

**The role of the HIV service organisations in supporting  
migrants' access to HIV care and support in Sydney**

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**Project report for the Extension program,**

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**Project title:** The role of the HIV service organisations in supporting migrants' access to HIV care and support in Sydney

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## **Declaration**

I hereby declare that this paper I am submitting is solemnly my own individual work. To the best of my current knowledge it contains no material previously written or published by another person, nor does it contain any material which has been approved or accepted for the award of any other degree or diploma at UNSW or for that matter any other educational institution. Where required in this paper, due acknowledgement has been made where necessary. Any contribution made to the research is explicitly acknowledged in this thesis.

I declare that the intellectual content of this paper is the product of my own individual work. However, I have received some assistance in regards to style, presentation and linguistic expression.

A handwritten signature in cursive script that reads "Sangnim Lee".

Sangnim Lee

23<sup>rd</sup> January 2012

## **Acknowledgements**

I would firstly like to acknowledge the support of my supervisors Associate Professor Heather Worth from the school of Public Health and Doctor Henrike Körner from the National Centre in HIV Social Research at UNSW.

I am very thankful to all staff members working in the service organizations of HIV who actively participated in this study. They kindly shared their time towards my research during their busy lives. All the information shared during these interviews provided me with invaluable data and insight into support for migrants living with HIV. This experience has made me more passionate about analyzing and developing this study further in my research and in my career. This thesis would not have been possible without their contribution and participation.

There are also many other people with whom I would like to acknowledge. Those include my friends, especially Joshua and Sandy as well as staff at the Learning Centre, UNSW. Their contribution assisted me to improve my English along with my writing skills. As a special mention, I would also like to acknowledge Mr. Alan Hodgkinson who suddenly passed away during my preparation period of this program. Without his encouragement and assistance I would not have enrolled in the first place into this special research program.

Finally I would like to thank my mentors in Japan, my friends and my parents who encouraged me to pursue this research project in a second language.

## **Abstract**

Australia is widely known for its success in responding to HIV infections. However, among newly diagnosed people, the proportion of individuals born overseas has risen in recent years. Many HIV-positive migrants tend to experience significant delays in HIV diagnosis and therefore delay seeking HIV care. This study aims to explore existing services and support that HIV service organisations provide for HIV-positive migrants in their access to HIV care and support. Semi-structured and in-depth interviews were conducted with six staff members from HIV service organisations in Sydney.

This study identified that HIV service organisations provide a variety of health, social, emotional, clinical and legal services for migrant clients, both inside and outside the healthcare system. These organisations play an essential role in making healthcare services accessible to migrant clients and helping clients stay engaged in healthcare. Their social and legal support enable HIV-positive migrants to have stable lives, which is a fundamental condition of stable access to healthcare. In order to support migrant clients who have diverse needs, active collaboration among all parties has led to the mobilisation of existing resources. This is one of the HIV organisations' strengths in delivering services to HIV-positive migrants. Despite the availability of a range of HIV-related services, stigma, confidentiality issues and migrants' negative perceptions towards government services can inhibit HIV-positive migrants from utilising these services. This indicates that multiple service options are needed for migrant clients to meet their needs. Findings also point to the necessity of strengthening community empowerment in ethnic communities in order to address HIV-related stigma and to promote migrants' early access to HIV care and support.

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## **1. Introduction**

The introduction of antiretroviral therapy has brought dramatic change in HIV infections, reducing HIV-related morbidity and mortality (Castilla et al. 2005, Walensky et al. 2006). However, access to therapy and access to healthcare and services more broadly, can be problematic for migrants living with HIV, especially migrants from non-English speaking and resource-poor countries due to a number of cultural, social and political factors.

This report explores HIV-related healthcare and service delivery for migrants from non-English speaking countries, from the perspective of HIV service organisations in Sydney.

The annual number of people born overseas who are diagnosed with HIV in Australia has gradually increased, from 352 people in 2006 to 458 people in 2010 (The Kirby Institute 2011). In addition, people from high-prevalence countries are more likely to be diagnosed late (Guy et al. 2008), and as a result, experience a delay in receiving healthcare and treatment. Timely access to healthcare has obvious benefits; it will help to reduce medical costs by decreasing the number of clients hospitalised (Beck et al. 2011), reduce mortality (Van Sighem et al. 2003, Palella et al. 2003) and prevent new HIV infections through decreasing risk behaviour (Gorbach et al. 2006).

Two Australian studies of migrants living with HIV (Körner 2007a, Asante et al. 2009) have identified problems relating to access to healthcare such as stigma, uncertain immigration status and limited English ability. However, very little is known about how

HIV-positive migrants are supported when trying to access HIV care. For example, U.S. studies which report on the success of having community health workers for migrants suggest that the utilisation of community resources is vital in ensuring access to HIV care (Takahashi & Rodriguez 2002, Bradford et al. 2007). Community support and services which promote migrants' access to HIV care have not yet been examined in Australian studies. This indicates necessity of identifying existing HIV services for HIV-positive migrants in Australia.

The purpose of this project is to explore the role of HIV service organisations in facilitating migrants' access to HIV care and support, and the kinds of care and support that are provided in Sydney. It also examines how these organisations perceive their strengths and challenges.

### **Research objectives**

The aim of this research is to explore the role of HIV service organisations in migrants' access to HIV care and support from the perspective of the HIV organisation staff in Sydney.

Objectives are:

- To identify programs and services that HIV service organisations provide for migrants living with HIV.
- To identify how migrants living with HIV are linked to these organisations.
- To explore how the organisations view the strengths and challenges of their programs.

Sydney was selected as the project site as it is the capital city of New South Wales (NSW) and the most populous state in Australia for migrants (DIAC 2009). This state



has many diverse ethnic communities as well as the highest number of HIV-positive individuals (The Kirby Institute 2011). There is also a significant number of community-based organisations working in HIV prevention, treatment, care and support in Sydney.

This study will focus on the views of HIV organisation staff members through interviews. Examining the perspective of staff members will help the researcher to explore a variety of services and to understand the context in which their migrant clients needed their support.

The findings will be reported to the individuals who participated in this study and their organisations. Findings will also help to understand community services, with the aim of improving supportive environments for migrants in their early access to HIV care and support in Sydney.

In this report, the term, ‘culturally and linguistically diverse’ (CALD) is used when discussing some specific resources which use this term. Governmental policies and specific services in Australia use this term because of the term’s broader applicability.

## 2. Literature review

### *Access to care for HIV-positive migrants in developed countries*

International research indicates that access to HIV care services is a particular challenge for migrants. Delay in accessing healthcare and obstacles to receiving long-term care are caused by several factors such as stigma and confidentiality issues (Green & Smith 2004), immigration status (Kang et al. 2003, Creighton et al. 2004, Thomas et al. 2010), language barriers (Dang et al. 2011), lack of health care information (Conviser 2007), financial difficulties (Craw et al. 2008) and inadequate support (Erwin et al. 2002).

UK studies have found that HIV remains a stigmatized disease within ethnic communities in both their host and home countries (Anderson et al. 2008). Many HIV-positive migrants suffer from strong HIV-related stigma, such as rejection from their relatives (Dodds et al. 2004). A study discussed that stigma among African migrant communities was possibly created by the image of HIV as ‘deadly disease’ (Burns et al. 2007). Most African migrants in another study had a memory of HIV epidemics in their home countries where HIV was strongly associated with death (Doyal 2009). Even though HIV infection is becoming a controllable disease in many developing countries because the accessibility to antiretroviral therapies has gradually increased (WHO et al. 2009), many migrants from resource poor countries may be unaware of this information.

Another study reported that many HIV-positive migrants perceived that the degree of HIV-related stigma in their home countries was extremely strong and this perception resulted in HIV-positive migrants being highly reluctant to return to their home

countries (Keogh et al. 2004).

The confidentiality of migrant HIV status remains a grave concern. Some migrants fear that disclosure may affect the immigration process and result in possible deportation (Othieno 2007). Notably, strong concerns about the effect of disclosure on relationships within their ethnic communities were found among African migrants in both the UK (Flowers et al. 2006) and in the US (Foley 2005), and among African and Caribbean migrants in Canada (Gardezi et al. 2008). Flowers et al. (2006) highlighted that these fears pertaining to disclosure prevented HIV-positive migrants from accessing the relevant community and social support groups. Such fears can result in HIV-positive migrants keeping a distance from their ethnic communities to avoid discrimination, leading to social isolation (Castro-Vázquez & Tarui 2006).

Immigration status affects migrants' access to HIV care. A US study showed that for undocumented migrants, confidentiality issues and cost barriers were a bigger challenge to accessing adequate treatment than for documented migrants (Chin et al. 2006). The same study also demonstrated that the former group was less successful in receiving HIV-related care than the latter (Chin et al. 2006). This trend of poor access to healthcare among undocumented migrants was even found in Italy where HIV treatment is provided anonymously and free of charge to all immigrants irrespective of legal and immigration status (Saracino et al. 2005).

Another obstacle for HIV-positive migrants in seeking healthcare services is the language barrier (Wohl et al. 2009). A US study reported that HIV-positive migrants with limited English proficiency faced difficulty in understanding and negotiating an unfamiliar healthcare system (Potocky et al. 2007). For example, these migrants may

either not understand doctors' explanations or not discuss treatment with them. Poor communication may result in migrants' discontinuation of taking prescribed medications (Desjardins et al. 2007). In addition, migrants' discontinuation of visiting healthcare services may be influenced by their distressed feelings. Several studies reported that migrants, especially those from resource-limited countries, tend to feel a sense of hopelessness after learning of their HIV status (Dodds 2006, Paparini et al. 2008). These indicate a necessity for healthcare providers to pay attention to migrant clients' mental conditions and their comprehension of current HIV treatments. Also there is a need to assist migrants in navigating the healthcare system.

