male participant reported being forced to have sex, and one male reported being touched without permission, while women reported the remaining cases. The questionnaire did not ask participants how old they were when they were sexually assaulted, however two women elaborated on the events, indicating that they had been abused while at school.

The question was then inverted to determine if the participant had ever been a perpetrator of sexual assault. Approximately two-thirds (21; 65%) of respondents said they had never participated in any form of assault, while 11 respondents, six of whom were men, admitted to perpetrating some form of sexual assault. Men were more likely to self-report acts of forced sex and rape, whereas women reported forcing someone to remove his/her clothes (two) or touching without permission (two). Four participants admitted to forcing another person to take off his/her clothes; eight admitted to touching another person's body without permission; six had forced someone to have sex with them; and three had raped another person. One person did not answer the question.

The results of this pair of sexual assault questions was extremely important, because within this sample, Deaf persons were more likely to perpetrate sexual assault than they were to be assaulted sexually. While it cannot be said that this sampling is representative of all Deaf people, it is important that the issue of sexual harassment and assault is brought to the fore during educational sessions on sexuality and

HIV with the Deaf community, to reinforce what is inappropriate and illegal, and that Deaf persons have the right to report any incidence of sexual assault.

While the majority of the participants were sexually active, the age of sexual debut varied widely. Six participants (18%) (Five males and one female) became sexual active between the ages of seven and 14. More than one-third (13, 38%) (six males and seven females) of the participants began having sex between the ages of 15 and 23; seven (23%) (five males, three females) began engaging in sexual intercourse between the ages of 24 and 32; and only one female (3%) became sexual active beyond the age of 33. The same number of participants (2; 6%) reported not knowing how old they were the first time they had sex, as those who were not sexually active. Judging by this sample, it is crucial that young people are educated on sexual health and STIs, as early as primary school, even if it is just in simple terms, since more than half of those surveyed became sexually active before the age of 24. Without accurate information, there is no way for them to protect themselves from HIV, other STIs and unwanted pregnancy.

Participants were asked how many people they had had sex with in the past 12 months, and there was a wide range. Approximately one-third (10; 32%) had only one sexual partner in the last year; eight (26%) stated they had between two and five different partners; five (15%) said they had not had sex in the past year; one (3%) reported 30 to 40 partners; and one (3%) reported more than 1000 partners in the last year, averaging three sexual partners per day. Three (9%) participants were not asked this question because they had never been sexually active. While it is encouraging to note that one-third of those interviewed were faithful to one partner, educational sessions should illustrate to the Deaf community that having multiple concurrent partners increases the risk of HIV transmission.

Exactly half (16; 50%) of the participants reported not using a condom the last time they had sex; while 12 (38%) said they had used a condom, and one (3%) reported removing the condom halfway through sexual intercourse. Three participants (9%) were not asked the question, as they were not sexually active. The low condom usage reported from this group indicates that while nearly all had been shown how to use condoms very few had internalized their usage. Education programs should emphasize that using a condom is the best way to protect sexually active persons from HIV and STIs and removing a condom half-way through sexual intercourse voids all protective effects. However, it is encouraging to note that all of the participants who had more than five sexual partners in the last year reported using a condom the last time that they had sex. For those who had between two and five sexual partners, five participants reported not using a condom the last time they had sex, and three reported using a condom.

More than one third (13; 42%) of the participants only have sex with other Deaf people. Nearly one third (10; 31%) reported having sex with both Deaf and hearing people; while six (18%) reported having sex exclusively with hearing people. Three (9%) participants were not asked the question, as they were not sexually active. The results illustrate that if there is any perception that having sex with only hearing or only Deaf persons is a means of protecting one's self from HIV, nearly one in three Deaf persons are having sex with both Deaf and hearing people, so the spillover effect may be apparent here.

