

*Anna Katrina R. Nicolas*

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## The Relationship of Profile into the Level of Participation in Advocacy Work: A Case Study on ASP's advocates

### INTRODUCTION

Individuals who are considered PLHIV<sup>1</sup> and at the same time are working as advocates for HIV/AIDS are solving challenges regarding HIV/AIDS prevention wherein knowledge on sociocultural and personal factors well-known to their situations is required because having such knowledge will help them in reducing psychological burden and promoting health maintenance especially for people with HIV (Sankar, 2011). In the Philippines, non-governmental organizations (NGO's) play a vital role in implementing HIV prevention programmes in the general and for high risk groups like the PLHIV. Peer paraprofessionals or assistants also known as advocates offer counselling in a systematic way which guides them in selecting specific activities appropriate to the level of readiness of a person to change his or her behaviour towards the situation (Tumwine, 2011).

Through this study, the advocates profile will prove the relation of their involvement to advocacy work they typically support. It shows the relation from the narrative manner about the engagement or participation mostly the advocates give their ability corresponding to their profile or status. Hence, there would be a comparison of stories with the relationship of this profile to the advocacy work they participate in. Being the key informants, PLHIV advocates of ASP are studied to what means they handle to keep the eagerness and motivation in pursuing the advocacies that will in return affect their clients as they themselves experience being HIV positives.

Furthermore, this study seeks to recognize how effective advocates perform with their interest on promoting advocacy works and their exceptional participation throughout the activities of the organization they belong to. This research argued that a profile

<sup>1</sup>PLHIV People Living with HIV

status of an advocate can be a factor of proving the level of engagement they do in an advocacy work thus it cannot be a hindrance as a way to help promote HIV/AIDS prevention and to spread information in the Philippines for they are also experiencing the said illness. It will distinguish the level of participation an advocate will or may accomplish. This may prove that some advocates who are PLHIV were participative because of the specific profile they possess and the identification for having the influence to those who are HIV positives were easy to deal with.

Perhaps the advocacy programs will expand the information about HIV advocates' participation in advocacy works as it brings awareness on HIV/AIDS in the Philippines particularly in Manila. ASP advocates contribution and support to the advocacy, makes the situation more manageable in helping the PLHIV community in developing and understanding advocacy works. To a larger note, this study can be recommended to the HIV community for their betterment and to develop each member's capacity on building advocacy works in improving the state health systems of HIV/AIDS in the Philippines. Ideally, this may also help future researchers in exploring more about HIV/AIDS, advocates, and advocacy work. More so, this research may serve as a source of data for further studies.

## **LITERATURE REVIEW**

This literature discussion consists of three topics that gave focus on the PLHIV (People Living with HIV), AIDS advocacy prevention, and NGO's AIDS advocacy in the Philippines. This research discusses aids advocates from non-governmental organization (ASP) that shows advocacy prevention and clarifies their advocacy works and level of participation to it as they are PLHIV. For the literature gap, there is inadequate review of what specific profiles of an advocate may consist of and what kind of profiles do advocate has to still perform a participatory advocacy work. Also, the literature about types of advocacy that is needed to present and be added on proving the connection of profile to what level of engagement an advocate does to his/her advocacy work.

### **PLHIV (PEOPLE LIVING WITH HIV)**

Individuals who are considered PLHIV and at the same time are working as advocates for

HIV/AIDS are solving challenges regarding HIV/AIDS prevention wherein knowledge on sociocultural and personal factors well-known to their situations is required because having such knowledge will help them in reducing psychological burden and promoting health maintenance especially for people with HIV (Sankar, 2011). PLHIV infections are resilient, despite the physical, psychological, and social challenges of this illness. This resilience among HIV positives should be directed toward motivation and disease management strategies so that this may influence their health outcomes (De Santis, 2013). Those who are discriminated and experiencing stigma are still resilient despite of this disease they have. HIV-related stigma is all over in the lives of people with HIV. It marks people as different and unusual just because they are positive. From experiencing stigma, this establishes discrimination and sometimes violent treatment to those people living with HIV. There are also stigmatizing attitudes that often take the practice of discrimination. For many PLHIV, the expectation of being discriminated prohibits social attachment and participation even when actual cases of discrimination are unusual (UNAIDS, 2011). Stigma can lead individuals to reduced self-confidence, loss of motivation, withdrawal from social contact and avoidance of work and health interactions (UNAIDS, 2011). Stigma and discrimination also play a significant role in the development of the HIV illness. It is well recognized that people living with HIV and AIDS experience this stigma and discrimination in an ongoing basis (Skinner D., 2004). These two have impact in which they go to the individuals infected with HIV and reach into the society as a whole. Both are disturbing the function of a community and gets more complicated to prevention and treatment of HIV/AIDS. Stigma also introduces people to a desire where they need not to know one's own status, and in testing, accessing the treatment for a PLHIV is being delayed. At a different level, stigma always weakens the person's identity and capacity to cope with the suffering they are experiencing.

Fear of discrimination limits the possibility of admission of their health statuses even to the most possible and important sources of support such as their own inner circle which includes family and friends (Rai, 2008). Also, stigma has impacts on behaviour change as it limits the possibility of using safer sexual practice wherein behaviour such as wanting

to use condoms can be seen as a sign of HIV, leading to rejection and stigma (Skinner D., 2004).