There is also the issue of migrants' access to health information. A UK research reported that confusion about the healthcare system made some migrants concerned about the burden of medical fees and they managed their health problems by self-medicating (Thomas et al. 2010). Findings from a recent US study indicate that information of existing medical and support services has not reached many HIV-positive migrants (Wohl et al. 2011). Given the considerable hardships and situations which HIV-positive migrants confront, further research should shed light on migrants' access to HIV-related healthcare in developed countries.

### ***HIV & migrants in Australia and NSW***

In Australia, at the end of 2010, it was estimated that approximately 21,400 people were living with HIV (The Kirby Institute 2011). The majority of those diagnosed with HIV are among men who have sex with men. However, 43.9% of people newly diagnosed in 2010 (1,043 people) were individuals born overseas. This proportion has risen over the last five years. More than half of these people who were born overseas came from high HIV prevalence countries in Asia and Southern Africa, and these people account for

42.9% of HIV diagnosis attributed to heterosexual contact between 2006 and 2010. Among those, 59% were women (The Kirby Institute 2011).

The state of New South Wales has the highest number of HIV-positive individuals (The Kirby Institute 2011). People from CALD backgrounds are included in the priority populations for the NSW HIV/AIDS program (New South Wales Department of Health 2006). A recent study in Sydney showed that uncertain immigration status, stigma, limited English proficiency and lack of Medicare were barriers for migrants with HIV in accessing health care (Körner 2007a). Some participants believed that HIV was a fatal disease due to experiences in their origin countries, and did not seek health services until they became clinically ill (Körner 2007b). Asante et al. (2009) identified the factors of late HIV diagnosis amongst individuals from ethnic minority background in Sydney, of whom the majority had Medicare. Asante and colleagues identified several commonalities within these participants including low perception of HIV risk, limited use of health services, the poor ability of some general practitioners to address HIV, and the fear of stigma and discrimination. This suggests that proactive intervention at the community level is necessary both to raise awareness of HIV and to encourage migrants' utilisation of healthcare services at early stages (Prost et al. 2008). Although a limited number of Australian AIDS studies of migrants identify the reasons for their poor use of health services, an analysis of the success in assisting migrants to access HIV care at early stages seems to be limited. Additionally, there appears to be a lack of research into the role of HIV service organisations in supporting HIV-positive migrants within Australia. The limited literature focuses on bilingual workers who assist migrant clients in accessing healthcare services in a culturally appropriate manner, but does not cover broader aspects of HIV services (Körner, H 2010, Körner et al. 2005). Thus, there is an opportunity to explore existing services and support provided by related organisations.

### *Examples of studies on HIV service organisations and community support*

International studies have provided insights into the effects of community support and community-based healthcare programs on HIV-positive migrants. In a U.S. study (Chin et al. 2006), community organizations and bilingual workers were reported to be effective in providing support to HIV-positive migrants via language assistance, client escort and advocacy at medical facilities, and health referral services. These programs helped migrants overcome social and cultural barriers in accessing HIV-related healthcare services. Chin et al. (2006) noted that the support provided by bilingual workers increased migrants' comfort by allowing them to be understood in their native tongue, this also gave migrants a feeling of cultural commonality. A Swedish study of HIV-positive Africans identified that a high proportion of participants contacted community organisations or large foundations looking for HIV-related community support (Asander et al. 2004). These organisations provided a social network and common ground for HIV-positive migrants to interact with other HIV-positive individuals, (see also Doyal and Anderson (2005)), and helped increase their knowledge about HIV.

In a Canadian study, migrant participants expressed a need for greater support from organisations working for migrants in the healthcare system (Gardezi et al. 2008). They desired to be treated fairly by healthcare providers so that they could trust the healthcare system. This indicates that HIV organisations could have a role in reducing institutional barriers to migrant clients by incorporating migrants' needs in the healthcare system.

Moreover, community-based organisations are expected to address the social conditions of HIV-positive migrants. Various studies emphasise the need for supporting migrants

outside the medical realm (Flowers et al. 2006, Foley 2005, Green & Smith 2004). Many migrants with HIV encounter considerable hardship such as uncertain immigration status (Anderson & Doyal 2004), financial challenges (Flowers et al. 2006), difficulties in accessing social welfare (Flowers et al. 2006), unemployment (Paparini et al. 2008), housing and a lack of basic necessity such as food (Weatherburn 2003). These acute issues influence their experience and response to HIV. For example, studies have identified that unstable housing conditions become barriers for HIV-positive people in accessing healthcare services (Rajabiun et al. 2007) and other HIV-related services (Marx et al. 2001). Therefore, it is necessary to strengthen community support and develop a multi-sectoral approach to tackling social, cultural and structural barriers that migrants face, so that HIV-positive migrants may receive adequate access to healthcare (Anderson 2008, Burns & Fenton 2006). At the same time, understanding the kinds of challenges that HIV organisations face in delivering services is important, as some challenges of community organisations were identified such as the financial sustainability and program management (Miller 2010).

Sydney has a number of HIV service organisations, but very little is known about their role in supporting migrants' access to care and support. Studies about experiences and perceptions of HIV organisation staff who support HIV-positive migrants in Sydney are very limited. In order to promote access to HIV care among migrants, factors which create supportive environments need to be thoroughly explored via this study.

Therefore, this study aims to identify existing HIV services for migrants by incorporating the experiences of front-line workers from those organisations. It will also examine how staff leverage their strengths and tackle challenges.

### **3. Methodology**

#### ***Qualitative methods***

This study aims to explore the role of HIV service organisations in migrant access to HIV care and support in Sydney and to understand the relationship between their support of clients and the social environments in which their clients need support. In order to understand the kinds of services that HIV organisations provide, reasons why the services are needed and how the HIV organisations provide support, a qualitative study is needed. Qualitative methods were used as they help to understand the sociocultural intricacies of client support circumstances and to capture the personal experiences and views of participants (Pope & Mays 1995).

This study employed semi-structured interviews, as the purpose is to explore participants' perspective of their experience of supporting migrants with HIV and participants' meaning of their services. To achieve consistency across interviews, an interview guide was developed in the form of the topics listed below for discussion. Participants could also raise issues that were relevant to their organisations.

#### **Sample interview topic list**

- Background information
  - position in the organisation
  - employment status (full time or part time)
  - staff size of the organisation
  - length of employment in this organisation
  - length of work experience with HIV issues and/or migrants



- Programs and services which this HIV service organisation implements and/or offers to migrants within the context of access to HIV care
- The route by which migrants with HIV are linked to this organisation
- Strengths and challenges of the programs

### ***Recruitment***

A convenience sampling method was used because the number of full-time staff in HIV service organisations who work for migrants is fairly small. Six staff members from HIV service organisations were recruited in this study due to the limited study time allowed. Two of the participants were from the same organisation, but they were in charge of different programs for migrants. Key HIV organisations were identified through meetings with research experts who supervised the researcher. Staff members of HIV service organisations were informed about the purpose of this study by the researcher via both telephone and e-mail, and staff were invited to participate.

### ***Participants***

Six staff members from five HIV service organisations participated in this study. The organisations included four non-profit organisations and one state government service. One organisation works specifically for CALD people. Four organisations were originally established to support HIV-positive people regardless of their ethnic background or their citizenship status. Participants included both males and females. The length of staff's employment in their current organisation ranged from one year and a half to more than ten years. The average was 5.5 years. All participants were full-time staff with diverse career backgrounds including social work, community care and support, HIV-related advocacy, legal and education.

### ***Data collection***

Six in-depth interviews were conducted in July and August 2011. A time and place for each interview was arranged according to each participant's availability, and all interviews were held in private meeting rooms at their place of work. Prior to the interview, the researcher described the purpose of the study to each participant verbally and provided an information sheet about the research. The researcher also explained the importance of maintaining anonymity of both the participants and the case examples they spoke about in order to keep the identity of individual clients confidential. This confidentiality was ensured in all reports.

The average time of each interview was 70 minutes (range from 35 to 120 minutes). All interviews were taped and key points were noted by the researcher. The researcher also took field notes after each interview. Notes consisted of participant's characteristics, personal impressions before, during and after the interview, a summary of the interview and a reflection on the interview method. These reflections helped the researcher to improve skills for the following interviews.

### ***Data management and analysis***

Firstly, all recorded interviews were transcribed verbatim. Secondly, the transcribed data were analysed using inductive thematic analysis. This is an approach that analyses themes which can be identified from the data, rather than using a specific theoretical framework (Braun & Clarke 2006). Data related to service provision were coded by type of support, for example, emotional, financial, legal and accommodation support. These codes were categorised into concept-related subthemes or service-related subthemes. The entire data was reviewed several times to identify potential new codes. Thirdly, the major categories of codes were compared and analysed in order to identify

the main themes. These selected codes were examined carefully to determine whether they matched the main themes. The themes were revised based on discussions between the main researcher and supervisors. All identifying information was removed or edited to ensure anonymity of both participant and case examples.

