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Overcoming Communication Barriers in HIV Prevention among In-School People with Disability (PWD) In Ekiti State - A Case of the Hearing Impaired and Visually Impaired Population

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Abstract

People with disability are at significant risk of becoming Human Immunodeficiency Virus (HIV) infected due to various factors including lack of education and resources to ensure safe sex, risk of violence and rape, stigma and lack of legal protection amongst others. Situation analysis of HIV prevention intervention amongst in-school PWD in the three specials schools in the state show that 48% of the total populations in these schools are hearing impaired, 16% visually impaired and 6% intellectually impaired. To this end, Ekiti State AIDS Control Agency with the funding of the World Bank and in collaboration with a Community Based Organizations (Eyelosun) carried out a two year intervention programme targeted at reaching the PWD population with HIV prevention services. The project community Entry phase activities included Issue Based Advocacy, Selection and Training of PWDs as peer educators, Community dialogue, Interpersonal Communication and Focused Group Discussions. Age peers' education approach was used to build the capacity of PWDs on HIV prevention. Peer Education manual and IEC materials were produced in Braille and sign language (target group specific communication materials) to ease communication barriers. Thirty five able teachers with specialization in Braille and sign languages were selected and trained as Peer Educator Trainers (Training of Trainers TOT) and 25 PWDs (hearing and visually impaired) were selected and trained by the trained teachers to carry out peer education using the Braille and sign language manuals. The use of Braille and Sign language HIV prevention specific materials to communicate with PWD improved their understanding and knowledge of HIV/AIDS with 80% increase in HIV Counseling and Testing (HCT) uptake and other HIV services. There was active participation of PWD in all the structural interventions including Community dialogues and Anti-AIDS club. However, the intellectually impaired, who are highly sexually active and at risk of HIV remain a neglected population due to communication challenge.

Keywords: In-school people with disability; HIV/AIDS prevention

Introduction

According to a United Nations (UN) report, an approximately 15.6 percent of the world's adult population is living with disability [1], with 80% of People with Disability (PWD) living in the developing world [2]. PWDs are at significant higher risk of becoming infected with HIV as disability could make a person more vulnerable to HIV infection [3], this is as a result of many factors including lack of education, resources to ensure safer sex, risk of violence and rape, stigma and lack of legal protection amongst others.

Persons with disabilities have been documented to engage in behaviors which place them at risk of HIV infection, such as unprotected heterosexual or male-to-male sex (including in the context of sex work) and injecting drug use. A large percentage of persons with disabilities will experience sexual assault or abuse during their lifetime [4]. PWDs in specialized institutions, schools or hospitals are at a particularly high risk [5]. In his handbook on preventing HIV among persons with disabilities, Ivom highlighted the need to provide persons with disabilities with behavioral change information on sexuality, sexual health, and HIV through an appropriate medium that will enable them take action [3].

Ekiti State which is located in the south west region of Nigeria as one of the 36 states is noted for relatively high coverage of educational and health facilities. The state over the years have been in the fore front of efficient and effective of HIV/AIDS service delivery in Nigeria as evident in the State HIV/AIDS Response Review and Strategic Framework. Ekiti State has an HIV prevalence rate of 2.9%. Ekiti State has a high number of people with disability, though no official data exists on the population of PWDs in the state. The state has three special schools dedicated to PWDs as well as other treatment/rehabilitation centres but HIV prevention program has never been extended to the centres. To this end, Ekiti State AIDS Control Agency with the funding from the World Bank and in collaboration with Eyelosun a Community Based Organization carried out a two year intervention programme targeted at reaching the PWD population with HIV prevention services, as well as build sustainable structure that will ensure continuous access to prevention, care and support services for PWDs in Ekiti State.