#### AIDS ADVOCACY PREVENTION

Together with the rest of PLHIV, these advocates promote specific behaviors such as HIV testing and treatment participation, condom use, and as well as general warning messages about protecting oneself from HIV infection (Tumwine, 2011). The peer-based participatory communication strategy was effective for encouraging condom use with casual sexual partners in the intervention group. It specifies that participatory involvement is the major driving force for HIV-related safer sex behavior and can be recommended to promote safer sex practice among men having sex with men (Yun Gao, 2007). Peer paraprofessionals or assistants also known as advocates, provide counselling using a systematic manual which guides them in selecting specific activities appropriate to the level of readiness to change a specific behaviour (Cabral, 1996). Another, with the help of paraprofessionals in HIV prevention, services can be an effective way to improve and spread services for women. There are also advocates advocating for this illness prevention and these people start from orienting youth. With this they choose to have an advocacy work for schools to provide effective HIV and sexuality education. As an including advocacy training in health education professional preparation, programs will focus on promoting advocacy among health education for faculty and students, and provide creative strategies to incorporate advocacy knowledge and skills into health education coursework (Thompson, 2012). While they work on treatment advocacy based in AIDS service and on clinics, they also engage HIV positive into care and support treatment observance only through centered counselling (Bogart, 2012).

HIV advocates promote health prevention from such illness that can destroy some lives and the feeling of being discriminated may be reduced from experiencing the support or the encouragement from the advocacy work itself. Hence, it is possible that the fear of being discriminated will be lessened. Further, HIV prevention interventions that teach risk reduction skills and then encourage participants to advocate behavior change to others appear to strengthen participants' capacity to change their behavior to reduce HIV risk (Kelly, 1997). Behavior can somehow be connected in participating within advocacy

works. Behavior seemingly affects the views of the advocates' clients on how life can be for them with the fact that s/he is an HIV positive. Risk reduction skills are included because these can strengthen the person from the condition (Kelly, 1997). It has to begin with the youth. Being an advocate, it is an advantage to those who encourage youth, for it is important to be oriented on promoting prevention as early as possible and develop change for controlling increase of HIV in the Philippines. It is a big impact to produce such progress in advocacy work and support advocacy participation with the advocates. To be effective and sustainable, HIV-prevention interventions need to be sufficiently powerful to counteract prevailing social norms and diffuse through the targeted community to provide social reinforcement for behavior change (Latkin, 2006). Behavioral interventions may enhance or introduce new identities and social roles to the extent that network members may discuss social approval to reinforce these identities and roles, leading to sustained behavioral risk reduction and changes in risk behavior norms (Latkin, 2006).

#### NGO'S AND AIDS ADVOCACY IN THE PHILIPPINES

In the Philippines, NGOs play a vital role in implementing HIV prevention programmes in the general and for risk groups like those PLHIV. According to Morisky (2010), NGOs fill the gap within the Catholic Church and from the government agencies to implement sex education and distribute contraceptive notions and condoms. Being offered by NGOs, non-formal education programme in a country such as the Philippines highlights the importance of environmental factors and the country's analytical ability in modifying HIV prevention behaviours.

This emphasizes the importance of developing structural and organizational involvements to prevent HIV/AIDS. In addition, to improve knowledge, efficacy, and skills related to needle use and safe sexual practices, health workers involved in these non-formal educational activities should work closely with community to create a supportive environment for HIV prevention (Morisky, 2010). AIDS advocacy works such as one of the program prevention called an *HIV awareness day for youth, PLHIV, and other links about the illness* are commonly known to promote awareness. This program continues to invest in scientific advancements like a vaccine and cure without forgetting the importance of

prevention plans to ensure equal access to information and healthcare for everyone. They will promote HIV testing, fight stigma, and start the essential conversation which concern as one of the social issue we encounter (Youth, 2008). For the selected organization of this research which is the AIDS Society of the Philippines (ASP), its common interest is into preventing the spread of HIV/AIDS and its one mission is on the promotion and support of activities to prevent and control the spread of HIV/ AIDS.

### **RESEARCH PROBLEM**

For the general problem, the study aimed to know how the profiles of the informants relate to their level of participation in advocacy work. Hence, this proposed study seeks to answer the following specific questions:

- (a) What is the profile of the advocates?
- (b) What are the available advocacy works?
- (c) What is the PLHIV advocates extent of participation in advocacy works?

### **THEORETICAL LENS**

The theory applicable for this study is Biosocial Citizenship from the concepts of Nikolas Rose and Carlos Nova's. Biosocial citizenship refers to a special kind of defining the individual by taking into relation the role of both biological and social aspects (Ene, 2009). Biosocial citizenship theory addresses an individual's choice of membership and the consequences of that choice. Historically, biological definitions of individuals are classified to their outer appearance: race and ethnicity that was based on physical features. Another means to discern people based on their biology is to divide them into groups: the healthy and sick, the sane and the mentally ill (Ene, 2009). People can either self-identify as to one of these groups through diagnosis. Furthermore, biosocial citizenship is about the role people play in their own health and illness (Ene, 2009). It looks at how people take the way and views in which they are described by the system and transforms that definition in order to negotiate it with their own identity. For the study related with the case of HIV/AIDS, this can be achieved by acting on supporting voluntary counseling and testing and raising public awareness of one's illness and change the image that society has of an individual with the targeted illness. One can act to create a new social group, such as an illness-centered association or public health focused organization developed.