During analysis, a map (Appendix 1) was drawn to visually represent the author's analysis regarding relationships between HIV organisations and other organisations in supporting migrant clients as well as key components of the social environment. In order to increase the researcher's understanding about the organisations' services and to develop analysis, the researcher also used multiple information sources of participating organisations: website information about both services and missions of each organisation as well as printed materials. Availability of printed materials such as brochures of organisations and annual newsletters was very limited. Confidentiality of client information was a reason that they do not publish specific documents about client support programs. Staff members also explained that program reports are usually created for internal evaluation only or for reporting for donors.

### ***Ethical approval***

Ethical approval was obtained by the Human Research Ethics Advisory Panels of The University of New South Wales. Signed informed consent was obtained from all participants.

## **4. Findings**

### **Chapter 1**

#### **Providing and facilitating access to care and support**

The inductive thematic analysis from the interviews generated three themes regarding the role of HIV service organisations in supporting migrants' access to HIV care. These are 'providing and facilitating access to care and support', 'collaboration' and 'challenges to service delivery'. This chapter will explore how these organisations facilitate access to HIV-related care and support for HIV-positive migrants.

This study identified that these HIV service organisations have played a vital role in meeting the diverse needs of HIV-positive migrants through a broad range of services and support both inside and outside the healthcare system. These organisations provide health, social, emotional, clinical and legal services for migrant clients. Organisations providing support in the healthcare system play an essential role in making healthcare services accessible for migrant clients and helping them stay in care. Organisations providing social and legal support play a significant role in enabling migrant clients to have stable lives, which is a fundamental condition for stable access to healthcare. Thus, this comprehensive care and support has empowered HIV-positive migrant clients to take control over their own lives.

#### **Making healthcare services accessible for migrant clients**

##### ***Improving mutual understanding between clients and healthcare workers***

A HIV organisation funded by the New South Wales state government runs a clinical support program for clients from CALD backgrounds. Many migrant clients face difficulties in negotiating the healthcare system and this organisation supports clients to

understand the healthcare system and to have better access. The organisation has approximately one hundred co-workers from thirty different language groups as health education officers. Under the supervision of clinical supervisors, co-workers assist clients from similar language and cultural backgrounds. For example, co-workers explain and negotiate the complexity of the healthcare system to the clients.

The services that we provide, there's the clinical support services, supporting people who are HIV positive by providing somebody who is of that same language background and same cultural background. Because what we found is that people come into Australia trying to negotiate the healthcare system, and really need somebody to help them, because it is very complicated healthcare system. (Organisation A, Participant A)

They (=co-workers), in the clinical program, they work with clients who are HIV positive. And what they do is they give support to those people. So, they can either go with their clients to a doctors' appointment, they can just meet for a coffee. They can, there are a whole range of things that they can do outside of an office, a bit like a professional friend, but they don't interpret. (Organisation A, Participant A)

Co-workers assist both clients and health professionals to improve mutual understanding and build trust. This includes not only language assistance, but also cultural understanding.

So, you can have somebody who can access, who is linked in with hospitals. But they might not actually understand what they are doing, or what they're meant to do there. So, their access to services can be quite, um, blocked...So, whilst they may come from a hospital, a referral might come from a hospital [it] doesn't mean to say that their access is as good as everybody else's. Because the healthcare system doesn't understand them, and they don't understand the healthcare system. So, we provide support to help make that connection better. (Organisation A, Participant A)

...one of the main things is communication and that's a huge thing, so, language. But also cultural understanding of how things work. So, somebody may speak English well. And the nurses and doctors can speak well, but their understanding of how something might work is different. So, we, you know, in all our culture, we assume something will occur in a certain way. It's a subcultural

thing. We just assume somebody will know something. But that's not always the case.  
(Organisation A, Participant A)

One important role of bilingual co-workers is to bridge the gap between clients and healthcare providers both in the clinic and outside the clinic. For example, after accompanying them to the doctor's appointment, co-workers interact with the clients outside of the hospital setting in a friendly and casual ways. This makes it possible for the co-workers to identify if clients, who hesitate to ask questions to healthcare providers, did not understand what was told to them. At other HIV service organisations without a bi-lingual co-worker program, staff also made efforts to assist migrant clients in receiving regular healthcare services. For example, they explained the importance of written documents from hospitals when clients visited their drop-in centre.

There was one lady who [had] very, very limited English skills, and every time she got a letter, or an appointment, for whatever within the hospital system, she would disregard it, she didn't understand it. So, in the end, she'd start bringing them here, and saying 'Okay, what does this mean?' and with very limited understanding between all of us, [we] were able to stress the importance and get her going to these things. And so, in the end, she realised that if she got anything in the mail, or if she went to the hospital and they gave her some paperwork she didn't understand. She knew that she could come here and we would then make the phone calls necessary to help her understand and let her know where she needs to be, and even take her there if necessary. (Organisation B)

The HIV service organisation staff members accompany clients on their visit, explain the importance of the next appointment and help clients to remain in the healthcare system. Several studies reported that these kinds of support are effective for HIV-positive clients to keep receiving healthcare services, particularly for those who are hard to keep in HIV-related healthcare services (Pillai et al. 2009, Bradford et al. 2007, Cabral et al. 2007).

### *Providing emotional support*

Bilingual co-workers provided continuous emotional support through helping migrant clients to understand health services and accompanying clients. This support was also helpful for staff working at healthcare facilities who faced difficulties in understanding clients' problems because of clients' limited English speaking ability. However, the language barrier was not the only reason to understand clients' situations. Some clients had difficulties in expressing their problems because they were overwhelmed by a feeling of hopelessness after stressful events such as abuse and HIV diagnosis.

The relationship ended up...being a lot of violence and abuse in the relationship. This woman didn't speak, doesn't speak, or didn't speak any English, didn't know how the healthcare system works, and was terrified. She'd just gotten HIV. She didn't have it when she left her country. She got it when she came here, and really didn't know what to do, was really really upset... So, the social worker rang us, said 'can you help this woman?' which we could. We got a Spanish speaking co-worker who then helped her along with the social worker, who was able to talk to her, and communicate in her own language. So, the woman was finally able to just talk about what have been going on for her. So, then everybody understood...So, we'd go with the client to the social worker appointment, we'd go with the client to the doctor's appointment...and explain to her why she is going, and what was going to happen. (Organisation A, Participant A)

The participant explained how their clients expressed their appreciation of having support from the co-workers. These co-workers became valuable supporters to whom clients can talk about HIV in their own language when nobody else in their private lives knew about it.

...there are some clients just say "there is nobody that knows about my HIV status except my co-worker and I really need to keep them" (Organisation A, Participant A)

many of our clients have said that they wouldn't have been enough to survive without their co-workers, that co-workers are the people who got them through all of this.( Organisation A, Participant A)

Other HIV organisations running drop-in centres also play vital role in providing emotional support. For clients who feel disempowered and isolated, their connection with those HIV service organisations can work as a safety net to better ensure that clients stay connected with the healthcare services.

So, it's something that we can then bring into a conversation and get them back on track, back interacting with their health providers and take care of themselves...I think it's very easy for somebody who, sure they might be seeing their doctors... but if it becomes, it's very easy to become depressed due to isolation. You don't wanna then take your medications, you don't wanna see the doctor, it can very much stop you from wanting to do anything. So, I think the social aspect of it is very important to-. It can help keep a lot of things on track, a lot of things...When they fall, we can pick them up and get them back in there again. (Organisation B)

### ***Linking clients to HIV service organisations***

The main way most migrant clients gained initial access to HIV service organisations was through referrals from social workers of hospitals or sexual health services. Two interviewees mentioned a common pattern with clients visiting the emergency department of hospitals due to severe medical conditions and then social workers contacting the HIV organisations after assessment. The ways that migrants accessed HIV service organisations were not only through referrals from health facilities, but also through referrals from other HIV service organisations as well as self-referral for those clients who learnt about the services from a website or through service users.

For the migrants, it's usually either the social worker at the hospitals, in the infectious diseases [department], because that's where they're likely to end up in an emergency. So they would contact us. Um, second to that would be the Sexual Health Services, because they've gone there for services... The other biggest one would probably be [Organisation E] themselves...(Organisation C)

Some organisations identified and assisted clients who had not yet connected with the healthcare system, although this happened in only a few cases. They have a role in



creating a pathway to allow initial access to HIV healthcare services before their clients develop physical symptoms. Expanding this role of HIV organisations is significant in accelerating migrants' access to HIV healthcare.

### **Support for improving fundamental conditions and resources for clients' health**

Many HIV-positive migrants confront a range of social issues. Their HIV status makes non-HIV related social problems more complicated. Some social problems are caused specifically as a result of their HIV status or health problems that HIV-positive people experience. Crucially several HIV organisations are addressing social issues outside the healthcare system. They provide a wide range of social and legal support in order to meet each client's needs, such as finding a place to live, buying food, getting access to education and finding a job. These social determinants are 'fundamental conditions and resources for health' (WHO 1986). For example, migrant clients need HIV organisations' assistance in negotiating public welfare benefits and living issues. This is because many clients face difficulties due to language barriers and unfamiliarity with the social system while also having limited personal support due to confidentiality concerns (Körner 2005).

### ***Assisting with government and private agencies***

#### ***Accommodation and housing support***

Several organisations provide temporary accommodation and help clients to find permanent housing. Some clients were given financial support, as they had no place to live due to discrimination by family members.

