kimmage DSC
development studies centre

Title >> The Self-Help Model of Service Provision as a Response to the Psychosocial Needs of People Living with HIV in Ireland

Author >> Laura Spring

Date of Publication >> 2011

Contents

Kimmage DSC© 2011

The vision of Kimmage DSC is of a world of equality, respect and justice for all. The mission of Kimmage DSC is to create an international, intercultural learning community which promotes critical thinking and action for justice, equitable sustainable development, and the eradication of poverty in the world. It aims to do this through facilitating the education and training of individual practitioners and groups working for social, economic and political change in society and so enabling all practitioners to work effectively for the holistic development of all.

Biographical Details

Laura Spring has worked in the development education sector in Ireland and is currently working for a not-for-profit organisation in Perth, Australia.

Contact Details

Email: laura_spring@yahoo.com

Abstract

This paper is a summary of a dissertation presented to Kimmage Development Studies Centre, Dublin in partial fulfilment of the requirements of the MA degree in Development Studies. It explores the correlation between HIV, the psychosocial needs of an individual and their sense of wellbeing. One organisational response to the psychosocial needs of people living with HIV- the 'self-help model' of service provision- is investigated through a case study approach and its effect on wellbeing is considered.

The primary research was conducted in Ireland in 2009 with 8 individuals, all of whom are HIV-positive and members of the case study organisation Open Heart House in Dublin. The findings clearly showed that HIV has profound psychosocial implications for the individual from the moment of diagnosis. The concept of HIV as a socially constructed entity and the inherent stigma was very evident from the research and appears to be a driving force behind the detrimental impact of HIV on a person's psychosocial wellbeing. The research also showed that the self-help model of service provision presents an effective, holistic response to address the needs of a person living with HIV, the result of which is a perceived improvement in wellbeing.

1. Outline of the Topic

The context for this paper is the devastating impact that HIV has had on the world since the virus was first discovered in the early 1980s. More than 25 million people have died of AIDS since 1981 and globally there are now an estimated 33 million people living with HIV (UNAIDS 2008). The first Irish cases were diagnosed in 1982. By 1985 it became apparent that HIV had become endemic in Ireland and that the virus was concentrated amongst intravenous drug users, men who had sex with men and through infected blood products (DOHC and Irish AID 2007).

By December 2008 there were a total of 5,243 HIV diagnoses, with 405 new diagnoses being reported during 2008 (HPSC 2008). Since 1999, there has been a general upward trend in the number of HIV infections being reported in Ireland and the profile is changing: the largest increase has been in heterosexual transmission (DOHC and Irish Aid 2007). The increased immigration of individuals from areas where there is a high incidence of heterosexual HIV infection accounts for a significant proportion of the increase, both in overall numbers and particularly in heterosexual transmission (ibid).

Huge efforts and resources have been dedicated to responding to HIV globally and progress has been made. Treatment of HIV with antiretroviral drugs, particularly in higher-income countries such as Ireland, now affords a HIV-positive person the possibility of a relatively healthy life. However, as Montgomery (2006, p.68) points out, there is a prevailing tendency to view HIV as a clinical issue rather than a social one, "to the extent that the psychosocial impact of living with HIV is not of real concern to physicians and policy-makers". This is regardless of the knowledge that exists on the social impacts of the virus; for example, stigma and discrimination. The noticeable absence of research on the psychological and emotional impact of HIV on the individual was a large part of the rationale for this piece of research.

1.1 Terms and Concepts

1.1.1 Psychosocial Needs

The concept of needs is, undoubtedly, an ambiguous one. Soper (1981, p.1) writes: "There can be few concepts so frequently invoked and yet so little analysed as that of human needs". Within the confines of this research, it was not possible to provide a comprehensive study of human needs theory. Rather, I selected two well-known theories frequently cited in the literature on human development. I considered the two theories in light of Gilborn et al's (2006, p.8) definition of the term 'psychosocial': "[a person's] intrapersonal (i.e. internal) emotional and mental state (psycho-) and his/her interpersonal network of human relationships and social connections and functioning (-social)".