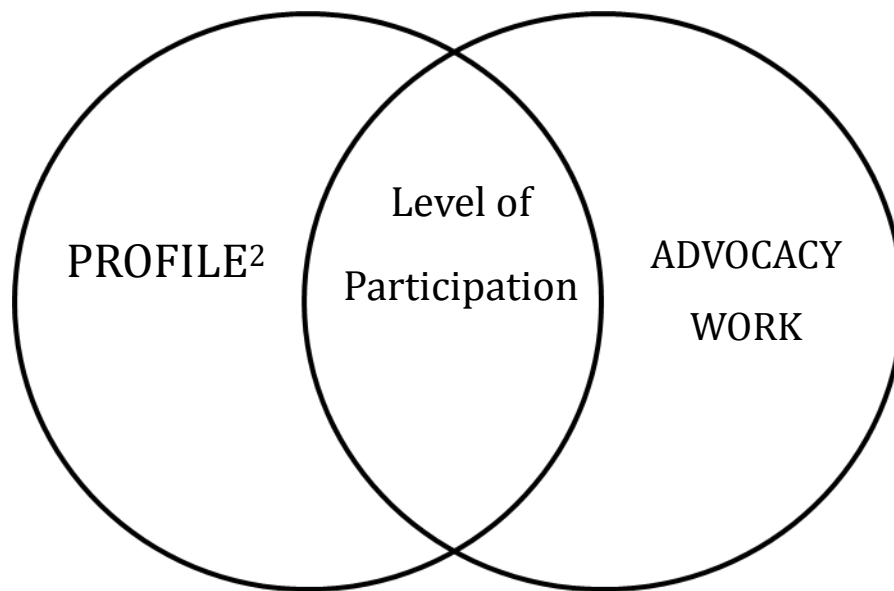
Biosocial citizenship, like national citizenship, is something one had with it and at the same time something one has a choice about it (Ene, 2009). Being at transmissible risk for HIV/AIDS is not a choice while becoming involved in the AIDS community is a matter of choice, will and commitment or grabbing one's organization for good. Also, like in the case of national citizenship, biosocial citizenship can be obtained when you have that illness by now or a persistent interest in the condition (Ene, 2009). This approach to organizations is that this advocates that are open to, and interact with the environment or to the society is merely possible to attain new resources through development and to continuously have progress in it (Development.Org, 2012). As an advocate, she or he has this social role wherein they affect others and their social interaction with their clients.

Considering this concept theory when relating to the advocacy work and being an advocate it has to be done within interactions with themselves and the external or the PLHIV they are encouraging to maximize the value of the organization (Amagoh, 2008). Today's citizens have engage in specific structures in order to advocate for better health care as well as raise social awareness of their condition in order to establish a positive and constructive social role for themselves (Ene, 2009). As HIV/AIDS is a public health issue, there are still questions how does an advocate achieve the goal of community participation, how does one get members engaged in advocacy works, and how does one translate their opinions back, so that they can be effectively utilized in implementing new public health measures. This explores that civil society for advocates or public health officials are part of the governmental section of the political scene. They are elected or appointed to take action based on civilians' needs. Civil society, composed of all non-governmental organizations (NGOs) and institutions is a mediating segment which can update the governmental one on the interests and will of citizens.

### **CONCEPTUAL FRAMEWORK**

Figure 1 explains from the profile of an advocate that simplify what factors affect his or her ways of advocating prevention and information. It shows how the advocates profile everyone needs to deal honestly and effectively with the challenges PLHIV face this can be associates with the advocacy work and distinguish the level of participation. Accordingly,

this research inquires the profile of PLHIV advocates as variable in developing the involvement in advocacy works.



**Figure 1. Profile and Advocacy Framework**

## **METHODS**

In this research, qualitative method will be used. This is a case study with five PLHIV ASP advocates as the informants. The informants were interviewed in a semi-structured method. Throughout the research work, an ethical procedure is observed to maintain an academic drive with its purposes. This is the informed consent letter that was prepared to be given to each advocate participant to give background or information about the study. The proposed research applies research ethics set and organized by World Health Organization (2009).

## **ETHICAL PROCEDURE**

This ethical procedure as would be followed by the researcher in compliance to the ethical practice. Before the researcher do interview, the participants are given informed consent form which contains information about the study, their rights as a participant, and other matters regarding the research. Also, another part would be the questions that will be asked in the interview. In this procedure, with the consent form, the participants are given time to decide whether or not to participate in the study. In choosing to

<sup>2</sup>Profile consists of education, employment status, occupation, marital status, income, gender, age, etc.



participate, confidentiality will be served and detailed information is provided in the informed consent.

#### SCOPE AND LIMITATION

The primary concern of the study is the advocates profile and their advocacy work in ASP organization. The researcher chose Metro Manila<sup>3</sup> sites of ASP with PLHIV advocates particularly SIOs<sup>4</sup> and PEs<sup>5</sup>. But because there is lack of informants, five were only chosen and interviewed. The respondent must be a member of the said organization and a PLHIV. The advocate's profile and its advocacies will be the highlight of the presentation in order for the study to give emphasis on the effects of each correspondingly.

#### RESEARCH LOCALE

Aids Society of the Philippines is located at Sct. Tuason, Tomas Morato, Quezon City. This organization handle cities and provincial municipalities with social hygiene clinics with its advocates that contribute a big responsibility to its programs like VCT<sup>6</sup> and LGS<sup>7</sup> to help spread information educate people and prevent them from HIV/AIDS. The research will only give importance to these following areas that would be participating as they were the selected sites that was given by ASP that has PLHIV advocates such as: Manila, Quezon City, and Caloocan.

#### FINDINGS

Five PLHIV informants from Aids Society of the Philippines were chosen and interviewed to answer the status of the advocates on their organization that mostly affects their advocacy participation and the advocacy that mostly influence and promote prevention to PLHIV through their life stories and experiences as a PLHIV advocate. Education, occupation, religion, income, years of being an advocate and their main focus on advocacy work were the evolving factors that manipulate a PLHIV from the level of participation every advocate has. From this, there will be information's about their advocacy work to relate it with their participation.

Informants named "Beth" was diagnosed year 1997 and has been an advocate since 1997, "Owie" diagnosed 2004, 7 years of being an advocate, "Ronel" from 2011 been an

<sup>3</sup>Quezon City, Caloocan City and Metro Manila

<sup>4</sup>SIO Site Implementing Officer

<sup>5</sup>PE Peer Educator

<sup>6</sup>VCT Voluntary Counselling and Testing

<sup>7</sup>LGS Learning Group Session

advocate for 3 years, “Mikee” 2013, 8 months advocate and lastly “Abcde” also diagnosed 2013, 6 months of advocate.

