

# **Sexual and Reproductive Health Information and Services for Deaf and Hard of Hearing Youth in Kenya: A Perspective on Contested Spaces and Pathways**

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## **Abstract**

*Various studies have indicated the disparities that exist between Deaf and Hard of Hearing youth in relation to adequate and accurate sexual and reproductive health knowledge. Even when efforts are geared towards improving sexual and reproductive health services and information processes for Deaf and Hard of Hearing youth, minimal adaption to the versatile virtual, social cultural, economic spaces in which these youth are embedded has compounded these disparities. This paper provides a perspective on these spaces from a perspective of the space they open and spaces that may close in such sites. We explore the various actual and symbolic services and information sites identified by Deaf and Hard of Hearing youth, how information is passed (pathways) in these sites, the barriers, tensions, attitudes of different providers at each site, as well as perceptions of effectiveness as well as normative and practical barriers. It is important to note that the problems Deaf and Hard of Hearing youth face are not just local, but should be seen from the context of both local level, contextual and macro level factors. In this paper therefore we also explore state policy and practice as an important site pertaining to people with disabilities but Deaf and Hard of Hearing youth in particular.*

## **Introduction**

Various studies have indicated the disparities, which exist between Deaf and Hard of Hearing youth in relation to adequate and accurate sexual and reproductive health knowledge (Swatz, 1993; Job, 2004). Even when efforts are geared towards improving sexual and reproductive health information and services for Deaf and Hard of Hearing youth, minimal adaption to the versatile virtual, social cultural, economic contexts in which these youth are embedded has compounded these disparities. This paper explores the various barriers that Deaf and Hard of Hearing youth face as they access information and services for Sexual and reproductive health. The discussions in the paper are drawn from a one-year research done in 2015 on the framing of sexual and reproductive health of Deaf and Hard of Hearing youth in western Kenya. In this research we worked with both in school and out of school youth in Kakamega and Siaya counties. We explored the various information sites identified by Deaf and hard of Hearing youth, how information is passed (pathways) in these sites, the barriers, tensions, attitudes of different providers at each site, as well as perceptions of effectiveness as well as normative and practical barriers in each site. It is important to note that the problems Deaf and Hard of Hearing youth face in this area should be seen from the context of both local level, contextual and macro level factors. Therefore, this paper also touches on issues of state policy and

practice pertaining to people with disabilities but Deaf and Hard of Hearing youth in particular.

### **Accessing the Voice of Deaf youth Differently: Working with Deaf Youth as Peer Researchers**

The research was undertaken in Siaya and Kakamega Counties in Kenya among the in school and out of school youth in the country and a range of stakeholders including teachers, policy makers and medical health personnel.

The sampling criteria was based on the population of the schools, considerations on gender, diversity of students in the school for example if students are drawn from other parts of the country or region or not, whether private or state owned, the level of school whether primary, secondary and tertiary and we ensured each was represented. For practical reasons, the proximity and accessibility of the schools was also considered. The population of student's aged 15-25 within the target population cut off was taken so as to determine the sample and thereafter determine the sample size.

To give the research wider applicability, in addition to interviews with key informants at the national level, we endeavored to deepen the findings by drawing on empirical research from Kenya, regionally and internationally.

In working with youth as researchers and specifically in disability research, we worked with deaf youth as peer researchers. In doing so, we were heeding to the caution by (Wickeden, 2011) who argues that we should ensure we do not continue to tell the accounts of people with disabilities. We should instead facilitate such people to tell their stories. The prevailing methods of research on the sexuality and reproductive health of the youth including youth with disabilities and those who are deaf, are dominated by adult (hearing) 'expert' constructions and assumptions about youth needs. This not only homogenizes youth and their experiences but also means that adult (hearing) assumptions underpin policies and programs for Deaf and Hard of Hearing youth thereby creating strategies that do not adequately address their needs nor reflect their experiences. These top-down' approaches in sexual reproductive health policies and interventions and research methods are implicated in the very erasure of the needs of the Deaf and Hard of Hearing youth. Our approach was in line with Okwany et al (2014); Ngutuku and Okwany, 2017) in viewing young people as key actors in knowledge production about their sexual and reproductive health needs, rather than mere subjects of study. We therefore foregrounded the perspectives of deaf youth as we worked with select Deaf and Hard of Hearing youth as co-researchers in generating information about their peers' perceptions of sexual and reproductive health and wellbeing.

The youth peer researchers; knowledge of local networks, social and power relations was instrumental in shaping data collection protocols. Working with Deaf and Hard of Hearing Youth empowered them in the sense that their voices were reflected in the construction of research tools, collection of data, in analysis as well as dissemination in diverse fora thus giving them an authorial voice. It was also a useful tool in helping to navigate the gatekeeping by parents, teachers and other adults in the area of adolescent sexual reproductive health programming. As noted by Tamale (2011) it aided in foregrounding the sexuality and reproductive health experiences (of these young people) as well as the meanings and interpretations they attach to these experiences.

In recognition that we were hearing researchers working with Deaf and Hard of hearing youth, we were constantly reflexive about our role. We minimized the “adult gaze” and the “hearing gaze” by continuously positioning the Deaf and Hard of Hearing youth as co-researchers with relevant and legitimate competencies in co-producing knowledge about their own sexual and reproductive health and who are best placed to be familiar with the coded languages and symbols used by young persons. In so doing we positioned them as active social actors in the production of data as it is also emphasized by (Christensen and Prout, 2002). We were aware that we were positioned as experts in reproductive health and sexuality of young people and the associated power issues that could influence the research. We however sometimes felt vulnerable since only one of the principle investigators was deaf and the rest of us who were interacting with the young people in the field had only basic skills in sign language interpretation. We circumvented this by working with deaf youth as researchers and constantly holding discussions with them during the process of data analysis and writing. This researching and writing calls for patience and planning well in advance because it is also time and money consuming. We however feel that it enabled us to access the voice of young people differently.

### **Space as an analytical Framework for Understanding Deaf Youth Sexuality**

In understanding the specific barriers deaf youth face in accessing sexual and reproductive health and information, we are guided by an analytical approach that lays emphasis on safe, healthy and responsible sexuality within the frame of the ecological model. The model calls for the need to place young people’s sexuality within, micro, meso and macro levels as opposed to a focus on individual factors. An ecological approach entails an examination of mutual-bidirectional transactions between the Deaf and Hard of Hearing youth and their environment in which they enact their sexuality as well as and seek reproductive health. In this model, an individual’s self-efficacy to overcome vulnerability, risk and realize sexual wellbeing and security is rooted in societal processes, which shape, enable, and constrain sexual health seeking behaviors (Ricardo et al 2006).