We worked to get him some public housing which his family also got but they, the step mother decided she didn't want him to come with them. So, he wasn't ready to be able to stay on his own,

so his cousin had him stay with him, but that didn't work out. So, he did eventually go into his own accommodation. So, we helped with that support. (Organisation C)

An accommodation service with respite care is provided by one organisation. This service assists clients who have difficulty travelling to access HIV healthcare services in Sydney. During their stay, clients can feel at ease without being concerned about HIV disclosure.

...the respite care where we have two bedrooms and a volunteer would stay on over the night if somebody is staying here, that's short term...We also have people come from up the North Coast, South coast if they need to come to Sydney for appointments at the hospitals or the clinics here. They will come here to stay overnight because it's too much of travel distance and also an expense to stay overnight anywhere else. So, because it's a HIV related stay, they would book in here and stay here if we've got the room. (Organisation B)

They help to negotiate with housing agencies on behalf of clients who might have language difficulties, or do not understand both the private rental market and their rights and obligations as tenants.

It would be housing. Yes. And a lot of that would have to do, because a lot tend to be in a private rental market or are waiting for governmental housing, social housing...they don't understand what the real estate saying to them, because, you know, their cycles are different, pay days is different to what the rent day falls due, things like, small things like that is what we tend to pick up on...We will often get them to give us permission to contact and act on their behalf and work with them that way. (Organisation B)

A participant recognized that some clients were reluctant to complain about public housing for fears that speaking up would make them lose their right to their home. Assisting migrant clients with housing issues and teaching them their rights were important aspects of their work.

If they've got public housing, we can help work with public housing to ensure that everything is okay. They often do not feel empowered to make complaints, if they get public housing they

put up with whatever, because they are frightened if they say anything they might lose their housing. So, it's about getting them to understand they have rights in this country and they can say they don't like something or they think something wrong...So, it's about ensuring they get their rights and they understand their rights. (Organisation C)

### *Social Welfare benefits*

Centrelink is the government program delivering a range of payments and social services for people who need support, such as those who are unable to work. Despite this public assistance, many migrants find it hard to negotiate with this service due to language barriers and a limited understanding of the system. Many organisations in this study often help migrant clients to resolve difficulties in accessing it and to receive all the benefits they are entitled to.

Sometimes, understanding the rules of the Centrelink who, when they are receiving government benefits. Some people just don't understand... But they don't realize that or completely understand that and then all of a sudden they've got no money, no payment, and can't understand why. So just trying to get to the bottom of it by that things like that... we can get on the phone ourselves and call Centrelink. And they can explain to us what's happening. So, that way, we can somehow, you know, get through there. (Organisation B)

### *Providing financial support*

One of the main programs of one organisation is financial counselling. This is necessary as financial problems can result in a huge amount of accumulated debt. Support in this area can involve negotiating with banks and helping clients to achieve a solution that is manageable by the clients.

She went to Vietnam to take the children back to the family. She did that on a credit card, then she couldn't pay it because she wasn't working. So, we were working with her around her debt and negotiating with the banks to wipe the debt. So, then she could just be on the pension till she got well, and then go back to work. But what she was trying to do was work, push herself to work. So, she could pay the debt off. So, there is a lot of stuff around debt. So, the financial counsellors come into their own there. (Organisation C)

Another area, where financial support is necessary, is the cost of antiretroviral therapy for clients who are not entitled to the Pharmaceutical Benefits Scheme. In this case, financial assistance for their medications is provided usually as temporary measures, because there is no budget that can cover lifelong medication fees. Some clients are even under the healthcare scheme, but they cannot afford the additional dispensing fee for their medications. Thus, financial assistance from this organisation enables these clients to access necessary HIV-related medicines.

If they meet our financial eligibility, then they would get financial assistance...There is a, what's called 'A No Interest Loan', they can borrow 1000 dollars, and they have to pay that back, but there is no interest...but in terms of anything else we do, whatever we approve that's it, they get it. So, if, for instance, they had a health card, and their HIV medication we would pay for that completely. So, we would set up an account with the hospital pharmacy. They would just go in and get their medication, and then we'd get the bill. (Organisation C)

### ***Support for legal issues***

In order to be entitled to social services, health services and subsidised HIV medications, legal support for navigating the immigration system is crucial. For migrant clients, legal issues usually revolve around their visa and their residency status. One organisation works specifically for legal support for clients with HIV.

It's a free legal service for people who have legal problems as a result of their HIV status. So, that can be quite broad. In terms of, specifically for migrants, we do work in immigration, because migrants who are HIV positive would have particular problems with the migration process...but for migrants particularly when they are struggling with, they might have been unlawful, in Australia for a period of time...they need to organise their migration status so that they can get access to things such as Medicare, so that they can, yeah, obtain medical assistance. (Organisation D)

Several participants mentioned the migration process as an area of their support for migrant clients. They usually refer their clients to the aforementioned legal organisation.

Assistance in the settlement process was important for clients who needed to stabilise their lives in Australia.

...she is now going through the legal process of getting her residency here... So, she went from the somebody who was in an abusive relationship, couldn't work, didn't know the healthcare system nor English, nothing. To be somebody who is now working, living with her daughter and working quite extensively with the legal service to get her residency here. And...to kind of set up her life here. (Organisation A, Participant A)

### ***Providing a safe space to interact with peers and staff***

Peace is an essential resource for health (WHO 1986). Emotional peace and safety in relation to HIV are provided by these organisations which offer safe places where clients can interact with supportive people with minimum concern about disclosure of their HIV status. One is a drop-in centre, and another is peer group meetings.

#### ***Drop-in centres***

At drop-in centres, clients can utilise facilities such as internet access and telephone, and receive services such as lunch and complementary therapies. These centres also provide a safe social space for people living with HIV.

...a 5 day a week drop-in centre where we provide access to low cost groceries...internet access and general access to TV...lunch service...reflexology and massage therapies...and generally people come here just to interact with their peers, other people living with HIV whether it's another person infected or just carers, family members, or just for the company of our volunteers who work here during the weekdays. (Organisation B)

Having a safe place where the confidentiality of their HIV status is kept is crucial for clients. Some migrant clients kept a distance from their ethnic communities due to a strong fear of disclosure of their HIV status. Thus, their connection with these services helped to prevent them from becoming socially isolated.

...a lot of people out here who [are] quite isolated...Socially isolated, I think...There was one case...she didn't want anybody to know her HIV status. So, once she was here in Australia. She would not have much do with anybody from her community, whatsoever. She was that frightened of somebody finding out that she was HIV positive. So, she would tend to come here, because there was nobody she knew. (Organisation B)

They know that it's here. Um, when you've got no family, you know, not a great support network outside of your home. I think it is very important to know that there is somewhere that you can go that completely understand everything that's happening with you. (Organisation B)

They offer an inclusive environment for clients regardless of ethnicity and sexuality. Staff members and volunteers have non-discriminating attitudes towards everybody with HIV who visits their organisations. They create a place where people feel acceptance from others.

One of the strengths of the whole organization would be that the diversity of our clients... They all get on so well, interact so well and support each other. It is quite a strength for somebody who feels that they may not be going to fit in somewhere. That everybody's so accepting, and willing and wanting to include new people into the fold rather than having their own groups...Everyone is always willing to include everybody regardless whether they can speak English, regardless if they different, they dress different, they look different. It really doesn't make a difference here. (Organisation B)

A participant mentioned that a strong fear about confidentiality was an obstacle for some clients in joining the group meetings. For these clients, having a connection with staff members who were not from their ethnic community was the most comfortable way to utilise their services.

The individual clients that I have, within my project, that are happy to access me, are not interested in a support group. And I had discussion with them around that. And that is because they're fearful of stigma and discrimination by other community members. (Organisation E)

### *Peer group meetings*

A peer group for HIV-positive African women had been organised monthly through the collaboration of three organisations consisting of non-governmental organisations (NGOs) and an Area Health service. It promoted vital psychosocial support among group members as well as health education. An African worker communicated with and approaches HIV-positive women from similar cultural backgrounds in a culturally appropriate manner. A participant who coordinated this group articulated that this African worker had contributed greatly to the development of this group.

It took a good 18 months to establish this group before we had our first meeting. There was a lot of legwork done to establish trust and make the women feel comfortable that it was okay for them to come to this. And that has built momentum. And people are talking which has let other people feeling comfortable to come to the group. That's been a strength...Having an African worker on the project has also been a great strength in establishing those connections. (Organisation E)

The organisers gave great attention to providing a safe environment for group meetings so that members can participate without concern about confidentiality or privacy. Through the meetings, members can interact with each other. Health education opportunities provided in the meetings can assist in improving members' treatment literacy and adherence (George et al. 2009). The meetings also provided women with positive gender-specific information about fertility and pregnancy (Worth et al. 2003).

We provide some form of health promotion education. So, we might have a guest speaker come along, and talk around a particular topic. That might be around supplements or medication updates or female sexual health and how to maintain, you know, your other health. (Organisation E)

It's private, so their fear around disclosure is almost nonexistence, because we have a room that we utilise as just for our group. (Organisation E).

Creating an inclusive environment for HIV-positive people from similar ethnic

backgrounds can have a beneficial effect as it allows them to freely express themselves about their HIV status and HIV-related experiences (Acevedo 2008). Clients who stayed in HIV care were also better able to accept their HIV status and had more HIV related support from friends than those who did not (Rajabiun et al. 2007). This was also evident in the data for this study.