The first theory I looked at was that of Abraham Maslow. Maslow (1954) proposes a hierarchy of human needs, beginning with the most basic physiological needs, such as air, food and water. On the next level are safety needs. These are not exclusively related to physical safety, but also encompass psychological and security needs. Included here too

are protection from illness, threat and violence. The next progression is to relationship needs, which are concerned with the need to give and receive love and affection and the need to belong and to be accepted. These needs are sometimes referred to as 'social' needs, placing them in a much wider context.

The next set of needs that Maslow (1954) describes is what he refers to as esteem needs, encompassing concepts like self-respect, self-esteem and personal endeavour. There is also a need to be respected by others, essential if an individual is to participate in communal and social activities. Also implicit in this set of needs is personal worth, ability and competence. At the highest level of the hierarchy is the need for self-actualisation, which Maslow (1968, p.25) defines as:

> *ongoing actualization of potentials, capacities and talents, as fulfilment of mission (or call, fate, destiny, or vocation), as a fuller knowledge of, and acceptance of, the person's own intrinsic nature, as an unceasing trend toward unity, integration or synergy within the person.*

The second theory examined was that of Manfred Max-Neef. Max-Neef (1989) organises needs into two categories: existential and axiological. The existential category contains the needs of Being, Having, Doing and Interacting. In the axiological category are the needs of Subsistence, Protection, Affection, Understanding, Participation, Idleness, Creation, Identity and Freedom. As Jackson et al (2004) point out, there are clearly some resonances between Max-Neef's axiological categories and Maslow's categorisation. In particular, the needs for Subsistence and Protection correspond closely with Maslow's physiological and security needs, while Participation and Affection, for example, are closely linked to Maslow's relationship needs and esteem needs.

A distinguishing element of Max-Neef's (1989) proposition is his differentiation of needs and satisfiers. He believes that "a prevalent shortcoming in the existing literature and discussions about human needs is that the fundamental difference between needs and satisfiers of those needs is either not made explicit or is overlooked altogether" (Max-Neef 1989, pp. 16-17). For example, food and shelter can be seen as satisfiers of the need for Subsistence. Equally, education is a satisfier of the need for Understanding. Max-Neef (1989) argues that human needs are the same across all cultures and in all historical periods; what changes is the way or means that the needs are satisfied.

Having considered critiques of both theories, key elements from Maslow and Max-Neef that I believe encapsulate both the 'psycho-' and '-social' were combined to form a theoretical framework that underpinned this study. Within this framework the impact of HIV on psychosocial needs was considered under the headings: Safety needs (security and protection), Relationship needs (belonging, love and affection, participation) and Esteem needs (esteem, identity, participation, idleness). Gender and sexuality were included as possible influencing factors. The services provided by Open Heart House were listed in the framework as satisfiers to achieve the outcome of psychosocial wellbeing, both interpersonal and intrapersonal.

1.1.2 Service Provision for People Living with HIV

When HIV first emerged in the 1980s, there was an initial tardiness on the part of governments to respond (Kirp and Bayer 1992, cited by Smyth 1998). Voluntary organisations and non-governmental organisations (NGOs) emerged to provide services in response to the needs of those affected by the epidemic and to fill gaps in public sector provision of those services. The services that such organisations began to provide to people living with HIV include: information; counselling; provision of meals; complementary therapies; emotional and practical support. Many of the services relate to the psychosocial needs of people living with HIV, as this was seen as particularly lacking in service provision by the formal health sector.

