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## Assessing the Readiness of Nairobi Deaf Youth to Accept a Best-practice HIV/AIDS Intervention

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# HIV Perceptions of Deaf Youth in Nairobi

Keala Morrell

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Kenya: Urbanization, Health and Human Rights

Fall 2013

Athman Lali Omar

Mohamud A. Jama

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## **Abstract:**

After nearly forty years of HIV/AIDS research in the global community, data on HIV/AIDS in the Deaf population is still disproportionately neglected. No surveillance system is in place to monitor prevalence, awareness or mode of HIV infection in the Deaf community. Additionally, prevention and education interventions have yet to be tailored to meet the specific needs of this highly vulnerable population.

*Purpose:* This project attempted to assess the readiness of the Nairobi Deaf youth community to accept a best-practice HIV/AIDS intervention. The broad objective of this research was to assess HIV awareness, perceptions and behaviors of Deaf youth in regards to HIV/AIDS in Nairobi, Kenya.

*Method:* This project used the snowball sampling method to conduct a survey using a combination of pre-coded, and open-answer questions conducted with 60 Deaf youth (18-35) in Nairobi, Kenya. Interviews included topics of HIV/AIDS knowledge, risk perception, and risk behaviors.

*Results:* The Nairobi Deaf youth community is unequipped to accept a best practice HIV/AIDS intervention at this time. Efforts need to be made to increase risk perception and develop social support. Also, comprehensive prevalence research needs to be conducted in this population.

*Conclusion:* Based on the data collected in this survey and a review of literature, a peer-led, extracurricular education campaign seems to be the most acceptable best-practice intervention for targeting Deaf youth. Additionally, a supplementary, video-based, multifaceted language component would be suggested.

## **Introduction:**

UNAIDS reports that roughly 40 million people are living with HIV/AIDS and 70% of them live in sub-Saharan Africa<sup>1</sup>. Last year, HIV/AIDS killed 1.6 million people and 1.2 million of those deaths were in sub-Saharan Africa<sup>2</sup>. The burden of HIV/AIDS tends to be shouldered by marginalized communities. Poverty, illiteracy and disability all increase a person's risk of contracting HIV. Concerns over lack of research around issues of disability and HIV have been reported in the World Bank Global Survey in multiple years<sup>3</sup>.

370 million or 5.3% of the world's population have disabling hearing loss (DHL). 67% of people with DHL live in developing countries<sup>4</sup>. DHL ranks 15th as a leading cause for the global burden of disease and 2nd in the leading causes of years lived with a disability. Rates of acquired deafness range from 2-10% globally, with the higher percentages falling in the developing world. The World Health Organization estimates that over half of Deafness and Hearing impairment is avoidable with appropriate ear and hearing care<sup>5</sup>.

According to global statistics, roughly three million Deaf people in Africa are living with HIV<sup>6</sup>. People with hearing impairments are less likely to have access to HIV/AIDS education, prevention, and care services. They are more at risk for infection due to marginalization, extreme poverty, sexual exploitation and illiteracy. Because Deaf

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<sup>1</sup> National AIDS Control Council. *Kenya AIDS Epidemic Update 2012*. 2013.

<sup>2</sup> UNAIDS 2012

<sup>3</sup> Yousafzi, Aisha, and Karen Edwards. *Double Burden: A Situation Analysis of HIV/AIDS and Young People with Disabilities in Rwanda and Uganda*. 2004

<sup>4</sup> "Deafness Prevention." *WHO*. N.p., Feb. 2013. Web. 29 Nov. 2013.

<sup>5</sup> Ibid.

<sup>6</sup> UNAIDS 2012, Ibid.

people are more at risk of infection while also less able to access care services, they are left with a double burden of disease in relation to HIV/AIDS<sup>7</sup>.

There has recently begun a grassroots movement looking to address the marginalization and exclusion of Deaf and disabled individuals from HIV/AIDS programming. In 2003, the World Bank published a report on HIV/AIDS and disability confirming that information is lacking about the epidemic in this population and insisting that inclusive approaches be taken in future programming and services<sup>8</sup>. And still, Deaf and disabled populations are not included in the UN definition of vulnerable populations, receive little specific funding, and continue to be marginalized in HIV/AIDS interventions<sup>9</sup>.

A study comparing the HIV prevalence in populations of 1709 Deaf and 1649 Hearing clients indicated that the prevalence rates are comparable for Deaf and Hearing populations. The study showed that, in Kenya, there was a HIV prevalence rate of 7% in the Deaf population while the Hearing population had a rate of 6.7% (varying from 6.4 on the Coast, to 15.6 in Nyanza Province). The regional variations were also concurrent in the Deaf population<sup>10</sup>. The Kenya AIDS Indicator Survey (KAIS) revealed that as many as 4 out of 5 of HIV-infected people in Kenya do not know their status. So, it can be deduced that the number of Deaf persons infected and unaware would add a significant amount to the prevalence rate<sup>11</sup>.

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<sup>7</sup> Shackleton, Joanna. "Exploring Perceptions of Deaf Persons for Recommendations towards Effective HIV/AIDS Programming in Nairobi." 2009.

<sup>8</sup> Yousafzi et al. "HIV/AIDS Information and Services: The Situation Experienced by Adolescents with Disabilities in Rwanda and Uganda." (2005): 1357-363.

<sup>9</sup> National AIDS Control Council. *Kenya AIDS Epidemic Update 2012*.

<sup>10</sup> Taegtmeier et al. "A Peer-led HIV Counselling and Testing Programme for the Deaf in Kenya." (2009): 508- 528

<sup>11</sup> Shackleton, Joanna. "Exploring Perceptions of Deaf Persons for Recommendations towards Effective HIV/AIDS Programming in Nairobi." 2009

## Setting:

Nairobi is a large, metropolitan city center - the capital city of Kenya. The total population of Nairobi is 3,138,369 making it the most densely populated region in Kenya<sup>12</sup>. The National HIV prevalence in Kenya is 6.7%<sup>13</sup>. Nairobi has a slightly higher HIV prevalence rate of 9%. According to the 2009 census, 1,330,312 people with disabilities live in Kenya<sup>14</sup>. Approximately 500,000 of them are profoundly Deaf<sup>15</sup>. Between 600,000 and 800,000 are hearing impaired and use KSL as their primary mode of communication<sup>16</sup>. The urban deaf population in Nairobi is primarily of low socio-economic status, most often working in the informal sector, unemployed or day laborers. They are also more likely to have low literacy rates, less access to healthcare and potable drinking water<sup>17</sup>. These characteristics increase the vulnerability of the Nairobi Deaf population to contracting the HIV virus.

In the past 10 years, Kenya has been rolling out a series of mass-marketing campaigns promoting voluntary counseling and testing or VCT services to the general population. In 2001, Kenya launched a 4-phase operation, consisting of radio, TV, billboard and newspaper ads. None of the materials were interpreted into KSL and there

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<sup>12</sup> Kenya Census 2009. Wycliffe A. Oparanya. Nairobi, Kenya, 2010.