As seen below (Table 1), social demography was used as an aspect to discern what profile the advocates got. This indicates the profile used was for basic social demography. Using these demographic variables can be an important formulating which is the significant advocate profiles.

Table 2 below, stated what available advocacy work were under ASP. ASP focuses only on the prevention and control setting. Their interest is in preventing the spread of HIV and AIDS especially in the Philippines. For this study, informants<sup>8</sup> advocacy emphasizes on VCT that includes counselling and testing.

Themed factors were answered from a social demography concept and an interview. These were the arising reasons that mostly affect the advocate’s level of participation that was from a PLHIV advocate basic profile. To give point at each, the researcher gave focused on six factors that commonly affect one’s advocate level of participation.

Level of participation where it identifies as a proof of how effective an advocate perform in their interest areas on promoting advocacy works and exceptional participation throughout the organization. Being an advocate of ASP, by what means do this people handle to observe the eagerness and motivation of pursuing the advocacies that will affect the clients or PLHIV’s as they are also considered same, experiencing the similar instance.

#### INCOME

All five experienced different work in diverse living. But one is similar, each advocate strives hard for their family to give them support and love. Through advocacy it gives them strength to make every effort possible not just for their first family but also for their first family but also for those who welcome them and give them openness.

Informant Beth was diagnosed year 1997; bear an infected child for 4 years. She experienced discrimination from people back then. But being with the advocacy for HIV/AIDS, she was destined to be an inspiration for every PLHIV. She was set to be an

<sup>8</sup>Informants-Peer Ed’s and Site Implementing Officers

example and helped other people succeed in life, not just for publicity but the meaning of her story really affects individuals. Through this it is a big thing for this people to serve as the narrator for Beth. She doesn't have to do it again and again there is someone else to do it for her, to encourage other people with her story. She became an advocate since after she was diagnosed, from treatment, care and support she transferred in prevention and control. As LGU officer she assists and monitors all sites handled by ASP. As she said:

“Hindi naman ito popularity contest. At least nakaestablish ka ng pangalan na hindi sira alam mong hindi ka pagdudahan na ay di yan marunong magtrabaho lagi yan madedespalko ng mga pera unlike sa mga positive di ba more on lalapit sayo para lang humingi ng dull out pambili ng ganito ganyan. Ako di ko naranasan na kahit may mga funds pwede mo iavail di ko naisip yun kase ako pag nagtrabaho ako yung pera ko para may masustain ako pang laboratory ko or kung ano man pagagawa ko na pera kong napaghirapan na hindi ako hihingi sa iba.”

*[This is not a popularity contest. At least you have established a name and you can be confident that people will think that you can work well, you won't steal money. Unlike being positive on HIV more people would come to you and they're the ones who'll give you something to buy this or that. I don't experience even though there's funds for us that we can avail I don't think it that way. I'm the person when I work, money will be used for my laboratory or anything and I know I work hard for it and I will not ask someone's help.]*

Beth said that through her passion with the advocacy, establishing her own name brings confident that people could see her work well with her case being a PLHIV advocate, people would come to her ask for her story and give her appreciation. But getting funds that available for them is a different story. She is the kind of person when she work, her income will be used for her laboratory or anything she likes to do knowing she work hard for it and without asking for others help.

For Abcde's story, he was diagnosed last 2013 and an advocate for 6 months now. He has multiple sex partners a risky behaviour as he says why he got HIV/AIDS. Aside from being a call center agent he is a peer educator giving information and lecture to clients through outreach programs. He says:

“So yung nagpush talaga sa kinineto is number 1 si jowa, number 2 para mag stop na yung spreading ng ganitong sakit alam mo yung sa sarili mo na kahit wala kang sinesweldo kahit wala kang na alam mo yun kahit konte lang yung sinesweldo mo sa isang buwan, atleast alam mo yung tulong in your own little way nakakatulong ka sa ibang tao magbibigay ka lang ng konteng information.”

*[What pushed me to be an advocate is number 1 my partner, number 2 for stopping the spread of this illness when you know in yourself even you don't get salary from it, or small amount for a month atleast you know you help in your own little way by giving other people information.]*

-Abcde

Such as when he comes to his province he gives lectures and information. Also by using gay sites like Grindr he is being an advocate. Another reason that pushes him to advocacy like this is that he does not want the illness to keep spreading especially with the LGBT community he's in.

## EDUCATION

The advocates all graduated with a college degree would rather chose to be an advocate for it will not just help their clients to go further but also their selves as well on pursuing something they really want.

Ronnel was diagnosed 2011. Same as Abcde, he has risky behavior where he looks for not just sexual partners but mutual partner in social media. He feels there's something missing in him until he became an advocate he learned how to cope up, he realize what is the right thing to do. He thought of HIV is not the end of his life.

It's just how he deals with it as an impact to keep him strong. As the informant shares on education:

“Minsan parang oo nga college graduate ako pero may instances kase yung kahit college graduate ka at nasa HIV program ka it's not enough na HIV councilor ka its not enough na dumaaan ka sa maraming taraining. Kailangan meron ka talagang will power pagdating sa pasyente mo kahit inaaway ka na halos.” *[Sometimes yes I'm college graduate but there's instances when even if you're a college graduate and you're in the HIV program it's not enough that you're a HIV councillor, its not enough that you did all the training. You will need will power when your clients fight you.]*

-Ronnel

Education and proper knowledge for him about HIV is nothing compared as to he has the power and ability to convey what clients can do to you.