1.1.3 Organisational Types

Cornu (1999), in a research paper on the involvement of people living with HIV in voluntary organisations, identifies three major organisational types:
- the charitable or compassionate model
- the assisted self-help model
- the self-help model

The level of involvement of people living with HIV varies between the different models. The charitable model does not cultivate active participation: the members are predominantly healthcare workers offering medical care for people living with HIV, whose role is more or less that of passive recipient of services (Cornu 1999). The assisted self-help model is described as a health or development organisation that has taken on HIV and AIDS care and support activities. While people living with HIV may be members of the organisation and act as service providers, they are not usually the founders of the organisation and are rarely involved in decision-making processes. The third type of organisation identified by Cornu (1999) - the self-help model- is founded by people living with HIV and their supporters. People living with HIV are involved throughout all levels of the organisation, including in leadership. Its mission is mutual self-help, and many HIV-positive members may act simultaneously as service beneficiaries and providers (Cornu 1999). This was found to be the most applicable model to the case study organisation, based on Open Heart House's 'Mission Statement', 'Rationale for the Model of Membership' and an interview with the Membership Development Manager.

1.1.4 Psychosocial Wellbeing

The concept of 'wellbeing' can be equated with quality of life. The term 'psychosocial wellbeing' has come to be preferred by development agencies over narrower concepts such as mental health, to the extent that it points explicitly to social and cultural (and psychological) influences on wellbeing (The Psychosocial Working Group 2003). Max-Neef et al (1989, p.19) postulate that "quality of life depends on the possibilities people have to adequately satisfy their fundamental human needs", which points to a correlation between needs, service provision (offering the "possibilities") and an impact on wellbeing.

2. Research Undertaken

The research I undertook in Dublin in 2009 was based on the perceptions and experiences of 8 people living with HIV and availing of the services provided by Open Heart House. The approach was a qualitative one, which aimed "to understand people not to measure them" (Sarantakos 2005, p.45). The small scale of this study meant that it could not lead to generalisations or be considered a widely representative study. However, as psychosocial needs are very individual and difficult to measure or quantify, the qualitative methodology allowed me to focus on exploring the meaning for people of being diagnosed and living with HIV. It also provided the scope to look at peoples' perceptions both of their needs and the impact of services on their psychosocial wellbeing.

The research was carried out through face-to-face individual interviews. As Laws et al (2003) point out, one-to-one interviews are useful when one needs to know about peoples' experiences in some depth and if the issue is sensitive and people may not be able to speak freely in groups. Both of these aspects were integral to the research topic. The interviews were semi-structured, so that there was a list of predetermined questions to guide the interviews but also allowing for the order to be modified based on my perception of what seemed most appropriate with each interviewee. I liaised with my contact person within the organisation, the Membership Development Manager, who identified suitable people on my behalf. I also carried out an interview with the Membership Development Manager about the structure of the case study organisation.

3. Summary of Findings and Analysis

3.1 The impact of HIV on a Person's Psychosocial Needs.

The research clearly indicated that HIV has a marked impact on a person's psychosocial needs but that the extent of this impact varies from person to person. There are also disparities in the psychosocial consequences of HIV for men and women.

As a serious illness, HIV disrupts a person's physical and psychological safety needs. This disruption begins at the moment of diagnosis and in this research this was the instance where there was the most commonality among interviewees. The most universal reaction was a fear of death, which was mentioned by 6 of the 8 interviewees. What is interesting to note is that this fear was specific to both people who had been diagnosed in the 1980s and those diagnosed within the last three years. So, despite the fact that treatment has transformed HIV from a fatal disease into a chronic illness in many parts of the world (Pence 2009), it appears that it is still perceived as a death sentence.

This perception endorses Crystal and Jackson's (1992) view that HIV is a socially constructed entity, not simply a biological phenomenon. At the beginning of the epidemic, the focus was on people dying with AIDS. AIDS became the engrained terminology in common usage for all aspects of the virus, often being used when HIV is meant (Crystal and Jackson 1992). Although antiretroviral treatment has radically altered the prognosis for HIV, it seems that the social construction of the virus has not altered at the same pace. This embedded association of HIV with AIDS and death seems to be what affects people so severely on a psychological level at diagnosis.