I think they're just so grateful that they have services available to them. And that people are willing to come and talk to them about being HIV positive. They think it's fantastic...For those women that they can come, they don't miss a month. It's really important to them, because it's about having that connection. They're meeting with other women that are in the same position that they are, and experiencing the same things that they are. (Organisation E)

Interaction with peers through group meetings can evolve into mutual support among members outside of the group activities. It can lead to a sense of community, where their commonality is their HIV status (Harris & Larsen 2007). This social relationship prevents clients from being socially isolated (Acevedo 2008) or stigmatised (Marino et al. 2007). In addition, having someone else who cares about their health can encourage HIV-positive women to take care of their own health (Edwards 2006).

...A lot of them meet on a weekly basis. They go to each other's house...So, they're always having access and communication and connection with each other outside of that one monthly group meeting. (Organisation E)

I think the one of the other strengths is around when the women did get together, that feeling and that acknowledgement that, they weren't the only person living with this condition, was amazing. And because of that, they've been able to form a really tight bond in the group. They're very supportive of each other...if someone is unwell, and has been hospitalised, they all get together. They cook food. They look after the children. They do whatever they can to help each other. It's incredible. (Organisation E)

Peer group interactions can also increase clients' knowledge of service choices and organisations.



Through the African women's group, the women are made aware of the other, external services and what we have to provide. (Organisation E)

### ***Providing support to families***

The participating organisations did not limit their services to HIV-positive individuals, but also included clients' families and carers. Families can come to group activities and drop-in centres as well as receive services such as counselling.

With the Women and Families project, it's people that are infected or affected. So, we look at the whole families. So, we might get a positive woman coming. We provide support for her family whether she has children, partner, but also vice versa could be the partner is positive. We would also provide services for the negative partner and whether they had family. (Organisation E)

One issue specific to women was responsibility of caring for children. To minimise barriers to participation for women with young children, childcare was opened to make activities more accessible for women.

I think in general, women will tend to put their healthcare needs behind the care of their family. Family is first, more important than their own healthcare...Within our projects, we try very hard to make sure that we have child care available so that people can come and know that they can still come and listen and have services available, but their children can be looked after so that they can do that. (Organisation E).

### ***Developing HIV-positive migrant's life skills so that they take control over their lives***

A HIV organisation helps clients to access vocational study and return to work. This makes an impact on client's quality of life. For example, migrant clients from non-English speaking countries received support for English language courses, because language proficiency will help them in their pursuit of employment and also in their

social lives. Providing skill training opportunities is beneficial for migrants to integrate into society. Improved employment outcomes and social skills will lead to self-reliance.

...he was classified as a refugee...but 'cause he didn't know how to go about that, but so that's why we supported him with... Then he was doing some TAFE courses. We were helping to pay for...So we have an annual figure that we will assist people to pay for their fees and an annual figure to help with the books, whatever. (Organisation C)

Some participants often saw their migrant clients caring for their families overseas rather than taking care of their own health. Thus, they tried to convince clients of the importance of healthcare which in turn enables them to take advantage of employment opportunities making their financial situation more stable as well as bringing benefits for their families.

So often when they are here, they are often responsible for a very large family back in their country of origin. So whilst they may only get a small pension here when they do qualify, often you find they are in very poor health, because the majority of that money gets sent back overseas...We try and demonstrate to them that the best chance, is to get their health up and skills up so that if they can work, they can balance their money a whole lot better. (Organisation C)

Each client has different issues that they need to deal with or skills to develop for stabilising their lives. The participant explained that the strength of their organisation is providing the best support for each individual to meet the particular needs of that individual. In order to achieve it, initial client assessment is an essential process to understand each client's situations. This study also found that most organisations take on board feedback from their clients about their services. Suggestions from these clients can lead to more culturally appropriate services and a general improvement in services according to clients' needs (Aranda-Naranjo 2007).

I guess the strength is that we committed to access for the clients. Whilst we have guidelines, it's about, as I said, ISP, Individual Service Plan. Keyword 'Individual'. And that's the strength. It's not about making everybody the same. (Organisation C)

### **Values behind support**

The staff in HIV service organisations had a strong belief in equality of support for the better health and well-being of people. Their efforts to help marginalised populations were underpinned by their values around human rights.

The strengths are that we provide much needed services to people who feel very isolated and who are alone...our program facilitates access to healthcare which is a universal right, I think, for people. (Organisation A, Participant A)

One organisation made a conscious decision to help clients based on humanitarian grounds rather than their residential status and their legal entitlement to services.

We investigated that by providing assistance to someone who is illegal we weren't aiding and abetting. It was a humanitarian thing, and because those migration issues were not seen as criminal. Okay, they are illegal, but they are not criminal. So therefore, we were not involved in criminal activity...So, we've never excluded any particular category of people whether by race, creed or their residential status. (Organisation C)

There was also a respect for diversity. Among the organisations in this study, only one runs specific HIV programs for people from CALD backgrounds. However, the attitude of all organisations' staff participating in this study showed that they were always willing to understand each client's circumstances, such as their cultural backgrounds, in order to find the best solution. It seems that staff members' positive perceptions towards the diversity of client backgrounds are underpinned by each organisation's values. The HIV service organisations are highly aware of sexual diversity. The major HIV service organisations in Sydney were established by gay communities and their efforts of ensuring rights for sexual diversity contributed to the development of HIV programs for

this community (UNAIDS 1998, Stewart & Penny 2003). In addition, Australia's multicultural context as a nation might affect staff members' familiarity with cultural diversity. However, due to greater cultural diversity, the complexity of HIV support increases. Thus, cultural competency training for HIV service organisations might have contributed to the heightened awareness and capacity of those organisations both for individual staff and the organisations as a whole.

This is the first study focusing on the point of view of staff of HIV organisations about their services to support migrants to access HIV care and support in Sydney. It highlights the significance of holistic care and support for migrant clients to manage their lives with HIV. Although the majority of migrant clients have access to the healthcare system, these clients are not always capable of utilising healthcare services due to reasons influenced by culture, language and social barriers, on top of their HIV issues (Körner 2007a). Wishing to avoid HIV-related stigma, many clients are reluctant to ask for support from their friends and families. HIV organisations respond to migrants' health and practical needs. Hence, their assistance helps to increase migrants' ability to access a range of HIV-related care and support. This indicates that providing medications alone does not bring stable access to HIV-related healthcare for many migrants. This study shows how these organisations in Sydney have responded to issues raised by other studies, which focused on HIV-positive individuals including migrants. These issues include empowerment of clients to communicate with healthcare providers (Cavaleri et al. 2010), the development of social work (Miller 2010), support for improving English language and employment skills (Keogh & Henderson 2004) and support for improving client well-being as a family unit according to their needs (Groft & Robinson Vollman 2007). This study also found that these organisations address socio-economic barriers which migrants with HIV face in utilising HIV related

healthcare services and social services provided by HIV organisations. These are similar to findings from another U.S. study (Chin et al. 2006). In order to overcome these barriers, HIV organisations provide support for client's travel to access healthcare services, Medicare access through legal assistance, and income generation. Furthermore, HIV organisations make their services accessible for women by reducing obstacles related to family responsibility (Körner 2007c). Confidentiality and stigma issues are addressed through organising services and group meetings.

While this study explores services for migrant clients, it seems to be essential for service providers to have clear values such as 'equal access' and 'respect for diversity'. In contrast to this finding, a Canadian study (Cain & Todd 2009) reported that some social service providers for HIV-positive people were reluctant to support clients from different socio-cultural backgrounds. Their study also found confusion among some workers about how to respond to the increasing socio-economic needs of their clients, which are not directly related to HIV. This indicates that the kinds of values found in the current study help service providers to maintain clear ideas underlying their work. HIV-positive clients' needs have been changing since HIV became a chronic disease through treatment development (Zablotska et al. 2009). In order to respond to clients' needs, HIV service organisations in this study manage in several ways. The next chapter will discuss 'collaboration' as a crucial approach in organisations' service delivery.

## **Chapter 2**

### **Collaboration**

The previous chapter discussed how the HIV service organisations work to provide the broad range of care and support for migrant clients with HIV in Sydney. These organisations' staff explained how they manage to provide necessary support for migrant clients with diverse needs. Each organisation worked through strong collaboration with other organisations and staff working at healthcare facilities in providing care and support for migrant clients, and this is their outstanding characteristic as well as being their strength. This chapter will discuss the elements, functions and enabling factors for collaboration in their work supporting migrant clients.

Partnership has been emphasised since the first national HIV strategy in 1989 (UNAIDS 1998, Commonwealth of Australia 2005). This partnership includes coordination between the government, healthcare professionals, non-governmental organisations, people from affected communities and researchers towards their common goals (Commonwealth of Australia 2010). In the recent HIV strategies of both New South Wales and the national level (NSW Department of Health 2006, Commonwealth of Australia 2010), the term 'partnership' has been still highlighted as a significant and essential principle. Collaborative working experience, through the development of HIV programmes predominantly targeting the gay communities, would have contributed to creating a basis of supportive working environment for workers addressing HIV issues of migrant populations. This collaboration is crucial in responding to migrant clients' needs and problems, because most of these issues are diverse and complicated. This

study identified that there were several collaboration patterns, namely 1) between HIV service organisations and staff working at healthcare facilities, 2) amongst HIV service organisations and 3) between HIV service organisations and social groups. In addition, there was internal collaboration within organisations.