Owie was diagnosed 2004 became an advocate year 2007. After graduating college he turns out to be a call boy just to help her sister in her studies. Applied to be an overseas Filipino worker but ended soon because of the illness. Chose to be an advocate because through his hardships in life still he can manage to fight for the illness he has. He says:

“Mas inintindi ko yung sarili ko sa health ko kesa mag apply nga ko ng malaking sweldo yung sarili ko naman maaapektuhan Tsaka sa ngayon kasi di ko kailangan ng malaking pera kasi sarili ko lang binubuhay ko sapat na sakin yun. Mas gusto ko kasi sa adbokasiya na to. Parang mas magaan sa sarili ko yung makatulong ka. Ikaw na nga yung may sakit nakakatulong ka pa.”

*[I worry more about myself, my health instead of applying with high salary afterwards it is me who will be affected. As of now, I don't need money since I support myself.]*

- Owie

Even though he graduated college and could find a decent job to earn money he chooses to cope with his health. He prefers in the advocacy to improve him and help others.

#### OCCUPATION

This marks the way they handle change in their lives for being employed that helps sustain their needs and it is because of supporting the advocacy, being an advocate, a peer educator or site implementing officer since they are also considered PLHIV. Through Aids Society of the Philippines is where they received help to cope up with their condition when they were assigned as peer educators, site implementing officer, and any other officer position.

Mikee is a peer educator diagnosed last year and an advocate for 8 months now. He grew up where abject poverty is part of his life, there were 9 members in the family being the eldest he needs to help to survive the needs of his younger siblings. Because of this he befalls to resolve the problem through entering different job. Until he participate in cyber sex, a resolution for his dilemma in life as he get way high earning from other job he got. That's were he has multiple sex partners and got HIV/AIDS. He says:

Nagpatest ako dito January kinausap ako ng isang SIO gusto mo maging peer ed ka. Syempre wala kong choice wala naman ako ginagawa sa bahay pa side line Pero talagang pinush ko naman mag advocacy ng HIV eh.”

*[I had my test January when a SIO ask me do you like to be a peer ed. Of course I don't have a choice. I am not doing anything at home, I only have sideline works. But really I decided to do advocacy on HIV that's different.]*

*-Mikee*

Because of another SIO he became a peer educator. Since he got nothing to do at home with all side line works he had. Being in the advocacy as his another occupation is a different thing for him since he is a PLHIV too.

## RELIGION

All were Roman Catholic. But in joining the advocacy everything really changed. They will always believe and thanked God for the trials they encounter because it just keeps them stronger everyday. As for Abcde's religion and belief he says,

"Pero alam mo yung pumasok ako dito nagbago na ang lahat. Minsan pa nga tinanong ko siya kung bakit ako nagkaganito. Pero hindi ko siya sinisisi, tinanong ko lang siya. Bakit kaya? Ayun po. Tapos yun may nagbago pero hindi ganun kalaki naniniwala pa din ako sa bible bible na yan pero yung paniniwala about science na lahat ng tao pwede magkasakit ng ganito hindi pwede hadlangan ng Diyos kasi kung binigay niya sayo alam niyang ibibigay niya sayo kung di mo kaya kaya mo nasagot ko na lang yung sarili ko na kaya mo binigay to sakin kasi kaya ko and I'm sure na pag sinabi ko or pag nag talk ako bigay ako ng chance na mag talk sa isang catholic school sasabihin ko lahat."

[When I came in everything changed. Sometimes I ask Him why me? But I don't blame Him, i just ask. Why? Something changed but not that significant, I still believe in a Bible but my belief in Science that all people can be sick. God will not intervene; it is His choice that all struggles can be surpass by that person. Given a chance to talk in a Catholic School I will tell them everything.]

*-Abcde*

He questioned but did not blame God for what he was right now. Through his experiences because of his belief that all struggles can be surpass when God gave problem that a person cannot handle, and so given the chance to talk in a Catholic school, he will say everything he knows about the advocacy.

## *Years of being an advocate*

Three of the informants spent years of their life in advocacy and two were only recently familiar with the programs for months now. All concurrently have high hopes in the organization and currently involve in spreading the advocacy. Informant Owie states:

“Nag start ako sa advocacy nung 2007 until now. Ngayon nasa project ako ng ASP ng Aids Society of the Philippines under ng Global Fund TFM...Dun na nag start nung 2007 2008 nasa Pinoy Plus ako. 2009 nag-start ako naman kasi project based lang yung sa Pinoy Plus. So nag start ako nung 2009 nagtransfer ako sa St. Camilus Catholic naman HIV ministry nila. Kung san san kami nagpunta nagbibigay ng mga information sa mga Catholic School hanggang 2014 nagdecide ako last February nag-transfer ako rito sa ASP nagapply ako ayun napunta ko sa Social Hygiene Caloocan.” *[I started in the advocacy year 2007 until now. Now I am under the project of ASP, Aids Society of the Philippines under Global Fund TFM... There it started 2007, 2008 I'm with Pinoy Plus. 2009 I transferred in St. Camilus Catholic in their HIV ministry. We go everywhere and give information in Catholic Schools until 2014 then I have decided last February to transfer here in ASP and applied at the Caloocan Social Hygiene Clinic.]*

-Owie

For all the years he has been through by exploring while in the advocacy he considers the progress of being an advocate and a PLHIV.

#### MAIN INTEREST OF ADVOCACY WORK

ASP is under the prevention and control program. Informants contribute so much on preventing the spread of HIV/AIDS. Though it's hard for them to gather people and conduct VCT's to community at least for them they know they help in being the cause of preventing individuals from being a PLHIV.