Relying on this model, we analyzed the diverse spaces and sites in this ecology of care and support. Morgan Wilemse with Meletse (2009) in their research on a South African Deaf, Gay and HIV/positive youth note that an orientation to place is important in enacting identities and for our case the experience of Deaf and Hard of Hearing Youth. This is because such an orientation brings to the fore the various spaces which young people may find constraining or enabling to their sexual and reproductive health experience. The diverse places or what we have called sites in this research are the home, the school, the medical centres as well as community. These are the sites that were named and /or emerged and are seen as important in giving meanings to sexual and reproductive health needs and experience of these youth. It is also these sites where discourses around their sexuality circulate. However, there are other spaces (some symbolic) like digital spaces, pornographic shops and spaces in the streets (looking for or hanging out with their peers) however seen as “loitering” by their parents, school assembly time, when

youth are gathered to get instruction and get direction from teachers among others. These spaces, interact with discourse, their material situation as well as alternative constructions of personhood by young people to influence their lived experience. In the sections that follow, we explore these sites and the enabling and disabling aspects in these sites in as far as sexual and reproductive health of Deaf and Hard of Hearing youth is concerned. The main thread running through out the analysis is the competence of these sites in assuring rights of young people in as far as their sexuality and reproductive health is concerned, needs to be enhanced to assure the deaf youth a right to self determination in reproductive and sexual health matters. Important to note that even though in our analysis we present these sites as distinct, they cross cut each other and influence each other in myriad ways.

### **Parents as Sexuality Education Trainers: Discourses of Protection and Threat**

The home is a site where knowledge and social cultural norms on Sexual and reproductive health are exchanged and passed on. Transmission of this knowledge varies with the various relationships with the home. Vertical transmission involves adults to children and or horizontally through siblings and extended family. Information for Deaf and Hard of Hearing youth is passed through mainly observation and nonverbal signs. The home site shapes their sexuality experiences within and outside the home through what is expressed or what is silenced in this space.

While it is expected that parents would be the first line of information for deaf and hearing youth as literature so assumes. Parents were not seen as first resort as discussions reveal. This was put in the context of the overall reticence of the parents to provide this information to youth based on the assumptions they have about the sexuality of youth but specifically for the Deaf and Hard of hearing youth, interacting with other structural issues within the context of their sexual and reproductive health domain. The main reason was given as the parents/caregivers' lack of knowledge of sign language that would be useful in delivery of the information.

*My parents I feel that they don't know how to communicate with me in sign language they always leave my problem to school teacher (16 year old youth, male Kakamega).*

There was especially a pervasive assumption amongst the teachers that parents were not doing enough to learn sign language.

*Parents who have deaf children do not care to learn sign language, how come their other hearing children are able to learn this language? (Male teachers, in Siaya).*

However, the young people put this in the context of the unequal power relations where their parents are being over protective of young people.

*They (parents) are cautious on that topic and feel it is time consuming when I start that topic its one way of starting a quarrel and being a child without respect (Female youth Mumias)*

*.....they prefer locking us at home by overworking us and ensuring that we don't have time to visit friends and get involved in bad habits causing those problems (female 14 years Kakamega)*

Parental reticence in providing sexuality education has also been noted in other studies with Deaf youth (Laitmon 1979; Schirmer 2001). Various reasons that are consistent with those identified in this study have been cited and include the notion that sexuality and reproductive health information should be provided at the school, the discomfort around talking about sexual and reproductive health, the lack of knowledge on the subject, the un-clarity about one's values around sexual and reproductive health, withholding information because of the notion that this would encourage young people to try out what they learn among others (Schirmer, 2001).

On probing further as to why parents do not have this language awareness, it emerged from interviews with parents that there were no avenues where parents could get this training apart from relying on their deaf children to teach them. In Mumias and Kakamega however, parents had received training on sign language from various NGOs and the Educational Assessment Resource Center however this support was mainly centralized within Mumias town and therefore in Siaya and in the more rural areas parents/caregivers were still unaware and had no access to opportunities for learning sign language.

The research by Valentine (2003) in Britain reveals the same constraints. In her research, hearing parents were presented as being unaware of the options available for their children and therefore the parents tended to follow the advise of the hearing professional to fit hearing aids on their children and also only learn basic lip reading skills and gestures as opposed to British sign language. Language choices define and influence the opportunities young people have in their day today spaces (ibid: 305). The research also revealed that a majority of hearing parents did not learn British sign language and so were unable to communicate with their children. Some children in her study reported being very close to their mothers and mothers as being interested in British sign language compared to fathers. Children also reported on the paradoxes of home as everyday spaces for deaf children where some relatives would be very supportive but also as a space where they experience a lot of loneliness and exclusions

Parents in Siaya noted that there are no support groups where parents/caregivers could access this support and receive classes on sign language. In Kakamega, however, parents within the municipality had formed support groups where they were able to access training on Kenya sign language from time to time. On another note, within the context of contentions between acceptable and unacceptable sexuality behavior for young people, even parents/caregivers who know sign language may be afraid of making graphic signs about sexual and reproductive health with their children. These signs tend to be very explicit and may be deterrence to parents/caregivers' ease of communication.

The challenge of parents not being able to access training on sign language should be seen from the backdrop of the fact that the Kenya National Association for the Deaf (KNAD) has as one of its objectives to train parents and other stakeholders in sign language. It was however revealed that due to poor funding, this has not been initiated. It was also noted that in situations where they have called the parents for training on sign language, few of them turn up due to poor mobilization but it is also notable that there is need for advocacy on the need for sign language for improved communication with their children because many parents may not be aware of the need for it. The dissemination workshop in Mumias revealed that even though Educational Assessment Resource Center had made arrangements for parents to be trained, the challenges of learning a new language in adulthood were given, as the reasons parents were not availing themselves. Later discussions with the Kenya Society for the Deaf Children in Kenya (A non governmental organization working on the wellbeing of Deaf Children) revealed that the non-governmental organization is working with parents in training them in Kenya Sign Language as well as mobilizing them to provide peer support to each other. The society has also developed a manual that is being used to train parents with children who are Deaf and Hard of Hearing.