This equation of HIV with death represents the most serious of threats to a person's psychological safety needs. According to Hough (1994, p.43), "when an individual's psychological safety needs are threatened, emotional disturbance usually follows". This "disturbance" manifests itself in several ways. For some of the people interviewed, it lead to the continuity of behaviour that they knew to be destructive, such as drug use, with the view that they were going to die anyway.

Most people experienced a lot of distress and anxiety, which correlates with the findings of psychosocial needs studies such as Schwartz (1987, cited by Osei-Hwedie 1994). However, Schwartz (ibid) also lists depression as one of the common findings, yet only one person interviewed for this piece of research overtly stated that she had been depressed.

Osei-Hwedie (1994) also includes depression in what he sees as the different stages that follow diagnosis with HIV: anticipatory grief, denial, anger, bargaining, depression and acceptance. All of these stages were mentioned in the interviews, but not necessarily in the progression that

Osei-Hwedie (1994) identifies and not all people went through all of the stages. Furthermore, it came to light that these stages can last different lengths of time for different people. A case in point is the acceptance stage. For one woman who was diagnosed with HIV thirteen years ago, she claimed that the most challenging aspect of living with HIV was accepting it. This is in complete contrast to the two heterosexual men interviewed, both of whom conveyed high levels of acceptance of living with HIV.

One of the main outcomes of this research is the reinforcement of the concept of HIV as a socially constructed entity and the impact that has on the continuing perception of HIV as a death sentence. The significance of this construct and perception is also in evidence in the findings on esteem needs and relationship needs.

3.1.1 Esteem Needs

The impact of HIV on esteem was only evident in the interviews with women. For these women, HIV resulted in a shift in the way they viewed themselves - they became "dirty" and "infectious". This negative labelling resulted in a lowering of self-esteem which, for some, seemed to persist for years after diagnosis. This appears to be "self-stigma" in action, which is "an individual's internalisation of the societal attitudes s/he experiences, or anticipates, in society. Self-stigma incorporates feelings of shame, dejection, self-doubt, guilt, self-blame and inferiority" (HDNET 2006). Themes of shame and guilt were also present in the interviews with women, particularly for those with children. This shame and guilt again relates back to the social construction of HIV.

The need for respect and wider social needs were clearly impeded for some people after they were diagnosed with HIV, for example, for the people who told friends and never saw them again. For others, there was a perception- possibly an accurate one- that if people knew that they were HIV-positive they would think differently of them or lose respect for them, so for this reason they felt unable to disclose their status.

3.1.2 Relationship Needs

The impact of HIV on relationship needs was a recurring theme across all of the interviews and it is clear from the findings that HIV affects the satisfaction of these needs quite drastically.

Osei-Hwedie (1994) attributes the impact of HIV on sexual relationships to the sexual transmissibility of the virus. This did become apparent from the interviews, with a number of people highlighting that HIV posed difficulties in new intimate relationships. However, the men described an ability to address the issue of HIV with their partner and to form successful relationships. For some of the women, on the other hand, they had a great degree of anxiety about the implications of HIV for an intimate relationship which acted as a major barrier.

However, HIV has an impact on a much broader range of areas than just that of sexual relationships. Relationship needs are often referred to as 'social needs' and encompass the daily social contacts which people require to give a sense of belonging and purpose to their lives. The issue of disclosure and the influence of stigma surfaced as interlinking elements that have the most profound impact on relationship needs.

Disclosure was much more of a concern for the women interviewed. Whether or not to tell someone about their HIV-positive status caused a lot of anxiety for most of the women, and they opted not to tell anyone other than their partner or immediate family. The negative social construct of HIV, as discussed above, is the reason for their reluctance to disclose their status. This reluctance brings with it what Williams and Sittitrai (1999) refer to as a "perpetual state of fear" of being rejected by society because of their HIV status. For some of the women, this fear was compounded by actual experience of rejection by close friends when they did tell them that they were HIV-positive. As well as distress, fear of rejection and actual rejection leads to a sense of isolation, both real and self-imposed.