Beth says in the advocacy:

Actually as lgu officer all over lahat ng site Pilipinas. Prevention ng Manila, Pasig, Caloocan, CDO, Davao, Cebu, Marikina, QC. Dun kase sa PAFPI kumbaga napapagod ka na airport to airport ka na lang lagi sa monitoring ganun. Ay sana sabi kop ag ASP ako office na lang ako lagi maagi uuwi hindi pala kase lahat nagkamali pero okay lang masaya at least nakakcontribute ka sa prevention marami kang buhay na nasasagip naliligtas na di sila mainfect naeducate sila namumulat mga kaalaman nila kase di ba may clinic pa kami so minsan nagcocouncil pa kami ng mga pasyente na magappahiv/test parang malaking bagay yun although sa tcs ganun din as councillor assist ka sa patient kung saan saan.

*[Actually as lgu officer all over Philippine sites. Prevention in Manila, Pasig, Caloocan, CDO, Davao, Cebu, Marikina, QC. There in PAFPI youre getting tired of getting airport to airport everytime there is monitoring. I said, I wish when im with the asp office so that I could go home earlier but it didn't at least Im happy I can contribute in prevention side there would be so many lives to be saved, those that cannot be infected, they can be educated in the clinic sometimes I do counselling with the patients who are going hiv testing although in tcs you can also assist counselling everywhere.]*

-Beth

Because of her involvement and choice of advocacy work it strengthens the level of participation she does. She showed support on the program when she handles her position and perform her interest on the assigned task.

**Table 1. Profile of the Advocates (Social Demography)**

<i>"The Relationship of Profile into their Level of Participation in Advocacy Work: A Case Study on ASP's Advocates"</i>		
		No.
Name:	Age:	Gender:
Highest Educational Attainment:	Contact No.:	
Employment Status:	Organization:	
Marital Status:	Occupation:	
Main interest of advocacy work:	Monthly Income:	Years of being an advocate:

**Table 2. Available Advocacy Works**

<i>Prevention and Control</i>	
Knowledge Management Capacity-building Partnership and Membership Building Resource Mobilization Clinical Advocacy (i.e VCT- Voluntary Counselling and Testing, LGS- Learning Group Session)	Research and development Clerical Communication Networking Education Events Coordination

**DISCUSSION**

Six common factors found in the profile of the advocate was identified main influences wherein it affects the level of engagement of a PLHIV advocate are as follows

- 1) Education that states their educational background as way to pursue their dedication on advocacies,
- 2) Income that keeps the advocate life situations manageable particularly on the advocacy,
- 3) Occupation that give advocates the reasons to convene with their advocacy interest,
- 4) Religion to be a manner of regaining their stronger belief and devotion to advocacy works,
- 5) Years of being an advocate as an indication how sustained they have been that participative in advocacy work and lastly their
- 6) Main interest in advocacy work to signify their common interest and point out their engagement on it.



### ***Profile of the Advocate***

The profile of the advocates is the basis where it influenced the engagement of the informants to a given advocacy program. Example is the occupation of the advocate wherein with their case it gives them more opportunity to strive well in the working area for they know they are well surrounded with people who understand them and they can motivate to be prevented from the illness. Occupation for them is somehow the turning point in their lives for when they feel stigmatized, still there's hope for them in the advocacy program. Choosing the advocacy wherein it also affects you as a PLHIV would help clients that the informants being an advocate promote awareness and educate not just other people but also themselves.

This research indicates social demography showing the advocates social economic status to help set meaning of what significant profile the advocate comprises. SES<sup>9</sup> affects everyone including differences in income and access to resources. According to Perry 1998, HIV is a disease that is rooted in social and economic inequity affecting those who has low SES (Ramjohn, 2012). SES is also a key factor in determining the quality of life for individuals after they considered a PLHIV. Those with fewer resources are often left with limited treatment options.

A lack of socioeconomic resources is linked to the practice of riskier health behaviors, which can lead to the contraction of HIV. These behaviors include earlier initiation of sexual activity and less frequent use of condoms (Adler, 2006). Meanwhile SES also affects a PLHIV treatment. Their status can be the determinants to access of HIV treatment. Individuals of low status may have delayed treatment initiation reducing their chances of survival.

Therefore, the status created from the profile build by PLHIV advocates affects their quality of life in terms of the level of participation they have in the advocacy. It means that by having high engagement on the advocacy leads them to high SES that can improve their quality of life. When they participate often in the advocacies it can lead them to progress and development being a PLHIV individual.

<sup>9</sup>SES Social Economic Status

## ADVOCACY WORK

For the available advocacy offered in ASP, VCT is the common advocacy work supported by site implementing officers and peer educators. Their job is to inform and ask people for voluntary testing. They educate PLHIV as to how to live happy and normal lives. They serve as guide when giving advices to clients. Advantage of ASP is that they have a clinic located in their office for sudden tests and counsel. They do outreach programs to communities with high risk behaviors and conduct group sessions for extending the information they know.

The AIDS Advocacy work that are commonly known to promote awareness; example is one of the program prevention, an HIV awareness day for youth, PLHIV, MSM<sup>10</sup> and other links about the illness. This program continues to invest in scientific advancements like a vaccine and cure without forgetting the importance of prevention plans to ensure equal access to information and healthcare for everyone (Youth, 2008). They will promote HIV testing, fight stigma, and start the essential conversation which everyone needs to deal honestly and effectively with the challenges we face as this concern as one social issue we encounter in our country.

With this, as ASP's mission is to provide expertise and facilitate information and resource exchange among communities to reduce HIV infection in the Philippines through advocacy. Therefore having VCT as their common program that facilitates voluntarism to clients and LGS for empowering them from being an advocate and PLHIV it serves that from this point forward promoting awareness is not a big hindrance to PLHIV advocates. It gives them the strength to give impartiality to what the organizations vision and mission is.

## FACTORS THAT AFFECT ADVOCATES LEVEL OF PARTICIPATION IN ADVOCACY WORK

### *Education*

The advocates all graduated with a college degree would rather chose to be an advocate for it will not just help their clients to go further but also their selves as well on pursuing something they really want. Because of advocacy they gain so much knowledge on what is HIV/AIDS. It is for them to be ready when they became peer educators they can

<sup>10</sup>MSM Male having sex with male

handle questions asked by their clients, they can give right information and have proper understanding on prevention.

“Kasi yung Tatay ko patay na nung bata pa lang kami. So lumuwas ako, pag graduate ko ng High School dumiretso ako ng Maynila. Tas nag aral ako nag trabaho part time tapos yung kapatid ko ng bunso gusto ding mag aral so pinaaral ko siya. Di ko na alam san kukuha ng pera ginawa ko nag call boy ako. Pumasok ako ng pagccall boy kaso yung.. Alam ko na yung HIV pero di ko siya inisip kasi akala ko sa mga babae lang naku-kuha ang HIV. Yun ang pananaw ko that time.” [My father died when we were young. After high school I went to Manila. I studied, work for part time to help my younger sister in schooling. I don’t know where I can get money so what I did is I became call boy. I know what HIV is but I didn’t think that it is also applicable to men. Knowing it’s only for women, that’s how I viewed it that time.]

-Owie

Before entering the advocacy they lack knowledge about the public issue. The way they gain knowledge about HIV/AIDS is insufficient that’s why mostly got positive from the illness. Education is well associated on how an advocate understands things, without it you can not progress and know what is proper for your condition.

Even if they graduate with a college degree again it is not sufficient to live accordingly with other people without knowing proper information a PLHIV could get from an organization handling prevention and control.

### *Income*

All experienced different work in diverse living. But one is similar, each advocate strives hard for their family to give support and love for them. Through advocacy it gives them strength to make every effort possible not just for their first family but also for those who give them warm welcomes.

“Nakakatuwa na ako yung mahiyain before na ang goal is tumulong lang sa family wala ko iba inisip kundi kumita para sa pamilya para mapagaral mga kapatid mo na ngayon pala mas lumawak family ko. Mas dumami sila.”

[I find it funny since I’m formerly shy, given that my goal is to only help my family and to support the education of my siblings but now I have bigger family.]

-Beth

They see the advocacy as way to help others like them who are PLHIV, to give support and encouragement. It is not about the income they could get, but it evolves on the deeper sides of their stories and it’s always about helping and to be accepted by other people treating them as inspirations. The amount they can get from their job is just for

them to be healthy everyday, the health maintenance they could get from it is a big help yet again it is always on the advocacy, the enthusiasm of being an advocate.

### *Religion*

When it comes to their religion, at first it is normal to think that what they experienced was really a bad one. But then suddenly it is still their religion which they look up to and thanked for they are still with the advocacy they support to give more knowledge to everyone affected.

“Yung faith ko about paniniwala ko sa greater power. Isa yun sa pinagkukunan ko ng lakas loob para makacope up. Nung mga panahon na yun confuse ako nun eh di ko alam pano sasabihin sa family ko di ba di ko alam pano sasabihin sa friend ko sa mga kaibigan ko”

*[My faith and belief about greater power. That's one of the things where I get my strength to cope up. That time, I was confused, I don't know how will I say it to my family and friends.]*

-Ronel

“Sinasabi ko na itong buhay ko ngayon is macoconsider ko na beside sa second life ano siya miracle bakit pa ko nabuhay ng ganito kahaba, ano pa purpose ni Lord di ba. Tinitingnan ko everyday na lang ako nabubuhay di na ko yung nageexpect na for another week another month everyday pa din prayer ko na thank you lord buhay pa din ako ngayon hanggang makatulog ako paggising ko di na ko yung ambitious na lord bigyan mo pa ko ng 3 years kase gusto ko pa bumili ng ganito wala na sakin yun material na bagay” *[I can say that I consider my life now as a my second life, it is a miracle that I am still alive this long. What's Lord's purpose, right? I see it as me living every day, I do not expect for another week, month. My prayers are for every day. Thank you Lord that I'm still alive until now, I fall asleep, and then wake up not the ambitious one, Lord give three more years because I want to buy this, I do not own material things anymore.]*

-Beth

### *Occupation*

As they were also considered PLHIV, being an advocate is never hard for them and they did not thought of it being a bad decision. After series of counselling and testing for the said illness, there comes the stage of coping up and they manage to be on the position they want to be.

“Nung una feeling mo may nawala sayo syempre di na rin nagiba yun tapos hanggang sa naging advocate ako I learn to cope up nung naging advocate ako natuto ako na ay ganito pala dapat. Dapat pala lagi ako nagppacheck up sa doc. Dapat pala lagi ako umiinom medication kung meron man. Ang hiv pala di pa siya katapusan ng buhay mo. It's just nasasayo yan kung pano mo titingnan. Papatalo ka ba o gagamitin mo siya bilang strength mo”

*[At first I feel there's something missing of course it doesn't change until I became an advocate. I learn to cope up. When I became an advocate I learn this have to be this and that. Everytime I should go to the doctor for my check-up. I need to drink my medications. Having HIV, is not the end of your life. It's just in your own how you can view it. You'll lose or you'll use it for you to be strong.]*

-Ronel

"Para mag stop na yung spreading ng ganitong sakit alam mo yung sa sarili mo na kahit wala kang sinesweldo kahit wala kang na alam mo yun kahit konte lang yung sinesweldo mo sa isang buwan, atleast alam mo yung tulong in your own little way nakakatulong ka sa ibang tao magbibigay ka lang ng konteng information"

*[For this illness to be stop from spreading even though you know you don't have any salary from it at least you know in your own little way you help other people and give the right information.]*

-Abcde

### *Main interest in advocacy work*

Choosing the right advocacy for them, somehow affects not just their concerns but also the involvements of their clients.