Within the analytical framework adopted for this research, we were interested in getting the perspectives of young people about the role of their parents in sexual and reproductive health and decision-making. The Deaf and Hard of Hearing youth indeed averred that some of their parents were least involved on issues to do with their sexual and reproductive health. The youth noted that this was within the overall perception of youth and Deaf and Hard of Hearing youth in particular as being asexual and the perceived assumption that that deaf are different from other children. Within the context of having children perceived as disabled parents' reticence was also seen as a way of protecting them as revealed by the assertions of youth study participants.

*My parents are so strict and do not provide any information and are also always checking to ensure I am not doing anything fishy because they think I am disabled [deaf] and still a young boy (15 year old male youth in Mumias).*

This kind of attitude towards issues of sexual and reproductive health were cited by the young people as a form of injustice to the deaf youth that should be addressed as the revealed by study participants.

*Parents don't want us to know any secret thing about our own Secondary Sexual development and they don't want us to know sexual misuse or pregnancy. They are cheating us (13 year old female youth, class 5, Kakamega).*

The youth noted that the reason their parents do not provide information is because of the perception that their children are deaf and so are deemed "innocent and asexual" and do not need information. The young people were also afraid of asking for information from their parents because they were afraid of being seen as sexually active already.

The youth within this context of censorship also reported that most of them were not keen on discussing these issues with their parents as a way of protecting themselves but also dealing with possible repercussions of their censured sexual and reproductive health life. For example some of them reported that they were reluctant to approach their parents lest they become very inquisitive and snoopy. Within the context of cultural norms that vilify young people's sexual and reproductive health, the Deaf and Hard of Hearing youth were also seen as keen in conforming to these norms but also rebelling by keeping their relationships secret.

*I do not want to share anything with my parents; this will bring unwarranted "Inquisitiveness" [curiosity] to the whole issue (FGD with in school going female youth in Siaya).*

*My Parents are strict when it comes to that area of discussion. They prefer we not even think about it many times and when they suspect or find out we are doing these things they will start complaining "unstoppable[continuously]" (14 years female primary school youth Kakamega Mumias).*

*Talk to my parents about my sexual and reproductive health? I will be quarreled and seen as being disrespectful (15 year old female youth Kakamega)*

Such sentiments have the potential to affect Deaf and Hard of Hearing youth negatively in as far as their sexual and reproductive health wellbeing is concerned because the youth noted that due to parents being excessively harsh, they are reticent to talk to them as revealed by their narratives

*"Parents and teachers are harsh hence we do these things (engage in sexual relationships) in private we don't care to share with them. They tell us to work hard in school and do not bother to hear from us about our sexual and reproductive health needs (16 year old female class six Kakamega)*

Some youth however from both counties and especially the in-school youth noted that they receive information from parents albeit in a problematic way. The information they received from parents was varied and mostly was based on normative assumptions about the deaf youth as well as their reproductive health needs and was protective. For example, it was noted that information rotated around the need to avoid sexual transmitted diseases and becoming pregnant.

*My parents talk to me about dangers of sex and that I should just focus on my studies (17 year old in-school male, Siaya).*

The youth also noted that parents tend to scare them against getting pregnant with indications that they would be sent away from home when they fall pregnant and some reported every being caned when they informed their parents about friends of opposite sex. Overall the information that the youth reported getting from parents is seen as 'shallow' and may not offer them enough skills on how to seek services as well as negotiate in sexual decision making.

*Parents and siblings provide us with on shallow information e.g. avoid being friends with girls to avoid impregnating them and getting HIV/AIDS but to concentrate in academic work and bring ( 17 year old male in class 6 Kakamega)*

These findings are not only limited to Deaf and Hard of Hearing youth but apply to young people with disabilities in general. For example they corroborate those of a study carried out by Sait et al (2011:514) in South Africa on the challenges mothers face in nurturing the sexual development of their daughters who had intellectual disabilities. Overemphasis on pregnancy was seen as one of the key protective measure employed by parents in a context where there was high rate of sexual violation within the home and the community. We also situate the prevalent emphasis on negative sexuality within vulnerability discourses, which intersect with dominant gendered norms on sexuality, which overly scrutinize girls more than boys. These on one hand veil sexuality related issues that Deaf and Hard of Hearing boys undergo, fail to interrogate the real contextualized structural factors and norms which sustain vulnerabilities for Deaf and Hard of Hearing youth and deny youth opportunities for meaningful comprehensive discussions which could otherwise provide them with tools to navigate their sexuality complex yet enlivened worlds.

It is however important to note that the perspective that parents are not providing this support is not homogeneous and it varied according to the context (urban or what was perceived for rural) as well as the background of the children, it was also determined by whether the parent was seen as informed or educated as the following reveal

*I do not have any challenges because my parents know sign language. But if hard me possible write give others to read (if I can't communicate, I write it down). My parent's advice about good life in future (17 year old primary in-school youth in Siaya).*

*My parents are very open to me, they always tell me the truth since both are teachers, they always advise me on sex, [pregnant], and preventive measures (Mumias, 16 year old, female).*

Due to the fact that Deaf youth often lack networks in the home and family, there is a tendency for some of them to travel and connect with their peers within the deaf community. This puts them on a collision path with parents who accuse them of “loitering”. Parents are seen as protecting them from being preyed upon because of their being seemingly weak. The concept of loitering or as it used in the local parlance and as youth put it “*kurandaranda*” has connotations of going to look for lovers and engaging in sexual acts outside the home.

Some young people noted that they were not allowed to travel and interact with their peers to protect them but unfortunately this means that they did not access any information

*.... I am kept at home like a prisoner and I don't communicate with anybody since am the deaf at home ( Deaf Female youth 14 years Kakamega).*

### **Siblings as Spaces for Modeling Behaviour**

The Deaf and Hard of Hearing youth identified siblings as another important category of family members who bear significant influence in modeling sexual and reproductive health. For instance older siblings were mentioned to provide access to a cell phone. Older siblings also provided advice on positive sexual and reproductive health behaviour for their younger siblings through verbal discussions or mainly by modeling positive behaviour.