### ***Collaboration with staff working at healthcare facilities***

Participants communicated with staff in hospitals and Sexual Health Clinics that referred clients to HIV service organisations, especially with social workers. Social workers have a pivotal role in coordinating care and support that meet the medical, social and legal needs of clients. International studies have shown that HIV case management strategy is used in institutions and communities in order to link clients with necessary healthcare and social support (Chernesky & Grube 2000, Lehrman et al. 2001, Husbands et al. 2007). Studies have identified its implementation to improved utilisations of HIV health service (Cunningham et al. 2008), fewer unmet needs of supportive services and increased medication use among HIV-positive individuals (Katz et al. 2001).

Participants described clear definition of responsibilities between social workers and the staff of HIV service organisations, with the social workers as the case managers deciding the overall strategy for individual clients, and participants collaborating with case managers to work towards the desired goals. Understanding each other's responsibilities is essential for good team performance (Baker et al. 2006).

So, the social worker is the case manager of the clients. And we are kind of, we provide support to the social worker, but the social worker kind of has control in a sense of what's happening. They are the driver. (Organisation A, Participant A)

We deal mostly around their social and social welfare day to day living things, not their clinical stuff. That's what we're supposed to do. We in fact get very involved in clinical stuff, but because our workers are not necessary social workers... we are not case managers. We are caseworkers. (Organisation C)

One participant emphasised the importance of their organisations' role as a provider of social support in assisting clients to solve problems in their daily lives. The participants believed that staff working at healthcare facilities had limitations in dealing with these issues, and that social support was integral. This suggests that a cohesive and holistic approach by healthcare facilities would be highly beneficial. However, due to current limitations, HIV service organisations strengthened the role of the social workers of the health facilities in dealing with social issues. HIV organisations' support in clients' personal lives can address barriers that could make their lives with HIV more difficult. Thus, it was necessary for HIV organisation staff members to keep in connection with the staff in healthcare facilities that referred the client to the HIV organisations.

As a worker, it's important that I must maintain the working relationships with the health providers and the other service users, because otherwise those clients would fall under the radar. Nobody would be able to, they wouldn't know although the hospital, the healthcare system are very limited in what they can do. (Organisation B)

I can then work around trying to point them into a right direction or steer them in different directions rather than counselling them, because we are not counsellors. Yes, I think social, social support can play major major parts in, you know, the lives of people especially when they are on their own. (Organisation B)

According to Himmelman (1996) who argued that collaboration within social services requires power sharing between organisations, trust is an essential component of collaboration. This was also evident in the data of this study. Participants described trust between their organisations and staff of healthcare facilities in order to achieve the best possible outcomes for clients.



I think in the HIV field. I think that we've got some really good people that work in the field, and they're very dedicated. I don't know if it is same for all other areas of medicine, but I think that, you know, that we're lucky here that we do have such good people who are very committed to saving lives. (Organisation A, Participant A)

Probably, only those who have anything to do with infectious diseases or sexual health, those ones, then yeah, they are generally very aware of who we are, and what we do. (Organisation B)

Particularly some of the bigger hospitals, they're usually quiet helpful. They'll waive the fees, particularly for, if they're seeking protection (visa). (Organisation D)

### ***Collaboration among HIV service organisations***

The participants in this study also collaborated with other HIV organisations to help their clients to access support and assistance which were not available within their organisation. One particular issue, where collaboration between different services was effective, was clients' sexual orientation and their ethnic backgrounds. Different organisations provided services specially for gay men, for heterosexual men and women, and for people from ethnic minority backgrounds. The good relationships between different organisations were a definite strength in providing services to a range of clients with diverse needs.

...it's in terms of strength, the industry, the HIV sector is very well-connected. Everybody talks to each other. Everyone makes sure that everyone is getting the assistance they need. So, being such a well-connected sector, it makes it-. It's a sort of easy or reach out to the different organisations that you need. So, the particular client is getting the right support and assistance. (Organisation D)

In order to meet client's HIV-related needs, mental health, employment, housing and social needs, the successful collaboration amongst all parties was illustrated by the following example.

He has got back on his feet, and he is working, somewhere stable to live, has made a lot of other friends, networks. His mental health is gradually becoming a lot more stable as well...So, there

is just like a joint effort of, you know, everybody coming together to support that one person. And he was, because he had that support. He was able to lift himself up, and go forward for himself. (Organisation B)

It appears obvious that staff members had advanced referral skills which promoted collaboration. All participants who were in charge of client support thought that it was their role to find other resources whenever it was necessary for their clients.

So, if there is anything that we can't provide, or we can see that there is something they can access through another HIV service, we will not hesitate to get on the phone and ask them to, yeah, help in that way. (Organisation B)

If it's a service that our clients require that we can't provide, then we would refer it on. And if I don't know who that would be, I would find a way to find out who it would be. (Organisation E)

For effective referral, the staff's wealth of knowledge is essential. A participant expressed that they were willing to expand their networks with other organisations and workers. This is because this relationship-building leads to an increase in staff's knowledge about social resources, which in turn is beneficial for their own clients.

So, always working on different working-parties and the committees to establishing different things that happening...It's good, because I am able to make different networks for my own clients. So for me to be able to provide a broad service and knowledge of what happening in different parts of New South Wales and across Australia. (Organisation E)

### ***Collaboration with social groups***

Participants made efforts to link their migrant clients to other non-HIV specific community resources, such as local religious or cultural groups. These resources are not only beneficial for extra support which is available in local areas, but are also an opportunity for clients to expand their social network (Simbiri et al. 2010). This kind of

social networking can become a strategy for migrants to cope with the stress of resettlement (Khawaja et al. 2008).

That's where I connected to a lot of non-traditional services. So where people had churches, I went often to their church, and connected with, 'cause many of them had a sort of community services program running in their churches...Trying to access some of the other traditions wasn't quite so easy. So, I went about doing that type of thing. And connected with a lot of the sort of social groups...I connected with a number of people there was um, a couple different organisations that I linked-. Some through TAFE, because they had a Cambodian teacher..., but he was also with one of the other cultural groups...(Organisation C)

### ***Internal Collaboration***

This study found that internal collaboration between staff and related workers was utilised to respond to the needs of migrant clients. These organisations mobilised human resources including migrants and non-migrants. Human resources from migrant communities were bilingual co-workers of a governmental service who were trained health education officers. This collaboration made their services culturally specific. In other organisations, trained volunteers who were not bilingual supported their services in various ways, such as; driving a car for clients to find housing, running accommodation services and providing emotional support by accompanying the clients.

...the volunteers. They were the ones who would drive him to look at houses, and keep him company when he, you know, just wanted somebody to talk to. (Organisation B)

HIV-positive people, who were originally service users, were also involved with some HIV organisations, for example, as volunteers. This approach had been employed to allow these people to get used to their organisations. The involvement of HIV-positive people as HIV-related service providers can improve their self-esteem (Dutcher et al. 2011). Furthermore, HIV-positive people can contribute their ideas for improving services that are more appropriate for HIV-positive people (UNAIDS 2007).

People might not want to come and drop-in. Drop[ping] into a group of people can be quite intimidating... They don't feel comfortable enough. So, if they are well, and they're looking for some sort of interaction, I encourage them to become a volunteer... They can, they get to know everybody, and become familiar that way. They have a purpose for being here rather than having to put themselves out there and open up to people that they don't know... And it helps us. (Organisation B)

### ***Further collaboration to improve services for migrant clients***

Whereas HIV organisations can refer their migrant clients in need to a government service which run cultural-specific clinical support, improving their organisations' social services appropriate for migrant clients was imperative for them. Participants perceived that there had been an increase in the number of migrant clients who are heterosexual. This had an impact on the HIV service organisations in Sydney that are mostly experienced in supporting HIV-positive gay men who are dominantly Anglo-Celtic—historically, the most affected population (The Kirby Institute 2011). Participants thought that this experience cannot simply be applied to migrant clients because of a number of factors such as differences in sexuality, values based on ethnic cultures and language (Körner 2007b).

Most of [Organisation E's] programs have been developed around targeting gay men, 'cause that is the highest population and the majority of people affected by HIV within Australia. However, we are seeing an increase in heterosexual HIV positive notifications. And a percentage of those are immigrants. So therefore, we now need to work really hard in taking what we already know we do really well, and evolving that for those target groups to make sure that the service we provide for them is meeting their needs from their HIV status as well as their cultural status. (Organisation E)

In order to make their social services and health promotion activities culturally appropriate, a participant expressed that building networks with HIV service organisations in migrants' home countries was advantageous. Exchanging information and experiences among HIV organisations from different countries should be promoted.

It's good to have connections with other organisations, overseas, to try and look at what they're doing and how they're doing within their own culture and see how we can bring that here and adapt that in a way that it makes people feel comfortable to access services...the information that's culturally appropriate, because I think as an organisation targeting Westerners, we do it really well, but we can't just take what we do for a Western culture and translate that smack into Thai or into Japanese or into Vietnamese, because it doesn't work. We need to have a cultural understanding of what acceptable from their cultural perspective. Because otherwise, it won't make a sense., 'cause it's not culturally appropriate. (Organisation E)

In summary, strong collaboration between HIV service organisations and other parties at multiple levels enabled these organisations to link their migrant clients with a wide range of services. This level of cooperative effort would have been built in a social context, as New South Wales has emphasised the partnership principle in HIV strategies. Simultaneously, these staff working for migrant clients had appropriate knowledge, skills and attitudes for effective collaboration. Furthermore, expanding network with HIV organisations in migrants' home countries would be beneficial in improving their services for migrants. The next chapter will discuss challenges from the viewpoint of staff in supporting migrant clients with HIV.