Actually as lgu officer all over lahat ng site Pilipinas. Prevention ng Manila, Pasig, Caloocan, CDO, Davao, Cebu, Marikina, QC. Dun kase sa PAFPI kumbaga napapagod ka na airport to airport ka na lang lagi sa monitoring ganun. Ay sana sabi kop ag ASP ako office na lang ako lagi maagi uuwi hindi pala kase lahat nagkamali pero okay lang masaya at least nakakcontribute ka sa prevention marami kang buhay na nasasagip naliligtas na di sila mainfect naeducate sila namumulat mga kaalaman nila kase di ba may clinic pa kami so minsan nagcocouncil pa kami ng mga pasyente na magappahiv/test parang malaking bagay yun although sa tcs ganun din as councillor assist ka sa patient kung saan saan. *[Actually as lgu officer all over Philippine sites. Prevention in Manila, Pasig, Caloocan, CDO, Davao, Cebu, Marikina, QC. There in PAFPI youre getting tired of getting airport to airport everytime there is monitoring. I said, I wish when im with the asp office so that I could go home earlier but it didn't at least Im happy I can contribute in prevention side there would be so many lives to be saved, those that cannot be infected, they can be educated in the clinic sometimes I do counselling with the patients who are going hiv testing although in tcs you can also assist counselling everywhere.]*

-Beth

Profiles stated set as bases on the extent of participation of an advocate. Through the advocacies, they strengthen their profile status in combining it with their performance in advocacy work. PLHIV is not just biologically defined, they are also defined socially through their own perceived sense of identity as well as the social interactions they are involved in (Ene, 2009). These social definitions of people are descriptions such as the

qualifications or Facebook profile of a person. They have to do with how people describe themselves and with how they are described by others. HIV/AIDS as a health condition becomes a social role when it affects social interaction. In this case, biosocial citizenship refers to a special kind of defining the individual by taking into account the role of both biological and social features (Ene, 2009). Furthermore, biosocial citizenship addresses an individual's choice of group membership and the consequences of that choice.

From the research, the profile of the advocates is built not just from their own qualifications and background of being a PLHIV but also on how people views from the interaction and involvement of an advocate to advocacy works. Because of biosocial citizenship, the advocate's chooses to participate to the advocacy and attain the degree suited for the profile they possess.

Creating programs like voluntary counselling and testing was for the betterment of advocating prevention of HIV/AIDS in our country. This supports the organizations' goal on achieving the spread of quality information to risk individuals involved. Today's citizens have engage in specific structures in order to advocate for better health care as well as raise social awareness of their condition in order to establish a positive and constructive social role for themselves (Ene, 2009). As HIV/AIDS is a public health issue, queries on how does an advocate achieve the goal of community participation, how do one get clients engaged in advocacy works and how advocates can be effective to be utilized in implementing new public health measures approves to be a source of improvement that they can achieve the mission of the advocacy program which is to prevent and with it's high participation in it, it will be successful.

Being an advocate, promoting awareness is an achievement for them. That is how they can show support and encouragement for those suffering also from the illness. All informant views VCT and other advocacy prevention program as a way to help saving people with all the different experiences they still manage to convey their identity to their aim which is to prevent the spread of HIV/AIDS. Since biosocial citizenship is about the role people play in their own health and sickness (Ene, 2009). It looks at how people

take the way in which they described them and transform that definition in order to negotiate their own identity. As related with the case of HIV/AIDS advocacy, this can be achieved by conducting counselling and testing and raising public awareness of their condition that can change the image society has of PLHIV. Alternately, now advocates can create more empowered dedication to such a HIV/AIDS organization like ASP.

## **CONCLUSION**

Personal statistics that include such information as their monthly income, gender, highest educational attainment, occupation, marital status were used for basic social demography. Using these demographic variables can be an important input when formulating data which are the significant advocate profiles. Therefore the profile was accurately patterned to distinguish what level of participation the advocate has. Because of focused ethnography conducted, this research classify what available advocacy work is offered by the organization. Through the researcher's background into the advocacy program and the advocate focuses onto, the advocacy was recognized because of linkage of profile stated by the informants as the basis of forming the level of participation. Hence it proves that through the profile as the centre of what level of participation the advocate has, is an improvement to the advocacy program they partake to, for it is a proof on the study that the profile status of an advocate affects the advocacy work. If the advocate continues to participate, therefore, the profile can be evidence that can impact and develop involvement to the chosen advocacy.

Since the profile can be a factor that involves the advocates level of participation to advocacy work, it cannot be a hindrance as a way to promote HIV/AIDS prevention and to spread information in the Philippines as they are now included in the concern of public health issue in our country. Also, this distinguished the extent participation an advocate accomplished. Hence, prove that some of the advocates were participative because of the specific profile they have influencing those PLHIV.

As advocates, they lead connections to PLHIV clients easily. It strengthened educational matter and dedication in pursuing an advocacy to build up prevention that was supported consistently just as what the organization anticipated. It did develop

relationships that could reach out each and every one of them as they did not just help somebody but also their selves. Moreover, it encompasses advocates involvement in advocacy work in a different condition. By using this study PLHIV advocates will be encouraged to help and create something different for themselves as they also conquer the stigma of the illness. It is under their own practices and accomplishments that they are considered successful within their specific doing.

### **RECOMMENDATIONS**

To fill the scholarly gap of AIDS studies this research suggests readers to investigate the analysis of profiles of an advocate that determines the level of participation in their advocacy work being a PLHIV advocate. This study can be recommended to the HIV community for their betterment and to develop each member's capacity on building advocacy works in improving the state health systems of HIV/AIDS in the Philippines. Furthermore, for ASP and DOH<sup>11</sup> as national government organization to improve programs in support for aids prevention and consider PLHIV advocates concerns. Ideally, this may also help future researchers in exploring more about HIV/AIDS, advocates, and advocacy work. More so, this research may serve as a source of data for further studies.

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<sup>11</sup>DOH Department of Health

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