3.1.3 Stigmatisation, Guilt and Fear

Edwin Cameron (2007, cited by UNAIDS 2007, p.7) states that "AIDS is probably the most stigmatised disease in history". The impact of this on the person is very evident from the findings of this research.

The reason some people live in fear of others finding out about their HIV status is because of the stigma that surrounds the illness, and this fear impinges on a person's psychological sense of safety and security. Stigma is also strongly associated with the impact of HIV on relationship needs. The issues around disclosure, feelings of isolation and marginalisation by society are all attributable to stigma.

As already mentioned, esteem needs include the need for respect, which is essential if an individual is to participate in communal and social activities. Stigma implies a lack of respect which thus suggests that a person's ability to participate in society is hindered. This was apparent in the findings on relationship needs, but it seems that it is more often a fear of stigma that hampers a person's social participation, rather than direct experience of stigma.

Stigma not only influences how an individual or group is viewed, but also the individual or group's self-perception and self-image. This influence is always negative, so the impact on the individual is a lowering of self-esteem. This was particularly evident among the women interviewed. As already stated, it appears from the findings that women engage more in "self-stigma", internalising real or perceived societal attitudes into shame, guilt and fear.

Holden (2003, p.7) ascribes stigma to the sexual mode of transmission of HIV. Interestingly, it emerged from the research process that stigma in Ireland is most commonly linked to men having sex with men and

to a mode of transmission which Holden (2003) omits - injecting drug use. Interviewees who had contracted HIV through other modes - heterosexual sex and at birth- expressed frustration at being automatically linked to either of these groups.

3.1.4 Gender

The research findings brought to light the fact that HIV has a different impact on the psychosocial needs of men and women. Specifically, disclosure was more of an issue for women than men. The women interviewed were also impacted more severely on an esteem level and found negotiating relationships more difficult than men.

Lynch (1992, cited by Osei-Hwedie 1994) claims that women use social support systems more than men, and in a more intimate and self-disclosing way. Potential rejection or isolation from these support systems, then, is bound to present more difficulties for women. Te Vaarwerk and Gaal (2001) discuss the fact that women have to deal with the implications of HIV for pregnancy, childbearing and bringing up children; issues which, they argue, do not apply to men. Undoubtedly, there was an added dimension to the issues of disclosure and stigma for the women with children, which could serve to partly explain the different impact of HIV on women's psychosocial needs. I would add here, however, that Te Vaarwerk and Gaal (2001) are maybe too quick to dismiss men's role in bringing up children in an Irish context. One of the men I spoke to is a father and he was very conscious of being a part of his children's lives and staying well for them. So while perhaps not as big an issue as for women, concerns around children are still present for men.

On the whole, the women interviewed for this research did seem to experience greater psychosocial consequences than the men. Due to the small scale of this piece of research, I am cautious of concluding that all women are affected more than men and that all men are affected less than women. However, because other studies have suggested that women as a group are more affected on a psychosocial level than men (Lynch 1992, cited by Osei-Hwedie 1994), it seems reasonable to conclude that women and men definitely have different needs and this should be borne in mind in any responses to HIV.

3.2 The Self-Help Model as a Response to the Needs of People Living with HIV

The interview findings irrefutably showed that people experience new areas of need following diagnosis with HIV and, thus, services are required in response. As HIV is first and foremost a health issue, the initial response is at the medical level. As mentioned earlier, this biological health need has received the most attention since the beginning of the HIV epidemic, often to the detriment of other needs.