Materials and Methods

A situational analysis of in – school PWDs in all the three specials schools in Ekiti state was carried out and two target population (hearing and visually impaired) of PWDs were selected for the project. The project implementation was done in three phases as stated in the National HIV Prevention Plan [6]. Entry phase activities included baseline survey, Stakeholders' meeting and community dialogue. Project goal and objectives were shared with stakeholders during this meeting. The intensive phase activities focused on delivery of the

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Minimum Prevention Package of Intervention (MPPI) to the target group where behavioural, biomedical and structural interventions were carried out. The Minimum Prevention Package Intervention (MPPI) is a combination prevention strategy designed in response to current global thinking that prevention program should include a set of approaches in the three level of interventions; This include Behavioural (Outreach, Peer Education, etc.); Biomedical (HCT/PMTCT/STI Control and Condom program); Structural (Community Mobilization, Income Generating Activities, Capacity Building, Policy and Legal Issues) to address barriers to change at individual, community and environment levels. The project closed with some exit phase activities which focused on sustainability of the gains derived from the project, end of project evaluation and endline survey was carried out. Various national HIV prevention tools were used in data collection over the two year project implementation period, while data was analyzed using Statistical Package for Social Sciences (SPSS20) and District Health Information System (DHIS2.0).

The Community Entry phase started with issue based advocacy, selection and training of PWDs as peer educators. This was followed with preparation, domestication and production of target specific peer education manual in both Braille and Sign Language for visual and hearing impaired respectively. The intensive phase utilizes a combination of different strategies tailored to the need of the audience. These activities include Community dialogue, Inter Personal Communication, Focus Group Discursion and Age Peer education activities to ensure community participation. The need for culturally acceptable and target specific information materials and its effect in ensuring participation of PWDs in HIV prevention activities have been identified [7,8].

200 copies of peer education manual was produced, 1, 747 Braille and 1, 000 sign language copies of IEC materials was produced and distributed. Bill Boards with messages that address disability and stigma were designed and erected in strategic locations through the state, Thirty five able teachers (12 males and 23 females) with specialization in Braille (10) and sign languages (20) were selected and trained as peer educator trainers (TOT). Amongst the special students (hearing and visually impaired), 25 Peer Educators (13 males and 12 females) were selected and trained by the trained teachers to carry out peer education using the Braille and sign language manuals. Selected Health workers were trained on effective communication with PWDs for HIV/AIDS service provision. While PWD led Anti HIV/AIDS clubs were formed in each school.

Results and Discussion

The organization in collaboration with Ekiti State AIDS Control Agency designed a comprehensive package on combination prevention for two years with special focus to improve on communication strategies which has been the bane of inclusion of PWDs in HIV and AIDS program in the state. The organization rolled out a number of activities based on evidence from the findings of stakeholders profiling and the rapid baseline assessment conducted at the project entry phase. This project cycle are divided into three major phases that include entry, intensive and exit phase with defined activities to reach PWD with prevention messages and services. The intervention was carried out in the three project sites namely; School for the Blind and the Deaf, Ikere-Ekiti; School for the Deaf, Ikoro-Ekiti; and Government Special School, Ido–Ekiti. After community mapping and branding, 500 Peers were selected and enrolled into the two year program by the trained PETs.

At the entry phase, 12 Advocacy visits were conducted to the community host and the gatekeepers and other relevant stakeholders to enlist their support, acceptance and approval, a specialized advocacy kits were designed and distributed during the visits to reinforce the advocacy messages. The organization also received technical support from Ekiti State Strategic Behavioural Communication Technical Working Group and the Good Samaritan International in the development and pretesting of the communication tools, Peer education manual, IEC materials and workbook in Braille and sign language.

Minimum Prevention Package of Intervention (MPPI) is the national standard for HIV related behavioral change programs. The MPPI ensures target population are reached at individual, group and community levels utilizing a combination of structural, behavioral and biomedical interventions tailored to the specific need of the target population. Within the two year period of the project, a total of 514 PWD were reached with MPPI.

The Figure 1 below shows the number of PWD reached disaggregated by sex and type of impairment.