<sup>13</sup> Ibid

<sup>14</sup> Ibid, "Central Intelligence Agency." *The World Factbook* Web. 03 Dec. 2013.

<sup>15</sup> Taegtmeier et al. "A Peer-led HIV Counselling and Testing Programme for the Deaf in Kenya." (2009): 508- 528

<sup>16</sup> Kakiri, Nickson O. "Challenges Facing Deaf in Accessing ICT." 10-11th May 2012.

<sup>17</sup> Kenya Census 2009. Wycliffe A. Oparanya. Nairobi, Kenya, 2010.



were no follow up studies conducted with the Deaf population to assess efficacy<sup>18</sup>. In fact, prior to 2003, there were no curricula, training materials, or interpretation services offered to the Deaf community in Kenya<sup>19</sup>.

In 2003, the HIV counseling and testing program for the deaf started to produce Deaf Friendly IEC materials<sup>20</sup>. The Liverpool VCT was the first organization to produce IEC materials in Nairobi. They reported facing numerous barriers in recruiting consistent funding, standardizing signs for sexual and HIV vocabulary and distributing materials to rural Kenya where the disease burden is reportedly higher<sup>21</sup>. The VCT's dissemination techniques followed a grassroots approach that was more accepted by the Deaf community. In a review study, it was found that Deaf clients were more likely to have learned about VCT services from community meetings, religious meetings, and peer education programming than from newspapers or mass media campaigns<sup>22</sup>.

The Nairobi Deaf population is a tight-knit and relatively small community. They share common schools, churches, language and values. Most of Kenya's Deaf are born into hearing families. This usually means communication barriers at home, and little family-based social support. These factors work to increase youth's reliance on the greater Deaf community for socialization and strengthen the unity of the population. Students report feeling that the Deaf community in Nairobi has become more of a family for them than their birth family.

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<sup>18</sup> National AIDS Control Council. *Kenya AIDS Epidemic Update 2012*. 2013

<sup>19</sup> Taegtmeier et al. "A Peer-led HIV Counseling and Testing Program for the Deaf in Kenya." (2009): 508- 528

<sup>20</sup> Ibid

<sup>21</sup> Personal Interview. Baraza & Ongo'o. 18/11/2013

<sup>22</sup> Taegtmeier et al. "A Peer-led HIV Counseling and Testing Program for the Deaf in Kenya." (2009): 508- 528

The highest concentrations of Deaf people are in the urban slum communities of Kayole, Dandora and Huruma<sup>23</sup>. These slum areas are characterized by high poverty rates, low educational attainment, high unemployment, pollution and poor access to housing and transportation. Informal settlements attract Deaf youth who are able to find the community and social support they crave, at an inexpensive cost-of-living. Young, independent and undereducated, Deaf youth in slum areas have developed a high-risk lifestyle that socially allows for free sexual interaction<sup>24</sup>. These cultural factors increase the risk of HIV in the Deaf youth population.

## **Objectives and Rationale:**

Upon review of more than 20 years worth of research, April Winningham discovered that a majority of successful HIV/AIDS interventions followed along a basic premise that in order to reduce risk in a population, the individuals in that population had to:

1. Perceive them selves to be at risk
2. Intend to change their behavior to reduce risk
3. Possess feelings agency and self-confidence that they can reduce their risk through behavior change
4. Have the social support to initiate and maintain behavior change<sup>25</sup>

In response, this project attempted to assess the readiness of the Nairobi Deaf youth community to accept a best practice HIV/AIDS intervention. The broad objective of this

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<sup>23</sup> Shackleton, Joanna. "Exploring Perceptions of Deaf Persons for Recommendations towards Effective HIV/AIDS Programming in Nairobi." 2009.

<sup>24</sup> Ibid.

<sup>25</sup> Winningham et al. "Lessons Learned From More Than Two Decades of HIV/AIDSs Prevention Efforts: Implications for People Who Are Deaf or Hard of Hearing." (2008): 48-54.

research is to assess HIV perceptions of Deaf youth (ages 18-35) in regards to HIV/AIDS in Nairobi, Kenya.

The specific objectives closely followed Winningham's baseline criterion for reducing risk. The first objective was to generally assess Deaf youth's HIV/AIDS knowledge. This was done through a series of multiple-choice questions about risk behaviors, transmission routes and epidemiology. The second objective was to look at risk perception and self-efficacy in the Deaf youth community. This involved multiple-choice questions about HIV/AIDS prevalence in the Deaf community, risk behavior prevalence, and agency evaluation in regards to sexual health. The third objective was to identify risky behaviors and barriers to behavior change in the Deaf community. This was assessed through multiple-choice and self-report questions regarding access to health services, education and social support from within the Deaf community. The fourth objective was to compile the data on perception and behavior-change and use that information to inform a best-practice HIV/AIDS intervention targeted toward the Deaf youth population in Nairobi.

## **Methodology:**

A review of current literature was conducted to establish a baseline understanding of the issues surrounding HIV awareness in Deaf communities and to develop a relevant questionnaire. Ten key informant interviews, consisting of a series of open-ended questions, were conducted to insure relevance and to inform adaptation of the project to the Kenyan Deaf cultural context. Key informants included the disabilities chairperson at the Liverpool VCT, the research coordinator and head teacher at DeafAID, the founder of

SahayaDeaf Kenya, the dean of students and counselor at the Karen Technical Institute representatives from the Deaf Welfare Society and the coordinator of HOPE from USAID. This initial research informed the design of an interview questionnaire based on the research methods, surveys and qualitative assessments frequently used in the field.

The questionnaire draft was taken for review by a Kenyan Sign Language (KSL) teacher, who was able to assist in writing out a gloss (written sign) of the questionnaire in KSL. She adapted the questionnaire to better suit translation into signed languages. The questionnaire was then passed to a Deaf VCT counselor. He analyzed the questionnaire for accuracy and acceptability. Modifications were made to address stigma and confidentiality. He also edited the gloss to incorporate signs more commonly used in Nairobi slang. The questionnaire was reviewed by a Deaf technical college teacher, as a native signer, he was able to best analyze the acceptability of the glossed survey. He made minor adjustments for clarity.

A pilot study was conducted using the edited questionnaire. Informed consent was secured by distributing an Informed Consent Form. A group of Deaf youth reviewed the informed consent form, and the questionnaire for clarity and to appropriate the survey toward a youth audience. The pilot study included five interviews conducted by the researcher in an informal setting. The participants volunteered after receiving a brief project description at the Mombasa Deaf Awareness Week closing ceremony.

After completing the pilot study, the survey was administered at the Karen Technical Institute of the Deaf, at the Deaf VCT in Nairobi, at DeafAID, and at the Immanuel Church for the Deaf. The participants were recruited through the snowball method due to the hidden aspect of the Deaf population in Nairobi. Participants had to be

between 18-35 years old and self-identify as Deaf or hearing impaired. These were the only exclusion factors. The researcher attempted to network both genders into the study, also participants from all tribes, socio economic backgrounds and education level. The snowball method is inherently biased, but the greater number of interviews allowed for some generalization.