The aim of the research was not to assess the medical model of care for people living with HIV. However, some of respondents were very

critical of public service provision for people living with HIV and I feel obliged to include this. Two people experienced stigma from doctors, with one of those people stating that she had been discriminated against in hospital because, she felt, she is an injecting drug user. The other woman, who did not contract HIV through injecting drug use, has been asked by doctors what her drug of choice is and claimed that she has to educate them about HIV. One person referred to the lack of support when he was diagnosed in 2005, basically being told that he was not going to die "and that was all". This substantiates Mason and Whitehead's (2003) view that the medical model does not adequately respond to the psychological and social needs of a person. In light of the wide ranging and often very individual needs discussed above, it is clear that additional responses are a necessity for the wellbeing of people living with HIV. The experiences of the people interviewed draw attention to a bigger problem, however- that of stigma within the medical profession.

In this research, the effectiveness of the self-help model of response was investigated through examining the model of Open Heart House. Ostensibly, the model of Open Heart House does not strictly fit the description provided by Cornu (1999). The main issue is that Open Heart House was founded by members of religious orders, whereas Cornu's (1999) definition states that a self-help organisation is set up by people living with HIV and their supporters. Conversely, one could argue that Open Heart House is a self-help model if one considers that its model was derived from the Boston Living Centre in Massachusetts, which was set up by a group of HIV-positive gay men. Furthermore, Cornu (1999) states that central to the mission of the self-help model is "mutual self-help", which could be equated with the peer support element that is at the core of Open Heart House. Another criterion of the self-help model is that people living with HIV are involved throughout all levels of the organisation.

The research findings highlighted the importance of the involvement of people living with HIV. In its 'Rationale for the Model of Membership', Open Heart House states that a member is not seen as a "'mere' service user". The organisation is 'member-led', so services are dictated by the members. Communication happens both on an informal basis and through a monthly meeting between members and management. The number of staff and volunteers who are living with HIV is also evidence of involvement in delivery of services. There are currently 12 paid staff in Open Heart House - 7 of these are in full-time positions and 5 in part-time. Five staff members are living with HIV and working in areas that have the most interaction with the membership, i.e. in the Membership Department, Communications and Reception. There are also approximately 60 active volunteers each week, with 25% of the volunteer base made up of people living with HIV. At the highest level, people living with HIV are involved in management, policymaking and strategic planning. Involvement of people living with HIV is inscribed in Open Heart House's mission statement and its 'Rationale for the Model of Membership'. That interviewees all felt the services in Open Heart House responded to their different needs and improved their wellbeing, and that there were few suggestions for improvements is testament that this involvement is happening.

The cornerstone of the self-help model is "mutual self-help" (Cornu 1999) or peer support. This element stood out from the findings as one of the most significant benefits of the model of Open Heart House. Cornu and Attawell (2003, p.102) suggest that peer support is a "key factor in contributing to improved psychological, mental and emotional health". The understanding and identification that people experienced in Open Heart House had major benefits for some of the needs most severely impacted by HIV, such as relationship needs and esteem needs. Sweetland et al (2005, p1) state that peer support enables people "to meet their needs and heal themselves, as well as assist others to do the same". The findings demonstrated that peer support in itself does not meet all of a person's needs, but that it is a fundamental component of a holistic approach. However, Sweetland et al's (2005) idea of peer support as a two-way process, in which people both receive help and help others, did emerge clearly from the interviews.

One further merit of the self-help model is that it can help to combat stigma and the resulting isolation and loneliness. The interview findings back up Sweetland et al's (2005) claim that the sense of social solidarity "can relieve emotional and psychological stress". Nevertheless, it appears that the effect on combating stigma is only evident when people are within the walls of Open Heart House, but that the problem of stigma remains as great outside.

Indeed, Cornu (1999) raises the issue of invisibility outside the organisation as a potential disadvantage of the self-help model. Invisibility is a strategy that is often used to protect individuals from possible discrimination and this is the case for Open Heart House. The interview findings highlighted that some of the members make a very strong psychological split between "inside" Open Heart House and "outside", and feel quite different in these two distinct environments. Rather than putting this invisibility down as a disadvantage of the self-help model, I would propose that it is a consequence of the stigma that exists in society and something that is beyond the control of the organisation. I think that the findings illustrate that people need that invisibility and confidential environment, where they do not have to worry about people finding out about their status and being treated differently as a result. Arguably, it is better that their "emotional and psychological stress" (Sweetland et al 2005) is alleviated for the time that they are in Open Heart House than not at all.