Findings from studies on the influence of siblings in sexual and reproductive health in Africa are not robust but few reveal critical sexual and reproductive health socialization process through non-verbal and verbal interactions. Appouh (2013) identified in a different study, diverse learning mechanisms among adolescents as they communicate with their peers. They include: “learning through opportunity” which involves overhearing the lived experiences of their siblings and their peers, “learning by differentiation” – not repeating an undesirable action by a sibling which led to an undesirable outcome like a sibling dying after abortion, and “learning by modeling behavior” of an older siblings positive or negative. Siblings are also avenues for counterchecking information passed on from adults and other sources (Bandura 1997). A study conducted by (Appouh 2010) in Ghana and Uganda on sibling influence on adolescent sexual and reproductive health indicated that siblings were an initial source of information and are seen by adolescents as a more legitimate source of HIV/AIDS and pregnancy knowledge than parents and were important in shaping the decision by adolescent in initiating or disregarding sexual activities. It should also be noted that most often, the siblings of the Deaf and Hard of Hearing youth are not Deaf or Hard of Hearing and therefore this difference in texture becomes important as a source of information and/or worldview. Therefore, the inclusion of siblings of Deaf and Hard of Hearing youth in sexuality and reproductive health education as mentors and together with their socializing mechanisms is important because they bear important influence on adoption of healthy or risky sexual and reproductive health attitudes and behavior.

### **Digital Sites as Enabling and Disabling Pathways**

Deaf and Hard of Hearing youth are now immersed in a world of multiple sources of sexual and reproductive information, of notable significance is the digital space which had provided alternatives for these youth to seek information about their sexual and reproductive health often by passing adult mediators. Because of the double role the digital space like the Internet can play in educating and entertaining youth, multiple interested actors have occupied digital positions and seem to compete for the attention of the youth including those who are Deaf and Hard of hearing (Oosterhoff, et al 2016). These actors include social media companies which seem to have blanket restriction of ‘pornographic-like content’ or wording even when these wording like breast could be

typed in by the youth to check for instance on breast examination. Other actors include internet engine providers; online sex educators who support youth with SRH information but face restrictions because the same terminology to access their site is used to access pornographic sites and involvement of pornography producers who provide limitless often visual content.

From our study some of the Deaf and Hard of hearing youth had access to cell phones and to video dens where they were exposed to pornographic content. These sites were considered by the young people as providing important sexuality education on what to do during intimacy, the types of positions and styles to adopt during intimacy since such information was not discussed during mainstream sexual education class. The narrative below is indicative of this state

*We get information by watching TV, we also watch pornographic videos and this can be sometimes very tempting for us to be involved in sexual activities (Female youth Primary 6 Kakamega)*

*We watch pornography and we can be easily misled. Most of them have a theme on the sex topic and how sex happens through prostitutes and drug abuse (14 years female youth primary 6 Kakamega)*

Pornography as a form of sex education is a recurrent motif in research on adolescent sexuality and reproductive health. A study conducted by Oosterhoff, et al (2016) reveals that the active mainstream guardians of sex education continue to restrict sex education in the private sphere but in the advent of the internet where there is more freedom youth have turned to internet pornographic sites which push sex to the public sphere. Oosterhoff, et al 2016 in their policy brief ask, “Is pornography the new sex education?” Young people are now producing their own pornography by taking nude photos and sending them to their friends. The same space has also been utilized to promote sexual violations among the youth.

However, we also note the positive spaces that open up when young people access sexuality and reproductive health through platforms seen as more positive and especially so within the context of the fact that the youth rarely receive adequate information in this area of their lives. Technology has a positive role in enhancing reproductive health of young people. Recently in Kenya, a sexuality education application was developed to fill the gap of inadequate information. This technology called Sex Elimu App is a new solution that has been developed in response to young peoples’ need for sexual and reproductive health information using Kenya sign language. The app teaches common terms but also leads the young people into responding to specific questions. This app was seen as a solution to the needs of young people where privacy and confidentiality has been an issue and the App was even downloaded in countries like the UK, South Africa within the first two weeks of its launch.

The challenges of such an App of course and within the context of our research is that one not only needs to have a smart phone, something that is out of reach of many young people but one also needs to be connected to the internet. Most young people in school are also not allowed to use mobile phones in school but this would be a good solution for the out of school youth.

There are also structural issues within the context of the programme being very expensive to maintain since it has to be developed continuously and based on the input of the deaf community and therefore a need for other stakeholders to come on board and support the continuous development of the App. The fact that there is a lack of enough signs in sexual and reproductive health would also mean that there is consensus that needs to be reached on how to present specific information. The need for working with a medical practitioner in development of the content in this app was also underscored by the developers (<http://techsahara.com/app-educates-deaf-sex-reproductive-health/>)

### **School as an Alternative Home and Teachers as Surrogate Parents**

There is wide acknowledgement that the school space is an important site for Deaf and hard of Hearing youth in accessing SRH education (Job, 2004; Swatz 1993; The knowledge sources in our study included teachers but also through intense peer-to-peer interactions. The findings of the research however also reveal that it was also a contested site. The role of passing information to the Deaf and Hard of Hearing youth should be seen from the context where most parents were reported as not playing this central role and therefore leaving it to the teachers. This was also because Deaf and Hard of Hearing youth spent most of their time with the teachers in boarding schools and therefore school for most of the research participants was seen as very important in passing reproductive health information and skills. Within the context of a situation where knowledge of sign language is limited at different spaces where deaf youth find information, it was apparent that teachers played a larger role as surrogate parents as well as sign language interpreters for the youth even outside of the school space.

*The young people even come to me for assistance even after they graduate from school. When they go home, they get challenges of communication and sometimes have to get letters from us to take to the doctor* (Female teacher Kakamega Mumias).

It is also important to note that given the context where the home was seen as a *place*, which was viewed as unfriendly to the young people, many study participants noted that they felt more comfortable in school, interacting with others and also their teachers. Within the context of poverty in their homes, it was noted that some youth wished to stay in school most of the time as noted during discussions on the training of youth researchers who revealed the perceptions of home as an unsafe space.

*“I prefer to be at school than home, I wish I was able to always stay at school”* (male youth aged 15 years ).