## Chapter 3

### Challenges to service delivery

This chapter examines how participants perceived challenges in service delivery for HIV-positive migrants. It also discusses how these organisations may be able to further develop their services by addressing these challenges.

#### *Stigma and strong fears of breaking confidentiality*

Stigma and strong fears of confidentiality being breached were considerable obstacles for many migrants living with HIV in accessing HIV organisations' services. There was a perceived refusal of migrant clients to utilise support provided by HIV organisation staff from the same ethnic backgrounds or communities. This is consistent with findings from other studies describing the perceptions of HIV-positive migrants (Körner 2007c, Körner 2010, Miller 2010). Participants reported many migrant clients who were extremely scared of discrimination or of being excluded from their ethnic communities, which was usually influenced by clients' experiences in their home countries.

I mean confidentiality is really really big issue with our clients, because that it's come from your background where HIV is very stigmatised. There is lots of discrimination. So, a lot of our clients are very reluctant to meet other people from their own culture who may know about their HIV status. Sometimes, our clients can be a little bit hesitant about getting a co-worker from their own community. (Organisation A, Participant A)

One day she came here, and there was somebody that she recognised...So, she stopped coming. So, it just really highlighted for me how people can be very afraid. It doesn't matter how many services there are, or how much 'reasoning' people can try to give them. They will still tend to, they can tend to isolate themselves, and, just for that fright of being...The stigma, yeah. The discrimination they've faced at home...They've seen other people face. They don't wanna face that themselves. (Organisation B)

A participant discussed the difficulties of setting up a peer group for HIV-positive women from Thailand, although they were identified as a high priority ethnic group needing support. The major obstacle to these women's participation was their strong fear of disclosure about their HIV status by other group members, and they worried about the negative impact to their families (Körner 2007c). For HIV-positive women, it was crucial to maintain relationships with their families and to avoid possible chance of stigma occurring (Foley 2005).

I think it's a cultural thing around family protection and being mindful of your family and your family is your number one priority. That is what's stopping this support group from developing...The feedback that I got from the Thai clients that I have on an individual basis, is that they're worried about stigma and discrimination and their families finding out. Because they don't, their families don't know about their status. So, that's an issue. (Organisation E)

The necessity of approaching ethnic communities was discussed by some participants as a measure to alleviate stigma as a service access barrier. Targeting ethnic communities is vital, because the formation of HIV-related stigmatised attitudes varies depending on sociocultural context (Hosseinzadeh et al. 2010).

We would like to see that [our services] expand. That's just how we engage with communities to feel safe to be able to do that.... working more with the broader community of those different cultural backgrounds in educating them around HIV, so that hopefully that stigma and discrimination shrinks and people feel safer to come and access services. (Organisation E)

One participant believed that HIV related stigma is a global phenomenon, but that a cultural approach is vital to tackle it.

There's stigma and discrimination that has no boundaries. That is everywhere regardless of the culture and the nationality...But the way in which you deal with that, and how that's managed as a culture is different, depending on where you are from. (Organisation E)

Some organisations in this study work to raise awareness of HIV issues in order to eliminate stigma and discrimination, and to promote early access to HIV healthcare among people in ethnic communities.

We recognise that culture has an impact on how you deal with health...We need to deal with that cultural perception about health in general and HIV in particular to be able to give the best outcome for people...We raise awareness, increase knowledge, increase their access to mainstream hospitals, decrease discrimination towards people living with HIV in that particular community. (Organisation A, Participant B)

Another issue raised was the image that people have of HIV services is services primarily for gay men. The participant recognised that some heterosexual migrant clients felt hesitant seeking HIV service organisations, because of concern about being seen as homosexual by others. This barrier is consistent with perceptions held by some HIV-positive migrants in other studies (Shedlin & Shulman 2004). This perception might be influenced by ethnic communities that tend to perceive HIV as a ‘gay disease’ (Gardezi et al. 2008). In addition, homosexuality is negatively regarded as being ignominious or immoral in these communities (Gardezi et al. 2008).

Some organisations were originally looked upon as having a culture being gay, ours is not a gay organization, ours is a HIV organization regardless of sexuality. That identity is often difficult to maintain. So, a lot of people who are heterosexual, sometimes feel, if they come to us, other people will think they’re also gay...So, it’s very important not to project that’s sort of image. (Organisation C)

### ***Clients’ negative perceptions towards government services***

Government services can be perceived as threatening by people who had experienced torture and trauma by other governments. As a result, people may be mistrustful of government services and not engage with them, even when they are entitled to such



services. This has also been found in other studies of HIV-positive refugees in New Zealand (Worth 2006), and of general African immigrants both in the U.S. (Simbiri et al. 2010) and in Australia (Sheikh-Mohammed et al. 2006).

There are a lot of people who come to our organisation who have a fear of healthcare services or a fear of government organisations...We are helping, but for a lot of people, governments and authority have been the ones who have tortured them or have taken away their family or have done something. So, there's so many different aspects. (Organisation A, Participant A)

Even though she had the legal status, she had no understanding of the system, of what she was entitled to, of any of the services. And she was very frightened to come to us...So, it is sometimes the fact that they just don't understand that there are services here, because they're so frightened of their own government. (Organisation C)

Negative experiences with government services can also have a follow-on effect on seeking help from non-government organisations and providing personal information.

She hasn't had a good experience of government in Vietnam. So, she doesn't have trust here, and 'cause all the organisations would be bureaucracy and asking questions. It sounds like government...But it makes it very hard to help if someone's not gonna give you the information. So, time-wise, I might speak to an Australian client, and I can sort things out in an hour and half/two hours, whereas someone from another cultural background, it could take weeks and months to get same result eventually. (Organisation C)

### ***Complex needs***

A huge challenge in supporting migrant clients was the complexities that are found in addition to HIV, such as traumatic stress, drug use, mental health problems and legal status, which are often intertwined. A participant articulated the tendency for their clients, particularly from refugee backgrounds, to have psychological problems attributed to harsh experiences. Other studies have identified association between poor antiretroviral treatment adherence and a client's history of traumatic events (Mugavero

et al. 2006), thus improving a quality of mental health care and support for these clients is crucial (Whetten et al. 2008).

Challenges are...trying to meet some of the more complex needs. I think we're seeing an increase in more, torture and trauma issues coming up with our clients coming from refugee backgrounds. So, that's a little more challenging. But, we definitely still work with them. But it's just we have to rethink how we are going to work. What other services they need. (Organisation A, Participant A)

There was recognition that HIV organisations need to build their skills in order to support migrant clients with multiple complex problems.

Sometimes, on top of the addiction, and their HIV, they are also a migrant on top of that again. So if there's mental health issues, it makes it even harder. So, we've got that situation at the moment. So, you've got quite a few different levels and yeah. That's the challenge, is the diversity, means you've gotta have more and more expertise, so training, keeping up training. (Organisation C)

Another participant explained that they need to distinguish between legal issues, which is their speciality and non-legal issues, which their clients express simultaneously.

They are speaking to us about quite personal issues often, even though we're dissecting the legal issues. It means there's a fine line between legal and social work...whilst we can ensure that they have counsellors and social workers. Sometimes, the clients who've spoken to us about such personal issues, just want to continue to speak to us about it... (Organisation D)

### ***Addressing cultural issues***

Difference of culture was discussed as a barrier for migrant clients in utilising HIV services. A participant believed that their migrant clients would like to have ethnic-based peer groups, as the groups are culturally specific. This was because some migrant clients seemed to have difficulty in acclimatising themselves to their drop-in centre. Other studies support this perception by describing Asian gay men's hesitance to

interact with other HIV-positive homosexual people from different ethnic backgrounds in peer support groups (Körner 2010).

They only come for a short time, because they really can't relate to other people here...., especially migrants, because there is nobody, who can relate to them, where they've come from, what they are going through-, ....because there is nobody from the same ethnic community.... because there is no connection there. (Organisation B)

### ***Funding for services***

There was concern about funding for running the HIV organisations' services. A lack of funding would clearly inhibit HIV organisation staff from making services more accessible for migrant clients. For instance, participants were willing to open their drop-in centre for clients who want to visit after their work or during weekend. However, there was no budget to enable staff members to work extra time.

Challenges would be funding on staff levels, being able to operate different times for those who work. (Organisation B)

Funding issues also prevented development of HIV services, as one participant mentioned in relation to culturally specific group.

I would like to see us be able to see all these different groups happening, but it's just not feasible, there is no money, there's no staff. (Organisation B)

Availability of sufficient funding can affect the perceived strength of their fundamental approach, which is listening to clients' needs when developing programs.

We'll have the discussion with the group and try and extract the best possible way before we proceed...They're probably the strengths. The challenges are to maintain that, to financially have a budget that will keep that going. (Organisation C)

In summary, the common perception was that both stigma and a strong fear of disclosure have prevented migrants from utilising HIV related services. This is consistent with findings from studies that conducted interviews with service providers in the UK (Burns et al. 2007), New Zealand (Miller 2010) and the US (Reif et al. 2005). Participants in the current study thought that these migrants' concerns were influenced by relationships with their families and communities, which is similar to what other studies have explained based on narratives of HIV-positive migrants (Körner 2007c, Shedlin & Shulman 2004).

Views from staff members suggest that multiple service choices are necessary to meet the diverse needs of migrant clients with HIV and to address perceived challenges, particularly stigma. For example, whereas some clients prefer bilingual co-workers from the same ethnic backgrounds who provide emotional support for them, other clients prefer workers who can communicate with them in the client's language or in English, but whose ethnicity is different. While some clients are encouraged by a peer group based on ethnic cultures, other clients avoid engagement with it. Moreover, participants emphasised the necessity of continuous development of HIV programs targeting ethnic communities in order to alleviate HIV-related stigma.