4. Recommendations and Conclusions

This research has clearly shown the serious impact that HIV has on a person's psychosocial needs and its impact is evident from the moment of diagnosis. What struck me from the interviews was the severity of the psychological and emotional effect of being told that one has tested positive for HIV. As I have already stated, the purpose of this research was not to evaluate the medical model of treatment or care for people living with HIV. However, from the research carried out, it is of vital importance that adequate resources are directed towards providing post-test counselling and support within the medical setting. If this is provided from the moment of diagnosis, it would seem that the distress and anxiety that people experience could be lessened.

Secondly, the severity of the shock of receiving a HIV-positive diagnosis is affected by the social construct of the virus in Ireland. As detailed in the interview findings, almost all of the interviewees initially thought they were going to die as a result of contracting HIV. The shock for some people was exacerbated by the fact that they were unaware of the risk of contracting HIV or thought that they were not at risk because they did not belong to the traditional 'high risk groups' (homosexuals and injecting drug users).

Both of these issues highlight a lack of knowledge and education about HIV. There is a need, as articulated by the interviewees, to raise awareness about HIV among the general public and step up efforts to tackle HIV-related stigma. At the moment, there is something of a vicious cycle in operation - ignorance about HIV is widespread which entrenches stigma; people living with HIV need to speak out to inform and advocate; yet the very nature of stigma prevents the majority from doing this. As one of the interviewees surmised:

> What I do is I teach people. I'm not afraid to speak out. And that's what's wrong - people with HIV are afraid to tell people because of the stigma and that's not fair on the people with HIV, because they haven't got a life. They're constantly living in fear that someone would find out this or they'd be treated differently because of that.

In terms of the self-help organisational model as a response to the psychosocial needs of people living with HIV, a few critical ingredients emerged from the case study of Open Heart House. The involvement of people living with HIV is key to any response to needs, if the response is to have a real and meaningful outcome for those people. Peer support is imperative, particularly given the stigma and lack of understanding about HIV that exists in Irish society. The different needs of men and women must be acknowledged and kept to the fore in programming responses.

Lastly, and perhaps most importantly, responses to HIV must put the person before the illness and be based on respect. I got a strong sense from the people that I spoke to for this research that they do not need or want sympathy, but empowerment. It is reasonable to conclude that Open Heart House is doing a lot to assist people in that regard but that stigma remains the biggest challenge to overcome.

Bibliography

Cornu, C. (1999) Positive, Engaged, Involved: PLHA Participation in Community-Based Organisations [Online]. Available from: http://www.popcouncil.org/Horizons/ressum/plhabf/plhabf.html [Accessed: 19/05/09].

Cornu, C. and Attawell, K. (2003) *The Involvement of People Living with HIV/AIDS in Community-based Prevention, Care and Support Programs in Developing Countries- A Multi-Country Diagnostic Study,* Population Council and International HIV/AIDS Alliance, Brighton, UK.

Crystal, S. and Jackson, M. (1992) Health Care and the Social Construction of AIDS: The Impact of Disease Definitions. In Huber, J. and Schneider, B.E. (Eds) *The Social Context of AIDS.* SAGE, CA.

DOHC and Irish Aid (2007) Report on the UNGASS Declaration of Commitment on HIV and AIDS [Online]. Available from: http://www.dohc.ie/publications/ungass_2007.html?lang=en [Accessed: 19/05/09].

Gilborn, L., Apicella, L., Brakash, J., Dube, L., Jemison, K., Kluckow, M., Smith, T. and Snider, L. (2006) *Orphans and Vulnerable Youth in Bulawayo, Zimbabwe. An Exploratory Study of Psychosocial Well-being and Psychosocial Support Programs,* Horizons Final Report, Population Council, Washington DC.