Participants were asked if someone had ever given them money, drugs or gifts, in exchange for sex, and only five (16%) said they had been; whereas three quarters (24; 75%) said they had never been bribed in exchange for sex. Three (9%) participants were not asked the question, as they were not sexually active. The question was inverted, to determine whether the participant had ever given money, drugs or gifts to another person, in exchange for sex. Seven (22%) participants had given some type of bribe to another person in exchange for having sex with them, but the majority (22; 69%) had never done so. Three (9%) participants were not asked the question, as

they were not sexually active. Training sessions should discuss the risks associated with this type of behavior, and address strategies for discouraging giving and receiving bribes for sexual favours.

There were seven participants who are not currently sexually active, either they had never had sex or had abstained for a year or more. When asked to explain why they were sexually inactive, two participants said they were afraid of partners cheating, and did not trust anyone. One woman said her parents had advised her to wait until marriage; another woman said she had children to care for; another man had been warned about HIV and wanted to live until old age; and two other women said they were fearful of men and prefer to stay home. Training sessions for the Deaf should address the rationale behind individuals' choices to remain abstinent, in order to empower those individuals to lead by example. The viability of abstinence-only education to significantly reduce the spread of HIV within the Deaf community is fairly limited, and should only be discussed in the context of the three-pronged approach to HIV prevention, Abstain, Be Faithful to one partner, and use Condoms (ABCs). In Kenya, there are significant cultural and religious pressures to focus on abstinence education, which cannot be discussed here at length[6]. These respondents demonstrate that their behaviours are a reflection of their own choices based on their understanding of the risks associated with HIV. While abstinence may not be a solution to the AIDS pandemic, it is worth noting it is the option chosen by several Deaf people.

Access to HIV Testing and ARVs

More than three quarters of the participants had been for an HIV test, while one-third did not know the status of their partner(s). Programming interventions should stress the importance of regular HIV-testing along with the importance of knowing one's partner's status. It was encouraging to note that of the three people who self-identified as HIV-positive, all were attending support groups, and two were on anti-retroviral (ARV) therapy.

The majority of the participants interviewed had been given an HIV test, with three (9%) testing positive and 20 (64%) testing negative. Nine out of 10 participants from Haruma had tested negative, and only one woman indicated she would not like to be tested. All but one of the 10 participants from Dandora had been tested, and that person would like to be tested. In Kayole, only five participants had been tested, four would like to be tested, and one would like to be tested again. Two participants had been for testing but did not know their status at the time of research. One participant had been tested, but chose not to disclose. Of those who had not been tested, four would like to be tested and two would not like to be tested. The results from this question were encouraging, as it suggests most of the Deaf community understand the meaning of HIV-positive and negative sero-status, and have been pro-active enough to go for testing in the past. Further investigation into the incidence of re-testing for Deaf persons is required in order to determine frequency of testing within this population. In the interim, future training should emphasize that HIV testing is advisable after every new sexual partner.

More than one third (13; 41%) of those interviewed did not know the HIV status of their partner. Nine (28%) said their partner was HIV negative; three (9%) said their partner was HIV positive; and seven (22%) did not have a current partner, so the question was not asked of them. In addition to the importance of self-testing, future training should emphasize that knowing your partner's status is equally important. Those persons who were HIV positive were asked if they were taking ARV medication, and two out of three were currently taking the drugs. They were also asked if they were attending HIV positive support groups, which all of them were. This indicates that Deaf PLWHA have managed to gain access to support networks that meet their communication needs, and this encourages them to maintain

[6] For more detailed analysis of the cultural, religious and political pressures to emphasize abstinence-only education in Africa, see Pisani (2009) and Epstein (2008).

their psycho-social well-being, as well as reinforces their physical health.