Participants also explained that barriers to migrants in utilising HIV services were affected by not only HIV-related problems, but also migrants' experiences in their home countries and their social conditions. Supporting migrant clients with HIV requires sufficient time to gain clients' trust and to understand them (Molitor et al. 2005).

In order to increase migrants' access to HIV services, extending service operation times (e.g. at night or weekends) would be appropriate for migrant clients who are unable to

use services during their working hours. Resources are needed to maintain current fruitful HIV services for migrant clients, (which also serve to increase their access to HIV care), and to further develop their services. These include continuous and greater financial support, time and sufficient numbers of staff (Rajabiun et al. 2007).

## **5. Conclusion and recommendations**

This study explored how HIV service organisations support migrants in gaining access to HIV care and support in Sydney from the perspective of HIV organisation staff. These organisations provide a wide range of health, social, emotional, clinical and legal services for migrant clients. They address cultural and social barriers facing HIV-positive migrant clients by cooperating with staff working at healthcare facilities. This contributes to making healthcare services accessible to clients, and keeping clients in care. Social support for migrant clients helps to stabilise their lives by dealing with social welfare, housing, financial issues, job skills and employment, as these all become more complicated as a result of their HIV status. Legal services assist clients with the immigration process, which affects their entitlements to medical services and public assistance. Additionally, there was a common perception that migrant clients tended to be socially isolated from families, friends and ethnic communities because of strong fears of HIV-related stigma. Thus, the emotionally safe places provided by these HIV organisations greatly help migrant clients by giving them a place where they can interact with people and connect with society.

The key finding was collaboration in delivering services for migrant clients. While each HIV organisation has a different speciality, they recognise the diverse needs of migrant clients. Thus, collaboration between services enables the mobilisation of existing resources for supporting migrant clients. This highlights the HIV organisations' strength in delivering services. This strong collaboration is likely to have been built through a long history of HIV response in New South Wales, predominantly targeting gay men, with the principle of partnership among all parties. Furthermore, there is still room for

these Australian HIV organisations to expand their collaboration internationally. Dialogue with overseas HIV service organisations would help develop culturally specific services and community programs for migrants.

A wide range of HIV services are available for migrants living in Sydney. However, stigma, confidentiality issues and negative perceptions towards government services were acknowledged by participants as being barriers for HIV-positive migrants in utilising these services. Each client has a different cultural background influencing service use. Thus, staff members of HIV service organisations need sufficient time to understand each migrant client's situation and problems. Staff members do this by establishing trust, so that they can communicate openly and find the best solution. Moreover, in order to make clients feel comfortable in using services, clients need to be provided with several service options, such as the ethnicity of workers and peer-group members. These characteristics of HIV services for migrants should be considered by donors and policy makers (especially governments) in order to understand the importance of these services and allocate sufficient funding.

Participants discussed several potential measures that could be used to reduce sociocultural barriers for migrants in utilising HIV services. For example, operation times of HIV services need to be reviewed, especially for migrant clients who have unstable and limited employment opportunities. In order to address HIV-related stigma, participants emphasised the necessity of strengthening efforts to approach wider ethnic communities.

One limitation of this study is that the sample size is very small. However, major organisations supporting migrants with HIV are located in Sydney, where this study was

conducted. Since this study focused on exploring support and services in a short period of time, opinions from migrant clients as service users were not incorporated. Views from users about these services help to explain the impact of the services on their access to healthcare and their unmet needs. However, views from front-line workers for HIV-positive migrant clients revealed a broad range of issues that HIV organisations address for their clients, how organisations have helped migrant clients' access to healthcare and made a difference in their lives with HIV. The use of in-depth interviews assisted in exploring the impact of HIV organisations' support for migrant clients who are constrained by socio-environmental factors. Simultaneously, this aggregated review of HIV-related services identified the need for further development at the ethnic community level for promoting access to HIV care and support services.

Most migrant clients of HIV organisations were referred from health facilities. Thus, HIV organisations should consider developing programs that reach more HIV-positive migrants before their health conditions worsen. There are people who confront hardship in accessing healthcare services, and there are also people who do not even know whom they can ask for help (Körner 2007a). A staff member mentioned that 'We weren't getting our services to enough people who are from culturally and linguistically diverse backgrounds, including migrants' (Organisation C). In order to promote early access to HIV healthcare services, continuous efforts working with ethnic communities is necessary (Bhattacharya 2004). There is a need to promote active involvement of ethnic communities in designing activities for: attitude change regarding HIV, education about health and HIV issues, and alleviation of stigma, all in culturally appropriate ways. Training community health workers in migrant communities would create a link between people with health consultation needs and the healthcare system (Henderson & Kendall 2011). Creating a supportive environment through community empowerment



would encourage potential HIV-positive migrants to access HIV healthcare services and social support at early stages.

While some organisations make efforts to raise awareness of HIV issues in migrant populations, it would also be helpful to deliver messages to eliminate access barriers to these HIV related services (Wohl et al. 2011). These messages include 1) that both government and non-government HIV services are for all people, regardless of residential status, nationality or sexuality, and 2) that their client information is treated with confidentiality.

Future research should include the effectiveness of these HIV services based on the views of migrant clients, comparisons of HIV services for migrant clients by state, how people in ethnic communities perceive sexual healthcare services and social support, and what these ethnic communities expect from their services in terms of accessibility.

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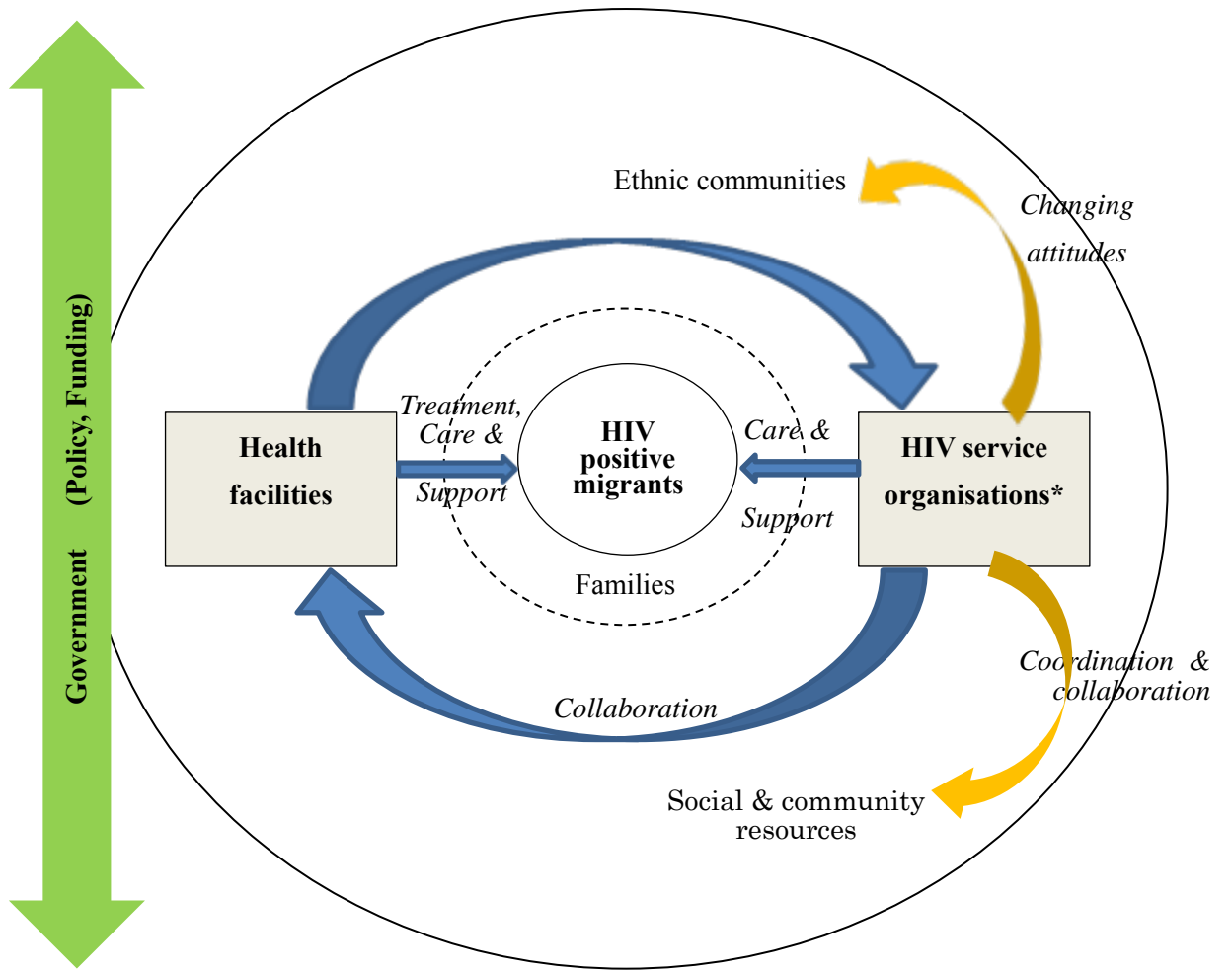
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**Appendix 1:** Analysis map of services for HIV-positive migrants



----- The dotted line means both existence and non-existence of family support

\* Both government and non-government organisations