*Some come from very a needy background. There is a girl who was sick and had to be admitted, upon discharge, she was given permission to go home but before she could fully*

*recover, she came to school, when asked why she said “at home problem full, food zero, school better [At home there is no food and I feel better at school] (Teacher Kakamega).*

This situation was also reported in Kakamega and Siaya during the dissemination and validation workshops where it was noted that, when some of the parents drop their children to school, at the beginning of the term, they do not visit again or even call the teacher. In Siaya too this was reported as the case as the following reveals

Parents who are disengaged might be driven by the superstitions that sometimes accompany disabilities with some children being seen as a curse. It however important to note that there is a need to be careful when vilifying parents in this way because there may be other structural issues that were not fully explored in this research. Poor parents might not have money to keep on visiting their children in school and with constrained resources.

### **Contesting Needs in School and Notions of Taboos**

The research sought to find out the type of services the school provides for the deaf youth pertaining sexual and reproductive health services.

It emerged during discussions that information about Adolescent Sexual and Reproductive Health was passed on by teachers using diverse methods including sharing information during lessons, placing posters in strategic areas in school, sharing information during assembly time as well as in limited cases of one-on-one discussions. From the teachers perspective providing sexual and reproductive health information was done in the science and the life skills lessons in the curriculum, however the challenges of meeting the wider school curriculum meant that life skills was not prioritized and other examinable courses were given more weight.

The researchers did not identify the use of any structured curriculum in passing of reproductive health information. However, the research was able to do a review of a manual for information on reproductive health services for deaf youth prepared for deaf youth by one of the Non-governmental organizations working in Siaya. Others like technical schools reported that they did not have a curriculum but the dean’s office was usually in charge of guidance and counselling.

It is important to note that it is only in 2015 after the enacting of National Adolescent Sexual and Reproductive Health Policy that the government has provided a framework for Age Appropriate Comprehensive Sexuality Education (AACSE). However, there has been and imbedded curriculum which is meant for sharing sexuality education with youth in schools. There are various avenues through which this imbedding is done and this includes guidance and counselling sessions by teachers appointed by the head teachers, occasional sharing of information during the periods slotted for games and sports, sharing during other clubs like Christian Union and science clubs among others (Biggs; 2013)

Through charts, young people said they get information on how HIV/AIDS is transmitted, importance of as well as how to avoid unwanted pregnancies. It was however

noted by several youth that information from such charts was not self-evident and there was a strong sense that youth needed further training. They also felt that the other out of school youth who do not know how to read and write were being left out in disseminating information. Youth also revealed that they get more information from textbooks around issues of reproductive health. Other avenues utilized in school for passing information involved clubs and more so the Christian Union club but not sexuality education clubs.

Perceptions by youth on Teachers and school as sources of Information

*Teachers give us only half information that is good but others they hide (Secondary school male youth Siaya).*

When students were asked if there were any sexuality education clubs where they could interact and share information, they noted that such school clubs in this regard were non-existent in most of the schools for the deaf as the following narrations indicate.

*Me no hear of any health clubs and it is important to have the principal to start one” (17 year old male youth in primary school, Siaya).*

*We only have environmental clubs; we do not have one that teaches us how to take care of ourselves (20 year female old secondary school youth in Siaya).*

*We do not discuss these in Christian union; I wish it was done (male youth Mumias)*

Youth in Siaya reported that in some schools there were clubs but they noted there were no interpreters. Health workers ran these clubs but they noted that these workers were not consistent.

*Yes there’s sometimes a club in school. When sessions are on, sometimes there is no interpreter the solution to these problems is that counselors should come to school every time. Most of them do not since they are employed in health centers (Siaya, FGD with male youth in primary school Kakamega).*

However, some youth noted that these clubs tended to overly emphasize abstinence messages and so were not seen by young people as very useful. Indeed, youth require holistic information and education so that they are better informed about their sexual and reproductive health and rights and is thus able to make healthier choices regarding their sexuality.

Some teachers also reported that students were embarrassed during discussions on sexual and reproductive health.

When teaching about sexual and reproductive health girls feel ashamed, as boys and girls will not concentrate since they will be watching each other admiring each other and confusing the lesson.

Such perspectives on teachers dis-ease with talking about reproductive health issues are consistent with Kibombo’s et al (2008) research in Uganda. In this research, the authors noted that teachers reported being embarrassed when talking about sexual and reproductive health issues and this was seen as conflicting with their perceived role as role models. One would also argue that for the case of teachers working with children

with disability and in most cases seen as ultimate role models accentuates this internal conflict.

The protectionist discourses were also cited as possible barriers to effective delivery of information and sexual and reproductive health support. Some of the teachers it was reported tended to emphasize prevention of pregnancy and HIV and were more concerned with the shame the school will suffer due to possibilities of the youth getting pregnant as the following reveal.

*Our teacher advised us that engaging in sexual activities is bad in our school since it can cause school name bad in public [affect reputation of our school when all female pupils get pregnant (class 19 year old female youth class 6 Kakamega)].*

Underlying the notion of pathologizing the sexuality of Deaf and Hard of Hearing youth is the myth and misconception that deaf persons possess a risky sexuality since they are immoral and oversexed (Job, 2004; Schirmer 2001). This meant the negative outcomes of disease and unplanned pregnancies are blamed on the individual and not on the systematic silencing of sexual and reproductive health of the youth and the constant stigmatization on account of their sexuality.

The youth also noted that the information they receive from the teachers is very shallow and does not cater for their holistic needs due to the assumptions about their sexuality. Indeed many reported that teachers assumed that the youth were asexual and coated their information only in terms of preventing disease. This was also corroborated by some of the teachers who said that they acknowledged that even when the curriculum exists; it does not explore issues in depth.

*Teachers give us only half information that is good but others they hide (17 year old secondary school male youth in Siaya).*

*Teacher enough information zero [teachers do not give us enough information] (20 year old male youth secondary school Siaya).*

*Some teachers see nothing and know nothing [some teachers make a lot of assumptions] they tell you only learn and marry later (17 years old in school male youth in Siaya).*

The above metaphorical perspective that teachers know nothing and see nothing would be a parody to teachers' positions as knowledge bearers. However it is indicative that teachers need to be aware of the perspectives and realities of young people if they have to provide appropriate information and support. It is a call for listening to the voice of young people if we are to provide for their needs and programme adequately for them.

Assumptions about sexuality of youth by teachers were also demonstrated when probed about the importance of schools clubs as avenues for sharing sexual and reproductive health information. When probed as to why there are no active clubs in school, one of the teachers reported that the reason they did not have clubs is because young people could take advantage of this and discuss sexually explicit information. Discussions during validation meetings indicate the persistence of this normative discourse,

*When you leave them on their own for even a minute and you come back, you find them giggling and discussing very 'fishy' issues, when they see you they keep quiet (Teacher technical school and in-charge of guidance and counseling in a school in Siaya).*

These responses are consistent with a study conducted by (Job 2004) who argues that the myth-conception on sexual and reproductive health education motivates Deaf and Hard of Hearing youth to engage in unacceptable behaviour. Operating under this notion, some teachers continually lock out spaces like clubs where the youth can freely discuss and receive guidance on correct and useful sexual and reproductive health education. It is also consistent with research by Tushabomwe and Nashon (2016) that explores the effect of perceptions by teachers as well as other contextual factors in sexuality education in Uganda. The authors note that that teachers may also draw from the repertoire of available social as well as state normative framework in forming perspectives about sexual and reproductive health of the young people. For example they argue that teachers in this research were drawing from the religious norms of separation based on gender arguing that since people are segregated on the basis of gender in Mosques, this should be the case also in school. In that particular research too, teachers emphasized abstinence for students and importance of dressing decently for girls without providing other information on how to deal with gendered power relations in sexual decision-making as well as influence of other structural factors.

Some young people seem to have appropriated this discourse and represent themselves in a similar way. Some noted that if there was a club, there would be more challenges because;

*The deaf people like disagreeing [on one thing after another] and can waste a lot of time [without solving it] the best way of communicating is one by one not in group (16 years, female, Kakamega class 6,)*

The generational age differences between the youth and teachers also play out within the context where teachers are facilitators in a topic often perceived sensitive and private. Youth reported that they were not able to ask teachers questions even when they did not understand because sexuality was represented as taboo topic. Due to this, the youth also reported being uncomfortable when the lessons on reproductive health were underway. They noted that that young people who are deaf are forced to make graphic signs when referring to their sexuality compared to the hearing. As a result, they may withdraw completely from discussions.

The teachers also reported reversed power relations when the male youth exercised their power over female teachers during sexuality education sessions. This would be expected especially where some of the Deaf and Hard of Hearing might even be older than some of their teachers.

*When one is teaching about sexually transmitted diseases, girls are more interested in the topic but boys want to know much about sexuality [meaning sex] (Female teacher in a secondary school Siaya).*

The type of information passed in school was individual oriented as opposed to addressing the structural issues that affect sexuality of youth in general but also Deaf and Hard of Hearing youth in particular and was seen as not equipping young people with skills on self-efficacy in sexual decision making.

*Teachers tell us we should not be found two of us in the same place, If they find you walking with a boy they think you are discussing sex and you get into trouble (16 years female youth in Primary school, Kakamega).*

Due to the pervasive norm that sexual and reproductive health of deaf youth is a taboo topic, the youth averred that the topic itself invites notions of embarrassment and shame and therefore they were uncomfortable discussing it. For example youth were not comfortable with the way teachers presented information on their sexual and reproductive health during the assembly hours, as this was deemed embarrassing. This type of information passed during such open sessions was seen as discomfiting to the female students especially when it was framed in a way that placed blame on their behavior and they were implored “not to embarrass the school by getting pregnant (FGD Kakamega with students in Mumias).

The youth also noted that display of reproductive system during discussions in class especially in mixed sessions was inappropriate and this was accentuated for the female youth. Both male youth noted that during the discussions, the information passed to them was judged as being sexually explicit and some of them reported that during the discussions, they tend to get attracted to the opposite sex and the sessions do not equip them with information on how to control them.

*When it comes to learning about reproductive organs and parts, I feel shy and even frustrated to learn (loose interest in learning). It happens like that when we are in a mixed class of boys and girls. I feel also being in love to boys [sexually excited] during that topic (16 years, Female youth primary school Kakamega).*

### **Communication as a Structural Barrier in School**

Article 24 of the UN Convention on the Rights of People with Disability puts the responsibility of facilitating the learning of sign language and the promotion of linguistic identity of the deaf community on the government (ANPPCAN 2013). The Kenya constitution 2010, Article 793b) obliges the state to promote development of Kenya Sign Language (KSL) to enable communication among those who are deaf or have hearing impairments. However, the mode of communication is one of the key issues that Deaf youth have to grapple with on a day-to-day basis. We sought to find out if there were any challenges youth faced in accessing information and services due to communication related issues. For the case of teachers, it was argued that some of them have inadequate knowledge on sign language. The youth felt that the concepts on reproductive health were very complicated and yet sign language had only limited vocabulary for these. It was also

noted that the politics on what constitutes the appropriate sign language in the Kenyan context also determined if the young people understood the content delivered by the teachers or not. For example, discussions with Kenya National Association of the Deaf revealed that teachers are trained in different sign language regimes by the Kenya Institute of Special Education (KISE), as opposed to Kenya Sign Language that KNAD advocates for. These had resulted in tensions between these two institutions. Indicatively, literature specifies that KISE advocate for Kenya Sign Language for Schools (KSS), which is similar to Signed English (SEE). This however was not established concretely during the research.

Mwari (2016: 97) notes that Signed Exact English (SEE) strives to produce exact English sentences as well as give a literal representation of English. In so doing, she avers that this forces the English structure on the Sign language producing some form of communication that is neither English nor Kenya Sign Language. While the discussions as to whether such a system benefits children was out of the scope of this study, the interactions we had with the youth during the trainings and research indicated that most of them were using Signed Exact English with perspectives that this type of language enables them to understand English better and fit into the hearing world and in our research the peer researchers tended to use SEE in translating the research.

There is another signing regime called total communication that uses both signs and speech. Indeed Taegtmeier (2009:509) notes that there are different types of sign languages in Kenya. Some young people noted that they get the information from school but it is not adequate because total communication (where teachers use both signs and speech) is slow as indicated below

*Yes, I get the communication on sexual and reproductive health, but sometime I don't get all information because total communication is slow in communication (In school youth, Kakamega)*

*Since I am illiterate, I chatted with the chemist attendant and we used total communication so I think some information I may have been missed from the chat and so I probed my friend (Out of school youth Kakamega).*

Total communication is used especially in school where deaf youth learn together with the hearing. It was also seen as important in ensuring the Hard of Hearing did not lose their hearing completely by being only exposed to sign language. The official from the Gender and Equality Commission as detailed below supported this and noted:

*“The main challenges for deaf persons is the diversities of sign language and minimal standardization” (National Gender and Equality Commission Official (NGEC)*

This lack of standardization was quoted as one of the barriers to passing information to deaf youth

The effect of the diversity of signing regimes therefore not only affected the learning in deaf schools but also the passing of reproductive health information. In school research

participants noted that they sometimes do not understand sexual and reproductive health information when some interpreters do not sign the hand vocabulary.

Generally, there is community incompetence in the community as shown by the way most information in Kenya is transmitted through means that make information inaccessible to deaf youth. Indeed Morrell (2015) notes that while the government of Kenya launched a concerted effort in 2001 in disseminating information especially within the context of HIV/Aids, it was only in 2003 when information was provided using Kenya sign Language. This he notes is because it was only in 2003 that Kenya sign Language was officially recognized as a national language.

### **Peers and Friends and Sexual and Reproductive Health: Getting into the waters together**

Peers were also cited as one of the most common sources of information on adolescent and reproductive health of Deaf youth (Fitz-Gerald and Fitz-Gerald 1985; Guest, 2000). This was especially so for the case of in school youth who said within the context of the reticence of the adults to share information with them, their peers were the only resort for information. Peers can pass positive or negative information about sexuality and reproductive health.

However some out of school youth noted that they did not have a circle of friends around the with whom they could interact with to share information as the following reveals

*Since my workplace is in deep village, sometimes I don't have bus fare to go to Kaka mega to meet my peers so that we exchange information about sexual and reproductive health (Out of school youth, Kakamega).*

It should however be noted that in the absence of correct information, the information shared with the peer group circles could lead to negative sexual and reproductive health outcomes as the following narrative indicates:

*Most of the friends I have at home they are my peers and we always play funny and share information about sexual information in sign language stories (15 year old male youth Mumias).*

*Peers involved me in tasting that life [engaging in sexual activities] (16 years, female, youth class 6, Kakamega).*

Due to the censorship of information, the Deaf and Hard of Hearing youth secretly resort to peers so as to circumvent this censure. This is in line with the contention by Sait et al. (2011:502) that due to the silences and over protection surrounding the sexuality of persons with disability, they become “aware of their sexuality through personal erotic experiences, peers groups, communities and media”, but often with potential deleterious consequences as the following reveals;

*We have good and bad friends- some good friends will advise us wisely on how to be careful while other bad friends are after spoiling our life by misleading us to engage in bad habits (Female 16 year 's Mumias)*

*When I am at home, I sometime mixed with young people of my age groups; sometimes we go for video shows at night. Some of the video is pornographic (14 year old Male youth class 8 Kakamega).*

*From the Internet we watch friend's different sex styles and we feel this is normal (26 year old female youth in technical schools Siaya).*

This supports findings of another study that reveals that the deaf grapevine is very effective in passing sexual and reproductive health information. One study found that deaf respondents were seven times more likely to receive information about HIV/AIDS from their friends than their hearing counterparts (Chava et al 2005:625). It is important to note that most out of school youth reported that they rely more on watching pornographic movies with friends in getting information. In school male youth reported experiencing pressure from friends to be involved in sexual activities as a sign of proving their virility and masculinity. For girls, the idea of being seen with a boyfriend by peers was what sometimes brought different friends together.

*Peers sometimes mislead us by saying if we don't involve {in sexual relationships} we are not strong (18 year old male primary school youth in Siaya).*

*I have learned from peers and through my experience. I have been seeing it among my friends and many of us youths like being loved and always telling stories how we have a boyfriend and how good we feel while together (16 year old female primary school youth in Siaya).*

### **Exploring the (In)competence of the Health Facilities as Avenues for Reproductive Health Information and Services**

Health centers play a major role in dissemination of information about adolescent sexual and reproductive health information. However, it was noted that the Deaf and Hard of Hearing youth encounter hurdles in accessing this information, mainly due to the assumptions about their sexuality as well as well as sign language communication problems. Youth noted that they had to resort to writing notes to the doctors when they went to see them. This was however more critical for some of the out of school youth who said they did not know how to read and write and therefore could not communicate using notes as the following interview data revealed:

*Challenges I face in accessing information is that I lack interpreters in the centers to talk to the doctor (out of school female youth Kakamega)*

As noted by Morrell (2013:23), the challenges that deaf youth face when accessing information or services was due to the presence of a third party in form of a sign language interpreter, typically a family member thus restricting confidentiality.

*The doctors ignore our pleas because communication is a barrier (26 year old Out of school youth Kakamega)*

The Kenya National Association for the Deaf noted that they had made efforts to work with doctors and train them in sign language. Kenyatta National Hospital, the largest

referral hospital in Kenya was the first to plan this. However as the following data indicates, there is no goodwill for these trainings.

*We tried with the hospital staff in Kenyatta National hospital and only two were interested. The uptake and interest to learn sign language is low (Member, Kenya National Association of the Deaf).*

The sign language incompetence was witnessed in drug stores where an out of school youth noted that the local attendants were lacking sign language skills and could not communicate with them effectively.

*When we get drug from chemist shop the attendant never give us enough instruct how to use them. They are only for cash (out of school female youth Siaya).* While noting that the inability of the health workers to communicate in sign language was a practical challenge, sometimes this was blamed on the attitude of the health workers and not the ability to communicate for example, one youth even demonstrated how these workers should exercise some form of competency by checking on their attitude when dealing with youth. For example he noted,

*Use friendly communication if you don't know any sign language but you could understand client (deaf youth problem) if you are concrete careful, "No, harshly and negative attitude" "use suitable facial expressions for example "always say easy" "hallo welcome: me help you how? [ the health works should have a friendly attitude even if they do not know sign language]*

In addition it was noted that, sometimes the local pharmacist is not proficient in sign language and therefore could read the gesticulations wrongly and therefore misinterpret the communication. The misinterpretation could lead to inefficient health interventions.

*"Most of the information obtained is on HIV/ AIDS, Sexually transmitted Infections and health. However, the problem is that most doctors and health workers cannot communicate with people who are deaf to meet their health needs. Also because information is not in sign language, it is difficult for people who are deaf to benefit. I remember-I had to take my son to the centre to act as my interpreter. That is the only way I can benefit from information provided from these centres since there are no sign language interpreters at these centres" (Deaf adult).*

In 2015, in addressing this issue within the health centers, Kenya National Association for the deaf signed a Memorandum of Understanding with Health facilities that would see these providers mobilize deaf persons, look for interpreters and advice the hospitals on what works best as far as working with Deaf people is concerned. It is expected that this will ease communication barriers that young people face as they seek health services.