The Way Forward

Although the results from the interviews represent a small sample of Deaf adults in Kenya, it offers important insight into the perspectives of Deaf persons in the context of HIV and AIDS. Future programming should continue to be offered in KSL, the Deaf community's primary language-whether through seminars with interpreters and Deaf lecturers, VCT HIV testing and counseling in KSL, or a new innovation : educational videos with Deaf actors. Such services and tools, tailored to the needs of Deaf persons, have been effectively implemented in the large urban centers of California, Texas and New York in the United States (Peinkofer, 1994). Written materials should be complementary and not the means to an end, and supplemented with clear illustrations. It is further recommended that Deaf persons are empowered and involved in the development of learning materials to suit their unique needs, and create a sense of ownership of future education, treatment, care and support programs. This recommendation is consistent with conclusions of Gaskins' (1999) research in the United States and Groce et al's research in Swaziland and Nigeria (2006; 2007), as both studies recommended the training and recruitment of Deaf peer educators to serve as outreach workers in the Deaf community.

Special attention should be paid to stigma-reduction in the Deaf community, in order to reduce the fear of associating with PLWHA, and encourage people to disclose their status and gain support from their community. It should be clarified that confidentiality is not a law, in that a person who tests positive for HIV is not restricted from telling others. It is only the health care provider and interpreter that must keep it confidential; it is the choice of the individual whether to disclose or not. Stigma reduction and open acceptance of Deaf PLWHA can create an environment whereby the Deaf community is empowered to communicate the realities they face, and strengthen linkages to the wider local community, and mobilize for better care, treatment and support services for Deaf PLWHA.

The issue of sexual assault needs to be addressed in the Deaf community as well, as the Deaf interviewees are both survivors and perpetrators of sexual assault, and this has serious repercussions for the security of persons and the spread of HIV and other STIs within the community. Prostitution is also an apparent phenomenon in Deaf community. Whether professionalized or not, persons who are Deaf both give and receive payment or bribes in exchange for sexual favours, and this can contribute to the spread of HIV within the community.

Finally, while rates of HIV testing are high within the Deaf community, it is important not to perpetuate a false sense of security that testing negative means there is no longer a risk. Further exploration of the relationship between risky behavior and HIV testing and counseling is still needed, to ascertain the present situation, and gauge the effectiveness and impact of existing services. Meanwhile, educational programs for Deaf persons should stress routine testing, especially for those with multiple concurrent sexual partners, as well as the importance of knowing your partner's status.

Recommendations for future research include conducting interviews with Deaf youths ages 15 to 24, since this is one of the most-at-risk-populations (MARP) in Kenya, with the highest recorded instances of HIV in 2009, and it is projected to rise in the next five years (National AIDS Control Council, 2008). With expanded scope and priority, a more representative survey of Deaf Kenyans, that covers all seven provinces, would also be particularly informative, as all participants in this research were from Nairobi province, and drawn from a snowballing sample. It would also be useful to address areas such as religious and ethnic practice in the survey, and assess whether these factors influence behavior and attitudes, or access to educational and employment opportunities, which then affect Deaf persons' awareness of HIV issues.

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Appendix 1: List of Interview Questions

Interviews questions for Deaf Kenyan Community members

A. Demographics:

1. Your age. _____ years.
2. Your gender: □ Male □ Female
3. Your parents are: □ Deaf □ Hearing
4. Do you have any other Deaf family members?
   □ No □ Yes [Who? _____]
5. How do you communicate at home, with your family? Check all that apply
   □ Use sign language □ Use writing
   □ Speak and lip read □ Use communication system developed by the family
   □ Use local language □ Use gestures
6. Are you_____ (married)?
   □ Single □ Separated □ Remarried
   □ Have a boyfriend (girlfriend) or partner
   □ Have more than one boyfriend (girlfriend). How many (number)? _____
   □ Are married or live with only one partner
   □ Are married to more than one husband (wife). How many (number)? _____
7. Do you have children?
   □ Yes [How many?_____] □ No
8. What do you do?
   □ Work (describe) _____
   □ Looking for work _____
   □ Are unemployed (reason, if any)_____
   □ Go to school (level) _____
   □ Volunteer (describe) _____
9. Where do you live? (name of city/town, etc.) _____

B. Education:

10. You went to a
    □ Deaf school □ Hearing school □ Technical school
    □ Deaf unit □ College □ Other _____
11. You completed (highest level of school) _____

C. Community involvement:

12. Are you a member of any deaf groups? Select all that apply.
    □ A member of a deaf religious group □ A member of a deaf sports team
    □ A member of a deaf social group □ Not a member of any deaf group
    □ Other _____
13. How do you communicate with other Deaf people, when they are far from you? Select all that apply.
    □ Cell phone □ Email □ SMS (text messaging)
    □ Send message with another person □ Send letter
    □ Other _____

D. Health services:

14. What do you do when you are sick? Select all that apply.
    - □ Go to the medical clinic/hospital
    - □ Go to the herbalist/natural healer
    - □ Buy medicine you think will help
    - □ Pray
    - □ Go to a doctor/nurse who understands KSL
    - □ Avoid seeking medical help
    - □ Other _____

15. How do you communicate at the hospital? (Select all that apply):
    - □ Speaking and lip reading
    - □ Help or support of a friend, family member
    - □ Using sign language
    - □ Using writing
    - □ Using an interpreter
    - □ Using gestures
    - □ Doctor/nurse knows sign language
    - □ Other_____

16. How do you evaluate medical services in Kenya?
    - □ Poor □ Fair □ Good □ Excellent

    Please explain your answer:_____

E. Education on sexual and reproductive health and STIs:

17. How did you learn about HIV and AIDS, STIs and sexual and reproductive health (Select all that apply):
    - □ Friends
    - □ Parents (Specify) _____
    - □ Other family members (Specify) _____
    - □ Teachers
    - □ Television
    - □ Subtitled TV program
    - □ Billboards and posters
    - □ Radio
    - □ Internet
    - □ Newspaper
    - □ Magazine
    - □ One-on-one counseling (Specify) _____
    - □ Seminar or workshop (Specify) _____
    - □ Social discussion groups
    - □ Community play or puppet show
    - □ Video with Deaf actors and sign language interpretation
    - □ SMS alert or hotline
    - □ T-shirts
    - □ Brochures
    - □ Condom distribution centers
    - □ I have never learned about these topics
    - □ Other_____

18. Which is the best way for you to learn about STIs and sexual and reproductive health? Select all that apply.
    - □ Friends
    - □ Parents (Specify) _____
    - □ Other family members (Specify) _____
    - □ Teachers
    - □ Television
    - □ Subtitled TV program
    - □ Billboards and posters
    - □ Radio
    - □ Internet
    - □ Newspaper
    - □ Magazine
    - □ One-on-one counseling (Specify) _____
    - □ Seminar or workshop (Specify) _____
    - □ Social discussion groups
    - □ Community play or puppet show
    - □ Video with Deaf actors and sign language interpretation
    - □ SMS alert or hotline
    - □ T-shirts
    - □ Brochures
    - □ Condom distribution centers
    - □ I have never learned about these topics
    - □ Other_____

F. Knowledge of HIV and AIDS, transmission:

19. What is the best way for you to avoid getting HIV and AIDS?
20. If you have sex with someone who has HIV and AIDS, without using a condom, can you get HIV and AIDS?
    □ No □ Yes □ Don't Know
21. If you use a condom properly, is there less chance to get HIV and AIDS?
    □ No □ Yes □ Don't Know
22. If you **kiss** on the mouth someone that has HIV and AIDS, can you get HIV and AIDS?
    □ No □ Yes □ Don't Know
23. If you **deep kiss** someone that has HIV and AIDS, can you get HIV and AIDS?
    □ No □ Yes □ Don't Know
24. If you only have oral sex, can you get HIV and AIDS?
    □ No □ Yes □ Don't Know
25. Can you get HIV and AIDS if you only have sex with people that you know very well?
    □ No □ Yes □ Don't Know
26. Can you get HIV and AIDS if you get a blood transfusion?
    □ No □ Yes □ Don't Know
27. Can married people get HIV and AIDS?
    □ No □ Yes □ Don't Know
28. Do you need to worry about HIV and AIDS if you always have sex with the same person?
    □ No □ Yes □ Don't know
29. Can you tell if someone has HIV and AIDS only by looking at them?
    □ No □ Yes □ Don't Know
30. Can a pregnant woman with HIV give birth to a baby that is HIV positive?
    □ No □ Yes □ Don't Know
31. Can you get HIV and AIDS if you share the same needle used by someone that has HIV and AIDS?
    □ No □ Yes □ Don't Know

G. HIV treatment, life with HIV:

32. You don't need to worry about HIV and AIDS infection because there is treatment.
    □ I agree □ I disagree □ I don't know
33. Do you think other Deaf people are worried about HIV and AIDS?
    □ No □ Yes □ Don't Know
34. Do you know anyone who has HIV or AIDS? The person is □ Hearing □ Deaf
    □ Yes, a family member □ Yes, a friend □ Yes, an acquaintance □ No

H. Opinions, Attitudes and behaviours:

35. Do you think a person who is HIV positive should be public about his or her status? Why or why not?
36. Did anyone ever demonstrate to you **how** to use a condom correctly?
    □ No □ Yes
37. How often do you drink alcohol?
    □ Never □ 1 or 2 time(s) per month □ 1-2 time(s) per week
    □ 3-6 times per week □ Every day
38. Do you smoke?
    □ Always □ Sometimes □ Never
39. Do you use drugs? If "Yes", select all that apply.
    □ No□ □ Marijuana □ Tobacco □ Cocaine □ Heroine
    □ Brown sugar □ Miraa □ Viagra □ Steroids □ Other_____

40. Has someone ever_____?
    - □ Forced you to take off your clothes
    - □ Touched your body without your permission
    - □ Forced you to have sex □ Raped you □ None of the above
41. Have you ever _____?
    - □ Forced someone to take off his or her clothes
    - □ Touched another person's body without his or her permission□
    - □ Forced someone to have sex with you □ Raped someone
    - □ None of the above
42. Have you ever had sex?
    - □ Oral □ Vaginal □ Anal □ Masturbation □ Breast sex □ Thigh sex
    - □ Sex with other objects (example: carrot, banana) □ Sex with animals
    - □ None of the above
43. Who do you prefer having sex with (Sexual identity)?
    - □ Heterosexual □ Bisexual □ Homosexual
    - □ Gay □ Lesbian □ Transgendered
    - □ Questioning or experimenting with your sexual identity
    - □ Other _____

I. For sexually active persons:

44. How old were you when you first had sex? (Age)_____
45. In the last 12 months, how many people did you have sex with?
    - □ Nobody □ 1 □ 2-5 □ 6 or more
46. The last time you had sex, did you use condoms?
    - □ Yes □ No
47. You have sex with
    - □ Men □ Women □ Men and women
48. The people you have sex with are:
    - □ Deaf people □ Hearing people □ Deaf and hearing people
49. Has someone ever given you money, drugs, or gifts in exchange for having sex with you?
    - □ Yes □ No
50. Have you ever given someone money, drugs, or gifts in exchange for having sex with someone?
    - □ Yes □ No

J. For not sexually active persons:

51. You don't have sex because:_____

K. HIV Testing:

52. Have you ever gone for an HIV test?
    - □ Yes [You are □ HIV positive □ HIV negative □ Don't Know]
    - □ No [Would you like to be tested for HIV/AIDS? □ Yes □ No]
53. Do you know the status of your partner?
    - □ Yes [He/she is □ HIV positive □ HIV negative]
    - □ No

L. Persons who are HIV Positive:

54. You are taking ARV medicine?
    - □ Yes □ No
55. You attend HIV positive support groups?
    - □ Yes □ No