The primary researcher conducted ten interviews. Then used a paper survey to complete the research due to time constraints. Fifty paper surveys were collected. To insure understanding, only two youths were allowed to fill out surveys at one time and the researcher was always present to answer questions. The surveys were filled out in an enclosed space, participants sat back to back to insure confidentiality. Informed consent was obtained through the distribution of an Informed Consent Form that was written in either English or Kiswahili. KSL signed consent was obtained for those who were unable to completely understand the written consent form. Surveys were offered in written English, written Kiswahili, ASL, or KSL. In some cases a combination method was used for clarity. Names were replaced by a simple code. The de-coding sheet was kept in a separate password-protected file from the original surveys. The surveyed population consisted of Deaf participants, ages ranging from 18-35 with an average age of 22. There were 19 Female and 41 Male participants. The participants came from 35 different neighborhoods in Nairobi.

The interview answers were put into an excel document and coded to ease calculations. Responses were summed and turned into percentages. Based on the data collected, the researcher was able to assess the readiness of the Nairobi Deaf youth community to accept a best practice HIV/AIDS intervention. The collected data was

distributed to NGO's and hospitals in the Nairobi area, by request. Upon distribution, health service providers asked for some sort of training to better address the concerns illuminated by the data. The researcher worked with Deaf leaders to start a script for a sensitivity training video. In the process of writing the script, an idea was floated to transform a previously written best-practice HIV/AIDS intervention curriculum into sign language interpretation for ease of implementation. Two Deaf youths and two master teachers (trained in KSL sex education) joined the group to discuss and write scripts for the curriculum.

## **Discussion and Analysis:**

### Demographics of the Study Population:

All of the participants in the study self-identified as Deaf or hearing impaired. The study population consisted of people with genetic and acquired deafness, though more participants acquired deafness at a young age. In sub-Saharan Africa, acquired deafness occurs largely because of preventable childhood illness such as - middle ear infection, malaria, meningitis and the use of ototoxic antibiotics (amino glycosides – frequently used to treat malaria)<sup>26</sup>. 46% of hearing loss in developing countries is due to chronic otitis media. Otitis media, or inner ear infections, are largely preventable with proper preventative medical care<sup>27</sup>.

All interviewees were between the ages of 18-35 with an average age of 22. This is the definition of youth in Kenya. According to the UN Declaration of Commitment on HIV/AIDS, the international community intends to reduce the prevalence of HIV in

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<sup>26</sup> "Deafness Prevention." *WHO*. N.p., Feb. 2013. Web. 29 Nov. 2013.

<sup>27</sup> *Ibid*.

youth by at least 25% in coming years<sup>28</sup>. Youth are identified as one of Kenya's most-at-risk-populations due to prevalence of high-risk activities, and low health-seeking behaviors. 14 thousand Deaf youth reside in Nairobi County<sup>29</sup>. The majority of Deaf youth surveyed reside in communal-peer houses with an average of five other Deaf youth or siblings. Most have left families in rural villages to look for work or educational opportunity in the city.

65% of the participants went to Deaf schools. The others attended Deaf Units in public schools, went to hearing schools or attended technical institutes. A survey by Deafax, a British NGO, found that 35% of Deaf schools provided no sex education curriculum<sup>30</sup>. It can be extrapolated that, because most respondents went to Deaf schools, they received little-to-no formal sexual health education. 95% of participants reported using KSL at school. "It's hard for information dissemination with the Deaf because there are no standard signs for sex vocabulary," reports a Kenyan sex educator, "everywhere we go we have to change to the local sign<sup>31</sup>." This kind of inconsistency lowers the impact of sexual health education campaigns.

A majority of the survey participants came from hearing households. 38% of participants used KSL at home, 35% used writing back and forth and 32% used primarily oral communication. In a study looking at knowledge about HIV/AIDS and barriers to prevention education in Deaf and Hard of Hearing people in New York State, interviews showed that Deaf ASL users had less knowledge about HIV/AIDS than oral deaf and

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<sup>28</sup> "UN Declaration of Commitment on HIV/AIDS." *UN N.p.*, 2001

<sup>29</sup> Kenya Census 2009. Wycliffe A. Oparanya. Nairobi, Kenya, 2010

<sup>30</sup> Swinbourne, Charlie. "Communication Barriers in Sex Education Put Deaf People at Risk." 05 Dec. 2012.

<sup>31</sup> Personal Interview. Jakki Odewesso 12/11/2013

hear of hearing participants<sup>32</sup>. The participants who responded that they used primarily oral communication usually became deaf at a later age and had received some sex education before becoming deaf. This increased their knowledge of HIV/AIDS.

### Knowledge of HIV/AIDS:

In Nairobi, 490,314 students attend primary school, 176,837 attend secondary school and only 69,345 seek higher education<sup>33</sup>. In a recent UNESCO study it was found that only 1-2% of children with disabilities receive education past a primary level<sup>34</sup>. Deaf youth are 64% less likely to complete secondary school than their hearing peers<sup>35</sup>. The amount of school one attends is directly correlated with the amount of HIV/AIDS information one receives<sup>36</sup>. This infers that Deaf students receive less HIV/AIDS education in addition to less education in general.

Even though Deaf students are significantly less likely to have received sexual health information at school, 87% of survey respondents strongly agreed or agreed that they knew about HIV/AIDS. "Since, they don't learn about sex in the school, you will find a lot of Deaf go to seminars and workshops about HIV/AIDS," said one key stakeholder in the Deaf community<sup>37</sup>. In fact, in a cross-sectional survey of Deaf Kenyans, among respondents who said they did not receive health education at school, 95% of Deaf participants said they had received HIV/AIDS education before and 58%

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<sup>32</sup> Bat-Chava et al. "Barriers to HIV/AIDS Knowledge and Prevention among Deaf and Hard of Hearing People." (2005): 623-34.

<sup>33</sup> Kenya Census 2009. Wycliffe A. Oparanya. Nairobi, Kenya, 2010

<sup>34</sup> Yousafzi & Edwards. *Double Burden: A Situation Analysis of HIV/AIDS and Young People with Disabilities in Rwanda and Uganda*. 2004.

<sup>35</sup> Taegtmeier et al. "A Peer-led HIV Counseling and Testing Program for the Deaf in Kenya." (2009): 508- 528

<sup>36</sup> Heuttel & Rothstein. "HIV/AIDS Knowledge and Information Sources among Deaf and Hearing College Students." (2001)

<sup>37</sup> Personal Interview. Charity Evanson. 11/11/2013



said they had with in the last 6 months<sup>38</sup>. 57% of respondents in this study said they would be interested in going to a sex education class outside of their formal schooling. Deaf youth are eager and willing to learn about HIV/AIDS through community-based educational seminars and workshops.

Obviously, Deaf people are able to access health information in some capacity, but with out standardization and regulation, it is hard to guarantee the quality of information received. For example, one study showed that 86% of Deaf participants were aware of HIV/AIDS and its transmission but at the same time they still believed in false modes of transmission – for example 41% said that mosquitoes could transmit HIV<sup>39</sup>. Additionally, in a study assessing knowledge of HIV/AIDS in the Deaf youth community, only 41% of Deaf students answered 9 or 10/10 questions correctly compared to 91% of the hearing students. Furthermore, 38% of Deaf students answered fewer than 7 questions correctly compared to only 4% of hearing students<sup>40</sup>. In another study, only 47% Deaf participants were able to answer more than 7 out of 16 HIV knowledge questions correctly, 100% of their hearing peers answered more than 8 out of 16 correctly<sup>41</sup>. These statistics indicate the severity of the knowledge gap between Deaf and hearing students.

The participants of the current study all reported having some prior knowledge of HIV/AIDS and sexual health issues. Still, a little less then half (42%) of the participants were able to identify that using a condom decreases the risk of contracting HIV, while

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<sup>38</sup> The Steadman Group. "HIV and AIDS knowledge, attitude, and practice: and accessibility study in Kenya, Nairobi."(2007)

<sup>39</sup> Giros S. "Prevention in practice: Three HIV/AIDS prevention programs for people with disabilities" (2004)

<sup>40</sup> Heuttel & Rothstein. "HIV/AIDS Knowledge and Information Sources among Deaf and Hearing College Students." (2001)

<sup>41</sup> Bisol et al. "HIV/AIDS Knowledge and Health-Related Attitudes and Behaviors Among Deaf and Hearing Adolescents in Southern Brazil."(2008): 349-56.

more, 47%, said that there was no effect. 43% of respondents said HIV and AIDS were the same illness. This indicates a need for further sex education and echoes the previous conclusion that one-time, basic education is not enough. Attendance at seminars and workshops cannot be used as an indicator for understanding in the Deaf community, further assessment shows that the quality of information or the ability to retain information presented is lacking and leads to serious misunderstanding.

It is encouraging to see that students were more knowledgeable about aspects of HIV/AIDS epidemiology. 60% knew that AIDS weakens the body's ability to fight off disease. 65% said HIV/AIDS was life threatening. 65% said it was preventable. 75% said it was not curable. 62% said it could be controlled with medication. The accuracy shown here indicates a high level of disease understanding. But that understanding is not reflected in the student's knowledge of risk behaviors. This seems to indicate that information has been disseminated about the disease itself, but with less focus on attitudes and behaviors.

This theory was further supported by the fact that medium and low risk behaviors were harder for students to identify. For example, 57% of respondents correctly acknowledged that kissing and hugging had no effect on your risk of getting HIV but only 47% said oral sex increases risk while, 39% said it had no effect and 52% said that abstaining decreases risk but 40% said that it had no effect. 48% of students said that asking your partners HIV status was not enough to decrease your risk of contracting HIV and 48% of participants said that having strong, healthy relationships doesn't change the risk of contracting HIV. 47% said that learning about HIV in sex education classes decreases risk but 30% said it had no effect. The reported percentages are not

significantly different: this shows that students believe many of the listed behaviors pose no significant risk in contracting HIV when, in fact, these risk behaviors can be just as dangerous as more commonly known high-risk behaviors.

Students were much better at identifying high-risk behaviors. For example, 67% said that exchanging sex for money was a highly risky behavior. 48% of students correctly identified drinking alcohol as increasing risk. 57% of respondents said that having multiple sex partners increases your risk of HIV infection. 63% of students said that using contaminated needles for drugs increases your risk. This shows that there has been some information disseminated to this population but there is a need for greater depth and understanding insurance for more complex facets of HIV/AIDS.

### Perceived risk and Self-Efficacy:

Perceived risk or susceptibility refers to an individual's estimation of their chance of contracting an illness or developing a condition. Across a multitude of studies, perceived risk has been closely connected to HIV-related risk behaviors. It's been suggested that perceived susceptibility is required before behavior change can occur in high-risk populations<sup>42</sup>. In this study, 65% of Deaf students reported being concerned about contracting HIV and 50% agreed that their friends are concerned about contracting HIV. This would suggest perceived susceptibility. In the largest recorded study consisting of 1709 Deaf Kenyans. 80% of participants perceived themselves as "at risk"<sup>43</sup>. In interviews with disabled adolescents, multiple Deaf participants described anxiety about

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<sup>42</sup> Wunningham et al. "Lessons Learned From More Than Two Decades of HIV/AIDS Prevention Efforts: Implications for People Who Are Deaf or Hard of Hearing." (2008): 48-54.

<sup>43</sup> Taegtmeyer et al. "A Peer-led HIV Counselling and Testing Programme for the Deaf in Kenya." *Disability & Rehabilitation* 31.6 (2009): 508- 528.

becoming HIV positive due to already experiencing hardship as a consequence of their disability<sup>44</sup>. Deaf youth perceive themselves as a vulnerable population.

One study found Deaf adolescents are 43.1% more likely to see themselves as at risk when compared to a hearing peer<sup>45</sup>. However, in this study, when participants were explicitly asked to compare the hearing community to the deaf community the totals of the responses were fairly similar across the board showing that there is little perceived risk differential between the two communities. For example, 1/3 of participants said Deaf people were less likely to be HIV positive, 1/3 said they were equally as likely and 1/3 said they were more likely to be HIV positive. Furthermore, 63% of Deaf participants said that compared to other people of their sex and age, they are less at risk for getting HIV. This indicates that while Deaf youth see themselves as a vulnerable population, they see their hearing peers as equally, if not more, vulnerable. Literature asserts that this belief is somewhat accurate. The prevalence rate of HIV/AIDS in Deaf and hearing populations are comparable. One study found a prevalence rate of 7% in the Kenyan Deaf population while the Hearing population has a rate of 6.7%<sup>46</sup>.

In terms of self-efficacy surrounding sexual health issues, 55% of students strongly agreed or agreed that they have little control over their sexual health. In interviews with disabled and non-disabled teens, low self-efficacy and low self-esteem among disabled peers in relationships were cited a significant number of times. For example, some mentioned that disabled partners (especially girls) have little control in

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<sup>44</sup> Yousafzi & Edwards. *Double Burden: A Situation Analysis of HIV/AIDS and Young People with Disabilities in Rwanda and Uganda*. 2004.

<sup>45</sup> Taegtmeier et al. "A Peer-led HIV Counselling and Testing Programme for the Deaf in Kenya." *Disability & Rehabilitation* 31.6 (2009): 508- 528.

<sup>46</sup> Taegtmeier et al. "A Peer-led HIV Counselling and Testing Programme for the Deaf in Kenya." *Disability & Rehabilitation* 31.6 (2009): 508- 528.

negotiating safer sex because they should feel “grateful” to be in the relationship in the first place<sup>47</sup>. Deaf girls and women are at particular risk of HIV infection because they tend to experience fewer stable/healthy relationships. They also tend to have lower self-esteem and less confidence navigating sexual and emotional connections. They also report feeling embarrassed or unequipped to negotiate safer sex practices with non-disabled partners<sup>48</sup>.

While participants felt they had little control in their sexual health, 58% disagreed or strongly disagreed that there was nothing they could do to protect themselves from HIV. And 77% said that if they could control the risk factors for HIV then they could prevent the infection. So, it seems that the respondents feel they have significantly more control over risk factors and behaviors rather than sexual health outcomes. This is a good sign of readiness in the Deaf population because it suggests that Deaf youth possess feelings agency that they can reduce their risk through behavior change. Generally, Deaf youth are proud of their overall health, 82% felt their daily actions were good for their health.

### Risk Behaviors:

When looking at risk behaviors, 37% of respondents said that Deaf people were more likely to have sex before 16 compared to their hearing peers. 48% they would have (or have had) sex before marriage. According to the literature, the age of sexual debut is, in fact, slightly earlier for Deaf people. But the ages are comparable with Deaf - age16 -

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<sup>47</sup> Yousafzi et al. "HIV/AIDS Information and Services: The Situation Experienced by Adolescents with Disabilities in Rwanda and Uganda." (2005): 1357-363

<sup>48</sup> Personal Interview. Jakki Odewesso, 12/11/2013

and hearing at 16.5 years<sup>49</sup>. In one study, 37% of Deaf participants reported engaging in sex before 16<sup>50</sup>, which proves that sex before the age of consent, happens in this community. In a study of Deaf adolescents in comparison to hearing peers, Deaf teens reported statistically similar sexual activity over a 12-month period<sup>51</sup>. This suggests that Deaf adolescents, like their hearing peers, are at high-risk for sexually contracting HIV/AIDS.

Even when risky sex was proposed - if your partner won't have safe sex, you will not have sex with them - responses were inconclusive, evenly distributed from strongly agree to strongly disagree. 43% of participants in this study said that Deaf people were more likely to have multiple sex partners. In the Steadman group study, 20% of Deaf participants said they had had sex with multiple partners and 14% said they had occasional partners. Once again proving the prevalence of this behavior and substantiating the risk level in the Deaf population<sup>52</sup>.

40% of this studies participants said Deaf people were more likely to be victims of sexual abuse. In the literature, it was found that girls who are disabled are twice as likely to be raped or forced into sex than their non-disabled peers<sup>53</sup>. Also, in a study comparing Deaf and hearing students, 31% of Deaf participants reported being victims of sexual abuse compared to only 2% in the hearing community<sup>54</sup>. In addition, a cross-

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<sup>49</sup> Bisol et al. "HIV/AIDS Knowledge and Health-Related Attitudes and Behaviors Among Deaf and Hearing Adolescents in Southern Brazil." (2008): 349-56

<sup>50</sup> The Steadman Group. "HIV and AIDS knowledge, attitude, and practice: and accessibility study in Kenya, Nairobi." *Handicap International* (2007)

<sup>51</sup> Bisol et al. "HIV/AIDS Knowledge and Health-Related Attitudes and Behaviors Among Deaf and Hearing Adolescents in Southern Brazil." (2008): 349-56

<sup>52</sup> The Steadman Group. "HIV and AIDS knowledge, attitude, and practice: and accessibility study in Kenya, Nairobi." *Handicap International* (2007)

<sup>53</sup> (Cheng & Udry, 2001)

<sup>54</sup> Bisol et al. "HIV/AIDS Knowledge and Health-Related Attitudes and Behaviors Among Deaf and Hearing Adolescents in Southern Brazil." (2008): 349-56

sectional survey found 7% of Deaf Kenyan participants indicated abuse at their first sexual encounter<sup>55</sup>. In discussions with disabled youth, rape was mentioned in all focus groups<sup>56</sup>. Incidence of sexual abuse and rape are alarmingly prevalent in the Deaf community. Not only is this a calamity of human rights, it also increases the risk of HIV infection in this population.

42% of participants in this study said that Deaf people were more likely to know their HIV status and 67% said they would be interested in being tested for HIV. In the literature it has been found that, indeed, more Deaf people get tested compared to their hearing peers (21.4% vs. 8%)<sup>57</sup>. 42% of respondents in this survey said they knew someone with HIV and 58% said they did not. In a study comparing hearing and deaf adolescents, 19% of deaf participants said they knew someone with HIV/AIDS, while the hearing participants knew no one<sup>58</sup>. In another study, 65% of the deaf participants reported that they knew someone who was HIV positive in their area<sup>59</sup>. It seems that Deaf people are more likely to know their status, and the status of others in their community.

A possible explanation for why Deaf communities are more aware of HIV status has to do with the Deaf culture “grapevine”. Numerous interviews cited that the close-knit Deaf community is notorious for excessive gossip. “You can say one thing in the morning and everyone knows by tea,” said one interviewee<sup>60</sup>. While HIV status is usually

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<sup>55</sup> Taegtmeyer et al. "A Peer-led HIV Counselling and Testing Programme for the Deaf in Kenya." *Disability & Rehabilitation* 31.6 (2009): 508- 528.

<sup>56</sup> Yousafzi et al. "HIV/AIDS Information and Services: The Situation Experienced by Adolescents with Disabilities in Rwanda and Uganda." (2005)

<sup>57</sup> Bisol et al. “ HIV/AIDS Knowledge and Health-Related Attitudes and Behaviors Among Deaf and Hearing Adolescents in Southern Brazil.” (2008): 349-56

<sup>58</sup> Bisol et al. “ HIV/AIDS Knowledge and Health-Related Attitudes and Behaviors Among Deaf and Hearing Adolescents in Southern Brazil.” (2008): 349-56

<sup>59</sup> The Steadman Group. “HIV and AIDS knowledge, attitude, and practice: and accessibility study in Kenya, Nairobi.” *Handicap International* (2007)

<sup>60</sup> Personal Interview. Charity Evanson. 11/11/2013

a well-maintained secret in the Hearing community, Deaf people tend to know which of their peers are “living positively”. While knowing the status of ones partner is helpful in preventing sexually transmitted HIV, the lack of confidentiality can be a deterrent from testing for Deaf people.

53% of respondents in this research project said they would be interested in using a condom during sex. While it’s promising that this number is over half, it is still shockingly low. The low level of condom use is reflected in focus group interviews with Deaf and hearing university students. Condoms were mentioned 45 times in short open-ended interviews by Hearing participants and only 15 times by Deaf participants<sup>61</sup>. The low level of interest in protected sex denotes a high prevalence of high-risk behavior.

Barriers to behavior change:

Across a systematic review of studies on the topic, it was found that counselors, practitioners, nurses and police officers are often not able to effectively communicate with Deaf people<sup>62</sup>. In a comprehensive study analyzing barriers to HIV/AIDS knowledge and prevention among Deaf and hard of hearing communities, almost all participants reported communication barriers with medical providers<sup>63</sup>. In this study, 78% of participants reported that they went to the hospital when they were sick but only 3 people said their medical provider understood KSL. 32% of respondents have family members translate for them and 45% said they rely on writing back and forth. When providers don’t understand KSL, the deaf communities primary form of communication,

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<sup>61</sup> Bisol et al. “ HIV/AIDS Knowledge and Health-Related Attitudes and Behaviors Among Deaf and Hearing Adolescents in Southern Brazil.” (2008): 349-56

<sup>62</sup> Hanass-Hancock, Jill. "Disability and HIV/AIDS - A Systematic Review of Literature on Africa." (2009): 1-11.

<sup>63</sup> Bat-Chava et al. "Barriers to HIV/AIDS Knowledge and Prevention among Deaf and Hard of Hearing People." (2005): 623-34.



it can be hard for Deaf patients to independently express their symptoms, ask for help, and ultimately understand the complicated disease of HIV.

In a study on HIV information and services, Deaf participants sited dependency on translators/interpreters as one of the major barriers in utilizing HIV services because of the fear of confidentiality being compromised<sup>64</sup>. Adolescents with communication disabilities were most likely to have concerns regarding confidentiality. Deaf teens were likely to acknowledge that the HIV testing and counseling process was supposed to be confidential, but they raised concerns about the contract of a third person either a family member, friend or interpreter who might gossip<sup>65</sup>. “Going for a test is not bad, but you know that testing has to be a secret, but by the time you go with an interpreter then you are three people now”<sup>66</sup>. Generally, 89% of respondents rated their satisfaction with the healthcare system, as acceptable, only 4 respondents were happy with the Kenyan healthcare system.

The low satisfaction levels with the healthcare system force Deaf adolescents to look for health information sources outside of the mainstream system. 83% of respondents to this survey said that they get most of their sexual health information from friends and peers. In a study of 34 Deaf Undergrads and 46 Hearing undergrads at competitive higher learning institutions in the US, a survey that assessed knowledge and sources of information about HIV/AIDS. 88% of Deaf participants said they get “a lot” or

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<sup>64</sup> Yousafzi et al. "HIV/AIDS Information and Services: The Situation Experienced by Adolescents with Disabilities in Rwanda and Uganda." (2005)

<sup>65</sup> Yousafzi & Edwards. *Double Burden: A Situation Analysis of HIV/AIDS and Young People with Disabilities in Rwanda and Uganda*. 2004.

<sup>66</sup> Yousafzi et al. "HIV/AIDS Information and Services: The Situation Experienced by Adolescents with Disabilities in Rwanda and Uganda." (2005)

“some” of their sexual health knowledge from friends this was in contrast to 16% of their hearing peers<sup>67</sup>. Peer information is less reliable and impossible to regulate.

## **Conclusions:**

After nearly forty years of HIV/AIDS research in the global community, data on HIV/AIDS in the Deaf population is still disproportionately neglected. Studies need to be conducted to assess and monitor prevalence, awareness and mode of HIV infection in the Deaf community. Additionally, prevention and education campaigns need to be tailored to meet the specific needs of this highly vulnerable population. Lack of appropriate and productive HIV prevention interventions for the Deaf population poses a significant public health and human rights challenge. This population is less likely to receive timely preventative care and bear a bigger burden of disease than their hearing counterparts while at the same time are more likely to experience discrimination and barriers to accessing care because of their disability.

In order to provide sustainable and suitable risk reduction, the majority of successful HIV/AIDS interventions required that individuals in the high-risk community had to first meet four standards. The community members had to perceive themselves to be at risk. Deaf youth do perceive themselves to be at some risk for HIV infection, but the risk is not deemed universal or urgent. This may be because there is no concrete evidence telling Deaf youth that they are an “at risk” population, and little anecdotal evidence that is made available to them. Data needs to be compiled to compel Deaf adolescents to heighten their perceived risk. A review of new programming at Gallaudet

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<sup>67</sup> Heuttel & Rothstein. "HIV/AIDS Knowledge and Information Sources among Deaf and Hearing College Students" (2001)

University in Washington DC, showed that HIV sensitivity training, using peer education, is generally more acceptable in the Deaf community because the participants are able to witness firsthand the disease through a friend<sup>68</sup>. This increases the perceived risk in a community.

The second requirement is community-wide intent to change their behavior to reduce risk. Based on the Deaf communities willingness to attend seminars and take part in extracurricular education materials it would appear that there is intent to protect themselves from HIV/AIDS. However, there are inconsistent results as to the actual level of behavior change.

The third condition is that the community members possess feelings agency and self-confidence that they can reduce their risk through behavior change. This study showed that most Deaf youth feel they have some control, over mainly risk behaviors but that these feelings don't necessarily translate to health outcomes. Further empowerment is needed in the youth community. Research shows that developing youth leadership enhances feelings of efficacy and agency. Deaf trainees have advantageous qualities in the dissemination of sensitive sexual health material. For example, where hearing participants have to be trained in attentive listening skills, eye contact and concentration, the Deaf trainees already exercise these characteristics due to Deaf culture. They are also more adept at reading and interpreting body language.

The fourth stipulation is that the community has to have the social support to initiate and maintain behavior change. In producing this study it was made clear that there is a vast amount of willing and eager individuals in the Deaf community who are passionate about sex education and HIV/AIDS dissemination. There also seems to be an

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<sup>68</sup> Personal Interview. Joseph Baraza. 18/11/2013

institutionalized system of continuity between Deaf NGO's through the Kenya National Association for the Deaf. However, many key informant interviews suggested that Deaf NGO's don't actively work together and instead focus on promoting their own organizations. In conclusion, it seems that the Nairobi Deaf youth community has a few steps to take before being able to accept a best practice HIV/AIDS intervention.

Based on the data collected in this survey and a review of literature. A peer-led extracurricular education campaign seems to be the best intervention idea. Additionally, a video-based multifaceted, language component would be suggested. Studies show that Deaf individuals who are native signers learned significantly more, and were able to retain much more from information and education materials delivered via videos filmed in ASL with captioning. They also found that the Deaf community could greatly benefit from multiple exposure or long-term exposure to the same health education message<sup>69</sup>.

## **Recommendations:**

### Limitations:

Time was the biggest limitation of this study; because of the short research time the population size and sample were affected. Limited time, combined with the specific nature of the Deaf community, meant it was most practical to use snowball sampling. However, this method of sampling adds a bias because it inherently draws from a population of overlapping social spheres. The first few participants determine the rest of the sample. Because snowball sampling anchors the sample population in a characteristic sphere, it is impossible to tell whether their responses are actually indicative of the target population as a whole. For example, in this research, the sample was rooted in higher

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<sup>69</sup> Folkins et al. "Improving the Deaf Community's Access to Prostate and Testicular Cancer Information: A Survey Study." (2005): 5-63.

education institutions, which meant 67% of participants were full time students. This demographic tends to know more about HIV/AIDS and therefore highly sways the results of the research.

Another time-based limitation was that there was not enough field time to gain the appropriate amount of trust needed to conduct a survey on a sensitive topic in a vulnerable population. Having an open discussion about HIV/AIDS requires a level of trust and comfort that was impossible to establish in the allotted time. This limited the kinds of questions the researcher was able to ask and forces the reader to assume that all participants were not completely forthright in their responses.

Language was another barrier; the researcher is a novice Kiswahili speaker as well as a beginning KSL signer. This meant that interviews took significantly longer because of clarity questions and some information was probably lost in poor translation.

#### Other Recommendations:

Determining, on a large scale, the prevalence of HIV-related risk behaviors and infection is the first recommendation for expansion on this study. Some grassroots organizations are working in the field to compile this data but to compose a published and peer-reviewed paper would be more beneficial to the community-at-large.

Additionally, testing, designing and implementing a best-practice intervention targeting youth (outside of school) would be a huge benefit for the community. The strong Deaf community in Nairobi is a powerful resource that can be positively utilized to make change. A project collecting stories and experiences of Deaf community members living positively with HIV would be a valuable way of increasing perceived susceptibility and increasing awareness about prevalence in the Deaf community.

It would be beneficial for a more longitudinal study to be able to decipher the incidence rate in the Deaf population and track the modes of transmission of HIV/AIDS. Because no long-term studies have been done in this population, it is hard to identify specific risk behaviors and tailor interventions to target them. Even an updated cross sectional survey would be beneficial in the field. The NACC suggests that rate of infection in disabled teens was suspected to rise over the past 5 years<sup>70</sup>. It would be interesting to know if that prediction came through.

The high incidence of sexual abuse and rape that has been reported in literature, and confirmed in this study, suggests that research needs to be done to address the underlying vulnerabilities that make Deaf youth so susceptible to sexual violence. Campaigns and support curricula should be developed to better address victims needs.

At this point in history, neglecting a promising population like the Deaf community in terms of HIV programming is simply unacceptable. The similarities found between the Deaf and hearing youth populations show that there is still research to be done about knowledge to behavior concept routes. It will be a global challenge to constantly tailor best-practice campaigns to help promote sexual health among diverse, heterogeneous and ever-transforming youths.

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<sup>70</sup> Kenya. National AIDS Control Council. Kenya Ministry of Health. *Kenya National HIV/AIDS Strategic Plan*. By NACC. Nairobi, Kenya: Office of the President, 2009.

## **Definitions and Abbreviations**

AIDS	Acquired Immune Deficiency Syndrome
ARVS	Anti Retro Viral Drugs
HIV	Human Immunodeficiency Virus
KNAD	Kenya National Association of the Deaf
KSL	Kenyan Sign Language
LVCT	Liverpool Voluntary Counseling and Testing
NACC	National AIDS Control Council
PWD	People with Disabilities
UNAIDS	United Nations Joint Program on HIV/AIDS
VCT	Voluntary Counseling and Testing
WHO	World Health Organization

**Best-Practice** - “Knowledge about what works in specific situations and context, without using inordinate resources to achieve the desired results and which can be used to develop and implement solution adapted to similar health problems in other situation and contexts (WHO 2008).”

**Disabling Hearing Loss** - “hearing loss greater than 40dB in the better hearing ear in adults 9(15yrs and older) and a hearing loss greater than 30dB in the better hearing ear in children (0-14yrs) (WHO 2013).”

**Disability** – “long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder a person full and effective participation in society on and equal basis with others (UN, 2006)”

## **Appendix 1: Survey Data Condensed**

### Demographics:

Ages 18-35  
19 Female 41 Male  
35 different neighborhoods  
9-18 people in household, average 5

### Education:

Deaf School:	39	65%
Deaf Unit:	6	10%
Hearing School:	3	5%
Technical Institute:	12	20%

### Communication at Home:

KSL:	23	38%
Writing:	21	35%
Oral:	19	32%
Local Sign:	1	1.7%
Gesture:	1	1.7%

### Communication at School:

KSL:	57	95%
Oral:	3	5%
Writing:	4	6.7%

### Employment:

Full-Time Student:	40	67%
Working:	10	16.7%
Volunteers:	4	6.7%
Unemployed:	6	10%

### Access to medical services:

Hospital:	47	78%
Chemist:	11	18.3%
Pray	3	5%

### Communication with medical provider:

Family interprets:	19	32%
Writing:	27	45%
Oral:	4	6.7%
Interpreter:	2	3.3%
KSL:	8	1.3%
Dr. knows KSL:	3	5%



Satisfaction with medical services:

Excellent:	4	6.7%
Good:	34	57%
Okay:	19	32%
Bad:	3	5%

Read the sentences and decide if the action Increases, has No Effect or Decreases the risk of HIV:

	Decreases Risk		Increases Risk		No effect	
Using a condom during sex:	25	42%	7	12%	28	47%
Asking your partners HIV status:	18	30%	13	22%	29	48%
Drinking Alcohol:	7	12%	29	48%	24	40%
Learning about HIV in Sex Ed:	28	47%	13	22%	18	30%
Having strong relationships:	22	37%	8	13%	29	48%
Having multiple sex partners:	6	10%	34	57%	20	33%
Using dirty needles for drugs:	11	18%	38	63%	11	18%
Having unprotected sex with a friend:	13	22%	31	52%	16	27%
Kissing/Hugging:	13	22%	13	22%	34	57%
Having oral sex:	9	15%	28	47%	23	38%
Abstaining from sex:	31	52%	5	8%	24	40%
Exchanging sex for money:	7	12%	40	67%	13	22%

Read the sentences and decide if, compared to hearing people, Deaf people are More, Equally, or Less likely to perform these behaviors:

	More		Equally		Less	
Have HIV:	17	28%	20	33%	23	38%
Have sex before 16:	22	37%	18	30%	20	33%
Have multiple sex partners:	26	43%	11	18%	23	38%
Be victims of sexual abuse:	24	40%	15	25%	21	35%
Exchange sex for money:	22	37%	11	18%	27	45%
Know their HIV status:	25	42%	16	27%	18	30%

Read the sentences and decide if you, Strongly Agree, Agree, Disagree or Strongly Disagree with the statement:

	Strongly A		Agree		Disagree		Strongly D	
I have little control over my sexual health:	16	27%	17	28%	14	23%	13	22%
There is little I can do to protect myself from HIV:	16	27%	7	12%	20	33%	15	25%
I am concerned about HIV:	16	27%	23	38%	17	28%	4	7%
My friends are concerned	8	13%	30	50%	13	22%	9	15%

about HIV:								
Compared to peers, I have more risk:	10	17%	12	20%	23	25%	15	25%
I know about HIV:	26	43%	26	43%	5	8%	3	5%
I can see when someone has HIV:	8	13%	11	18%	21	35%	20	33%
I feel my actions are good for my health:	26	43%	23	38%	6	10%	4	7%
If I control risk factors, I can prevent infection:	26	43%	20	33%	6	10%	7	12%
I know where to get HIV information:	23	25%	25	42%	8	13%	3	5%
I get sexual health information from peers:	26	43%	24	40%	7	12%	2	3%
If my partner won't have SS, we won't have sex:	14	23%	16	27%	16	27%	14	23%

Read the following statements and decide if they are True or False:

	True		False	
HIV/AIDS is life threatening:	39	65%	21	35%
HIV/AIDS is preventable:	39	65%	21	35%
HIV/AIDS is curable:	15	25%	45	75%
HIV/AIDS can be controlled:	37	62%	23	38%
I know someone with HIV:	25	42%	35	58%
HIV and AIDS are the same:	26	43%	34	57%
AIDS weakens immunity:	36	60%	24	40%
A person can be infected and not show symptoms:	40	67%	20	33%

Read the following sentences and decide if you would be Interested, Maybe Interested, or Not Interested in the behavior:

Being tested for HIV:	40	67%	15	25%	5	8%
Using a condom during sex:	32	53%	15	25%	13	22%
Having sex before marriage	19	32%	12	20%	29	48%
Going to sex education class	34	57%	8	13%	18	30%

## **Appendix 2: Survey**

1. Your Age: \_\_\_\_\_
2. Your Gender: \_\_\_\_\_
3. Where do you live? \_\_\_\_\_
4. How many people live in your house? \_\_\_\_\_
5. You went to a:
  - Deaf School
  - Hearing School
  - Technical Institute
  - Deaf Unit
6. How do you communicate at home?
  - Sign Language
  - Writing
  - Speak/Lip read
  - Local sign
7. How do you communicate at school?
  - Sign Language
  - Writing
  - Speak/Lip read
  - Local sign
8. Are you
  - Working
  - Unemployed
  - Volunteering
  - Full time student
9. What do you do when you are sick?
  - Go to a clinic/ hospital
  - Buy medicine at chemist
  - Pray
  - I do not seek medical attention
10. How do you communicate with your medical provider?
  - Sign Language
  - Writing
  - Speak/Lip read
  - Help of a friend or family member
  - Using and interpreter
  - Doctor/Nurse knows sign language

11. Satisfaction level with medical services

- Bad
- Okay
- Good
- Excellent

Read the sentences and decide if the action:	Increases risk of HIV	Has no effect on risk of HIV	Decreases risk of HIV
1. Using a condom during sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Asking about your partners HIV status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Drinking alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Learning about HIV in sex education classes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Having strong, healthy relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Having multiple sex partners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Using dirty needles for drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Having unprotected sex with someone you know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Kissing/Hugging	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Having oral sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Abstaining from sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Exchanging sex for money	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Read the sentences and decide if you:	Strongly agree	Agree	Disagree	Strongly disagree
13. I have little control over my sexual health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. There is not much I can do to protect myself from HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I am concerned about HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. My friends are concerned about HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Compared to other people of my sex and age, I am more at risk for getting HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I know about HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I can see when someone has HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I feel my actions are good for my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. If I control the risk factors of HIV, I can prevent infection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I know where to get information/tested for HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I get most of my information about HIV from friends and family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. If my partner won't have safe sex, I won't have sex with that person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Read the sentences and decide if, compared to hearing people, Deaf people are:	More Likely to	Equally Likely to	Less Likely to
25. Have HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Have sex before 18	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Have multiple sex partners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Be victims of sexual abuse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Exchange sex for money, gifts or food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Know their HIV status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Read the sentences and decide if they are:	TRUE	FALSE
HIV/AIDS is life threatening	<input type="checkbox"/>	<input type="checkbox"/>
HIV/AIDS is preventable	<input type="checkbox"/>	<input type="checkbox"/>
HIV/AIDS is curable	<input type="checkbox"/>	<input type="checkbox"/>
HIV/AIDS can be controlled	<input type="checkbox"/>	<input type="checkbox"/>
I know someone with HIV/AIDS	<input type="checkbox"/>	<input type="checkbox"/>
HIV and AIDS are the same illness	<input type="checkbox"/>	<input type="checkbox"/>
AIDS weakens the body's ability to fight off disease	<input type="checkbox"/>	<input type="checkbox"/>
A person can be infected and not show symptoms	<input type="checkbox"/>	<input type="checkbox"/>

Read the sentences and decide if you are:	Interested	Maybe Interested	Not Interested
Being tested for HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using a condom during sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having sex before marriage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going to sex education classes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Becoming a peer educator of sex education classes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### **Appendix 3: Key Informant Interview**

1. Name: \_\_\_\_\_
2. Position: \_\_\_\_\_
3. In your opinion what are the barriers that the Deaf community faces in accessing HIV education?
  - a. HIV treatment?
4. What policies are in place to specifically address the special needs of the Deaf community in regards to HIV/AIDS?
5. How does the LVCT work to overcome the obstacles faced by the Deaf community?
6. What behaviors and attitudes qualify youth as a most-at-risk-population in Kenya?
  - a. Are people with disabilities considered a Most-at-risk-population?
  - b. What policies about HIV/AIDS are directed toward disabled youth in Kenya?
  - c. Are there any policies crafted with the input of youth?
    - i. What about people with disabilities?
7. What would you estimate to be the general level of HIV awareness in the Deaf youth community?
  - a. Are there goals or benchmarks for this population?
8. Is there an adapted HIV/AIDS sensitization curriculum focused toward the special needs and issues of the Deaf community?
  - a. How do you craft a Deaf specific HIV/AIDS sensitization curriculum?
9. What are the policies supporting the equality and inclusion of Deaf people in the LVCT's HIV/AIDS awareness and prevention?
10. How do you recommend Deaf youth become active participants in their sexual health?
  - a. Does the LVCT support any peer led initiatives?
  - b. How do you convey the importance of individual participation in sexual health?
11. Do you know of any other organizations I should contact in regards to HIV awareness and Deaf youth?
- 12.** Would you like to receive a final copy of my findings?

## **Appendix 4: Informed consent**

You are being asked to take part in a research study to assess HIV awareness of Deaf youth in Nairobi. I am asking you to take part because you self-identify as Deaf or Hearing impaired and are between the ages of 18 and 35. Please read this form carefully and ask any questions you may have before agreeing to take part in the study.

**What the study is about:** The specific objectives of this research are to assess adolescent awareness of the biology and behavioral aspects of HIV/AIDS. Identify barriers faced by the Deaf population in accessing information and treatment for HIV/AIDS. To assess behaviors that impact the vulnerability of the Deaf population to HIV/AIDS. Finally, to inform and implement peer led HIV/AIDS and sexual education programming targeted toward Deaf youth in Nairobi.

**What I will ask you to do:** If you agree to be in this study, I will conduct a short interview with you in the language of your choice. The interview will include questions about basic demographics, HIV awareness, barriers to health, and health behaviors. The interview will take about 20 minutes to complete.

**Risks:** There is a small risk that you may find some of the questions invasive or sensitive. You should not feel pressured to answer any questions that cause discomfort. You are free to terminate the interview at anytime.

**Benefits and Compensation:** Your participation in the study will help to improve health education curriculums in the Deaf community. You will also be able to receive a copy of the final research paper upon completion. If you choose to participate, you will be cordially invited to a results showcase and celebration on Dec. 3<sup>rd</sup> The National Day of People With Disabilities.

**Confidentiality:** All of your answers will be kept confidential. A coding system will be assigned to your interview and your name will never be directly associated with your results. In any sort of report I make public I will not include any information that will make it possible to identify you. Data will be available to the primary researcher for 5 years and will be destroyed after 5 years.

Please ask any questions you have now.

If you have questions later, you may contact Keala Morrell at keala\_morrell@brown.edu or at +254-0731824439

You will be given a copy of this form to keep for your records.

**Statement of Consent:** I have read the above information, and have received answers to any questions I asked. I consent to take part in the study.

\_\_\_\_\_  
(Printed name)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Signature or thumbprint and witness signature)

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