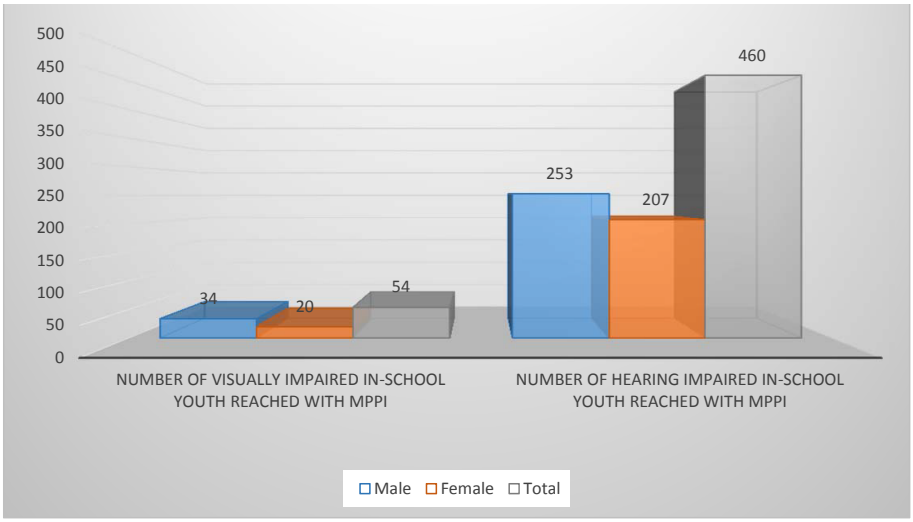

Figure 1: Number of PWD reached with MPPI disaggregated by sex and type of impairment.

Training of specialized teachers in each school as ToT was very effective as the teachers in turn trained peer educators selected from among the PWDs using either Braille or Sign Language manuals depending on the type of impairment. The peer sessions were not only useful in presenting peer specific information on HIV prevention, care and support and other health related information, it also helped in discussing challenges experienced by PWDs in access health care at the community level. Earlier studies had shown that higher risk of HIV infection among PWDs is attributed to the challenges PWDs experience including poor access to information about HIV/AIDS and safe sex, inadequate treatment programs, and issues such as confidentiality within the community, difficulty in getting information from the media and lack of specific targeted prevention programs [9,10].

The PWDs, during their peer sessions identified the various barriers to accessing healthcare services by the target group. These barriers were used to develop talking points and disseminated in a training organized for health care workers. The training focused on effective communication and stigma reduction by health care workers in caring for PWDs – the two most prominent challenges identified as barrier to health care access by PWDs Ezinma and Kelechi. The use of different but appropriate mode of communication that are PWDs friendly such as pictorial, role model, Braille, Audio materials, Repetition and play away method significantly improve access to health services. Specifically, the use of Braille and Sign language HIV specific materials to communicate with PWD improved their understanding and knowledge of HIV/AIDS while continuous interaction/training of health care workers led to 80% increase in HCT uptake and other HIV services. This is in line with Ezinma and Kelechi submission in their report that poor access to HCT among PWDs is attributed to low knowledge of HIV and lack of skills among teachers and health workers to effectively integrate HIV prevention to PWDs activities [11] (Figure 2).

Situation analysis of HIV prevention intervention amongst in-school PWD in the three specials schools in the state show that 48% of the total populations in these schools were hearing impaired, 16% visually impaired and 6% intellectually impaired while the remaining 30% have more than one type of impairment (Figure 3).

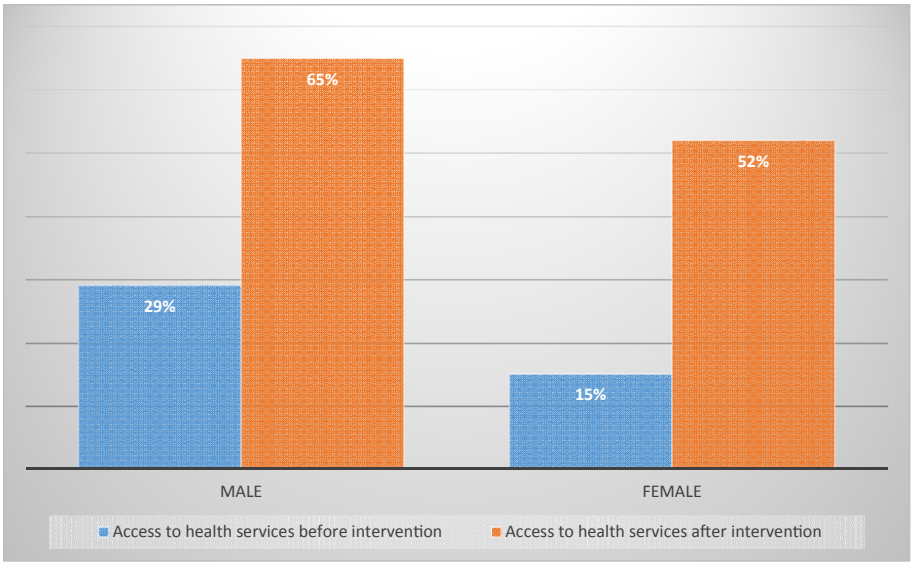

Figure 2: Improved access to health services attributed to reduction in stigma from health workers.

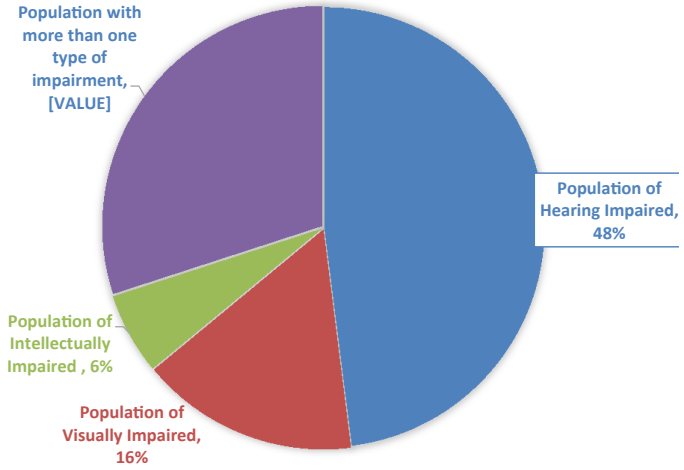

Figure 3: Distribution of in-school PWDS in EKITI state by type of disability.

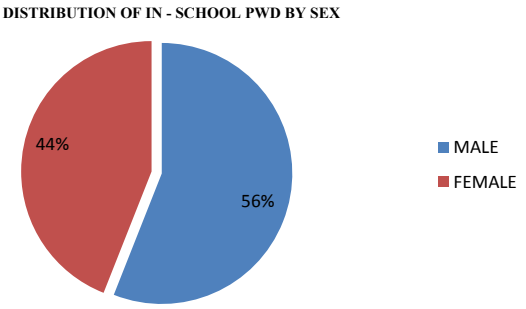

Figure 4: Distribution of in-school PWD by sex.

The sex analysis of in–school PWDs in Ekiti state reveal that male PWDs were more (56%) than female (44%). An indication of gender disparity in access to education by PWDs. Research studies in Nigeria have documented the inequality in access to formal Education in favour of the male; despite the nation's commitment to equality of all, irrespective of race, sex or gender [12]. It is there no surprise that access to education for PWDs shows a male dominance reflecting the overall national inequality. It should however revitalize our collective effort in promoting education of the girl child. The difference is also a call for all stakeholders to involve PWDs in education programming for the girl child across Nigeria (Figure 4).

Conclusion

There was active participation of PWDs in all structural interventions including community dialogues and Anti-AIDS club. The project successfully helped to bridge the communication gap, increased in the knowledge of hearing and visually impaired persons on sexuality and reproductive health, improved health seeking behaviors and access among PWDs as impact evaluation has shown. It is hoped that gains of the project will be sustained beyond the project cycle. There is the need to intensify action on HIV prevention among neglected populations and advocate for funding of interventions targeting PWDs either in closed settings (institutions) or in the larger community. Though this project was able to work with visual and hearing impaired PWDs, however the intellectually impaired, who are highly sexually active and at risk of HIV remain a neglected population due to communication challenge.

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