Even organizations that are entrusted with the welfare and wellbeing of the persons with disabilities noted problems with having deaf interpreters in their own organization. For example, while the National Gender Equality Commission has made attempts to hire sign language interpreters and hire deaf staff but due to limited education levels only two

people applied for the job of translators. Such a scenario is then attributed to their lack of education as the discussions with the equality commission reveal

*Among the groups with disability, the deaf are the most disadvantaged and complex. Education levels are low (National Gender Equality Commission official).*

### **Community and Disabling and Enabling Perspectives**

We note that unlike their hearing counterparts, Deaf and Hard of Hearing Youth are faced with even more limited opportunities for accessing information within the community. Being a Deaf and Hard of Hearing youth means that incidental learning through verbal discussions, literary text, radio or television by passes most of them according to (Fitz-Gerald & Fitz-Gerald, 1985). The community was identified as an important site for enabling or disabling access to sexuality and reproductive health information. For example within the community there are various formal and informal institutions (norms) that govern sexuality and reproductive experiences and practices.

One of these is the religious institution like the churches, which were found by parents to be important in providing Sexual and Reproductive Health information and sexual morality. For parents these religious institutions were important spaces for reinforcing and reaffirming the messages they were passing to the Deaf and Hard of Hearing youth at home. Most of the messages within these spaces centered on abstinence, preserving the purity of the body, prevention of pregnancy and diseases and the punishments that befall those who fall short.

However, the role of the church in enhancing these messages was inadequate because as noted by one parent in the dissemination workshop. Inclusion of deaf sign language interpreters during church preaching and other related services was minimal. Even when attempts had been made to include sign language interpreters, they were viewed with excess curiosity and anomaly by the congregants to the extent that the church officials had to do away with them. This hearing bias therefore excluded the Deaf and Hard of Hearing community from accessing vital sexual and reproductive health information that was relevant to them.

While it is expected that non –state actors would also work together with the government in provision of services. It was revealed that only a few of these were reaching out. Many of the sexual and reproductive health programmes in schools due to budgetary constraints may not programme around the needs of youth with disabilities mainly because of the extra costs associated with such programmes. An operations research carried out for a project that was implementing sexuality and education programmes in school in Uganda in 2013-2016 indicated that the programme did not reach out to special needs schools. The project leaders reported that even though in the beginning there was an attempt to include schools for children with children with disabilities, the cost of doing so was very high and for example in twenty one of the schools for the deaf targeted initially in this

project, the teachers noted that it was difficult to translate the sexuality education terms into sign language and so the focus on schools for the deaf was shelved (Okwany et al 2016:20-21).

It is therefore clear that even though young people with disabilities require and may express a need for sexual and reproductive health information, the costs of programming around such children and youth is often given as reason. A question that needs to be raised is why donors and policy makers would see such a cost as unjustified in the first place. It is also important to note that the UNESCO (2009) guidelines on provision of Sexuality education programmes put a firm emphasis on the need to focus attention on young people with disabilities.

### **In-Conclusion: Contested Spaces, Enhancing Competence in Sexual and Reproductive Health of Deaf and Hard of Hearing Youth**

Space has emerged as important in the way deaf youth and their sexuality is perceived (or self-perceived), as well as in access to services. We unearthed a range of discourses that govern the sexual and reproductive health of deaf and hard of hearing youth in these sites. These discourses have been traced to different sites, of the school, the home, and the health care seeking sites as well as the community and other symbolic sites like digital spaces and the state.

For example, school has emerged as an important but also a paradoxical space. It is a space where sexuality of Deaf youth is enacted and experienced, where discourses of (over) protection and care and problematic sexuality live hand in hand with those of censure and blame. It is also the school as a specific space where access to these services is enabled. This enabling within the specific space inheres from the fact that information is provided for Deaf youth in this space but also that teachers play a specific role of surrogate parents thereby the role of information. In playing this surrogate role, teachers were however reported to be gatekeeping the sexuality and reproductive health of Deaf and Hard of Hearing youth in ways that were sometimes seen as problematic. These findings point to the need for engaging with such shortcomings, in-competencies in these sites but most importantly to make these sites to respond to the needs of deaf youth.

The discourses that circulate in these sites are what have been termed as ‘Myth-conceptions’ (Job, 2004) and they may have negative effects on youth. These perceptions may also be exclusionary and serve to constrain the space in which meaningful dialogue about the reproductive and sexual health needs of Deaf and Hard of Hearing youth takes place. The emphasis of stereotypes may also eclipse the positive aspects of Deaf and hard of Hearing Youth identity and may also fail to nuance the problematic of observed character. The findings in this research are consistent with the assertion by Morgan et al (2009) who note that other axes of difference like space influence the experiences of deaf youth in that there are some spaces that might feel safe for the young person to enact his sexuality and there are others that were seen as being hostile to the young person.

At the macro level of the state emerging as important. For example, the policy inertia around enhancing communication pertaining to communication as a key barrier. Kenya Human Rights Commission in their compendium to the convention on the rights of people with disabilities in Kenya, note that there is a need for a sign language policy in Kenya within the public service. This would ensure that sign language interpretation

services are provided in all government sectors as well as in media broadcasts. They note that it is important for the government to cater for the costs of these language services as opposed to ceding this role to non-governmental organizations, or the deaf, as it has been the case.

The state as the final arbiter of sexual and reproductive health and rights of Deaf and Hard of Hearing youth can be seen as having abrogated in its role by failure to put in place a curriculum that can address the reproductive health needs of youth in general and Deaf and Hard of Hearing youth in particular. This has left space for ad-hoc activities by non-state actors who lack a standardized curriculum but most importantly lack awareness that sexual and reproductive health issues may need to be communicated differently because of the reliance on the spoken language as the medium for communication. A realization that this curriculum beyond addressing the needs of the Deaf and Hard of Hearing youth, may also call for the need to listen deeply to the context and needs and understand notions of obscenity and inappropriateness vis-à-vis what can or cannot be communicated through sign language is an exercise that requires a continuous and ethical dialogue. Overall we point to a need for enhancing the competence of these spaces as pathways to sexual and reproductive health for Deaf and Hearing youth.

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