HDNET (2006) *Living on the outside. Key findings and recommendations on the nature and impact of HIV/AIDS-related stigma.* A joint publication of Health and Development Networks and the AIDS-Care-Watch Campaign.

Holden, S. (2003) *AIDS on the Agenda: adapting development and humanitarian programmes to meet the challenge of HIV/AIDS,* Oxfam, Oxford.

Hough, M. (1994) *A Practical Approach to Counselling,* Pitman Publishing, London.

HPSC (2008) *Newly diagnosed HIV infections in Ireland,* June 2008, Health Protection Surveillance Centre, Dublin.

Jackson, T., Jager, W. and Stagl, S. (2004) *Beyond Insatiability: Needs Theory, Consumption and Sustainability.* In Reisch, L. and I. Ropke (Eds) *The Ecological Economics of Consumption,* Edward Elgar, Cheltenham.

Laws, S., Harper, C. and Marcus, R. (2003) *Research for Development- A Practical Guide,* SAGE, London.

Maslow, A.H. (1954) *Motivation and Personality,* Harper, New York.

Maslow, A.H. (1968) *Toward a Psychology of Being,* Second Edition, D. Van Nostrand Company, New York.

Mason, T. and Whitehead, E. (2003) *Thinking Nursing,* Open University Press, UK.

Max-Neef, M. (1989) *Human Scale Development- Conception, Application and Further Reflections,* Apex Press, New York and London.

Max-Neef, M., Elizalde, A. and Hopenhayn, M. (1989) Human Scale Development: An Option for the Future. *Development Dialogue Journal,* Vol. 1, 7-80.

Montgomery, D. (2006) Ireland Today. In HDNET (2006) *Unveiling the Truth: Shedding light on HIV stigma and discrimination. A report from the XVI International AIDS Conference, Toronto, Canada-August 2006,* A joint publication of Health and Development Networks and the AIDS-Care-Watch Campaign.

Mason, T. and Whitehead, E. (2003) *Thinking Nursing,* Open University Press, UK.

Osei-Hwedie, K. (1994) AIDS, the Individual, Family and Community: Psychosocial Issues. *Journal of Social Development in Africa,* Vol. 9, No. 2, 31-43.

Pence, B.W. (2009) The impact of mental health and traumatic life experiences on antiretroviral treatment outcomes for people living with HIV/AIDS. *Journal of Antimicrobial Chemotherapy,* Vol. 62, 636-640.

Sarantakos, S. (2005) *Social Research,* Third Edition, Palgrave, UK and New York.

Smyth, F. (1998) Cultural Constraints on the Delivery of HIV/AIDS Prevention in Ireland. *Social Science & Medicine,* Vol. 46. No. 6, 661-67.

Soper, K. (1981) *On Human Needs- Open and Closed Theories in a Marxist Perspective,* The Harvester Press Ltd., Sussex.

Sweetland, A., Freeman, M., Lazarus, R. and Saloner, K. (2005) Psychosocial Support Groups in Antiretroviral (ARV) Therapy Programmes. *Mental Health and HIV/AIDS Series,* WHO, Geneva.

Te Vaarwerk, M. and Gaal, E.A. (2001) Psychological distress and quality of life in drug-using and non-drug-using HIV-infected women. *European Journal of Public Health,* Vol. 11, No. 1, 109-115.

The Psychosocial Working Group (2003) Psychosocial Interventions in Complex Emergencies- A Conceptual Framework. *Working Paper,* Queen Margaret University College, Edinburgh.

UNAIDS (2007) *Reducing HIV Stigma and Discrimination: a critical part of national AIDS programmes. A resource for national stakeholders in the HIV response.* UNAIDS, Geneva.

Williams, G. and Sittitrai, W. (1999) *Candles of Hope - The AIDS Programme of the Thai Red Cross Society,* Actionaid, London.

Notes:

Notes: